Ethical Principles in Practice

Evidence from participatory action research

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ABSTRACT

A significant challenge for all participants in the autism spectrum disorder participatory action research (ASD PAR) project, including the Ministry of Education, the local project teams (LPT) and mentors, was the lack of availability of a single ethics approval process for the project in its entirety and, in particular, one that could accommodate the iterative, dynamic and participant-led action research process. To address this gap, participants in the ASD PAR project adopted both individual and shared responsibility for ethical reasoning. As with ethics in general, there was no one right answer that could be routinely applied to ethical dilemmas. A guiding framework of ethical principles proved useful for participants. Central to the success of the ASD PAR project was participants' ability to self-reflect, question and share resolutions. In essence, reflections on ethical dilemmas as they arose were an interwoven strand through the life cycles of the ASD PAR project.

Keywords
Action research, autism spectrum disorder, effective practices, participatory action research, reflection, research ethics, responsibilities.

INTRODUCTION

In May 2002, the Ministry of Education, in conjunction with the Autism Spectrum Disorder Reference Group, set up the autism spectrum disorder participatory action research (ASD PAR) project. Teachers, parents and young people, as the local project teams (LPT) working with their mentors, were responsible for reflecting on their situation, defining their problems, implementing solutions to produce a "better" situation, and for evaluating these solutions. The ASD PAR project sought, therefore, not just to understand but to empower teachers, parents and young people to act and create change.

Early in the ASD PAR project, there were difficulties in obtaining ethics approval for the project as a whole. Further, there were noted tensions in seeking to apply traditional ethics principles to a participatory action research (PAR) project. This article shares the ethical challenges faced by the ASD PAR project, focusing on five ethical principles applied and the strategies used by many people involved in the project to facilitate ethical reasoning. Appendix 1 presents an overview of questions developed by Zeni (2001) to assist ethical review and reflection through the action research phases. People who are planning to use action research in education contexts may find Zeni's questions useful.

INDIVIDUAL AND SHARED ETHICAL RESPONSIBILITY

From the outset, it was anticipated that the national project management team would be able to facilitate access to a single ethics committee for all the individual LPTs. When the project management structure changed, the links to the ethics committee were no longer available. Mentors from tertiary organisations sought and received ethical approval for their ASD PAR project teams from their respective accredited ethics committees. However, for the equally senior and experienced mentors not aligned to a tertiary organisation, there were no existing accredited ethics committees from which they could seek review and approval for their ASD PAR project teams. This situation reflects the fact that currently in New Zealand, while there are ethics committees accredited to assess health research as defined by the Ministry of Health (2006) *Operational Standard for Ethics Committees*, there is no equivalent accreditation process for social and education research. The Health Research Council (HRC) is currently scoping the need for such a function.

At the time the ASD PAR project took place, guidance was sought from the HRC that advised that even though the project focused on children with autism spectrum disorder (ASD), accredited ethics approval was **not** required as the research activities focused on normal classroom practice. This response was disconcerting to participants who felt there was a need for a mechanism to address ethical issues. While the ASD PAR project as a whole could not obtain accredited ethics approval, ethical consideration and reasoning was an integral strand woven through the project. In line with the principles of PAR, the Ministry of Education endeavoured to ensure control for the ASD PAR project rested with the LPTs. In this context, and consistent with codes of ethics and practice, ethical considerations were the responsibility of each individual involved in the project, that is, the LPTs and their mentors, and the special education and the research division in the Ministry of Education. In addition to individual responsibility for ethical behaviour, there was also a shared and interlinking responsibility towards ethical reflections and considerations for the ASD PAR project. In response to ethical dilemmas that arose, the Ministry of Education developed a draft guideline on ethics and the ASD PAR project.

Figure 1, developed to illustrate the responsibilities of the various participants in the ASD PAR project, and drawing on the work of the Institute of Medicine (Federman, Hanna & Rodriguez, 2003), summarises the ethical responsibilities of each stakeholder and their linkages within the ASD PAR project. It shows that consideration of ethical issues mirrors the cyclical action research process of reflection, collaboration and action. Thus, ethical consideration in the ASD PAR project was a dynamic and ongoing process of open and transparent communications between the stakeholders. In this way, ethical management is continuous throughout the entire research process (Alton-Lee, 2001).

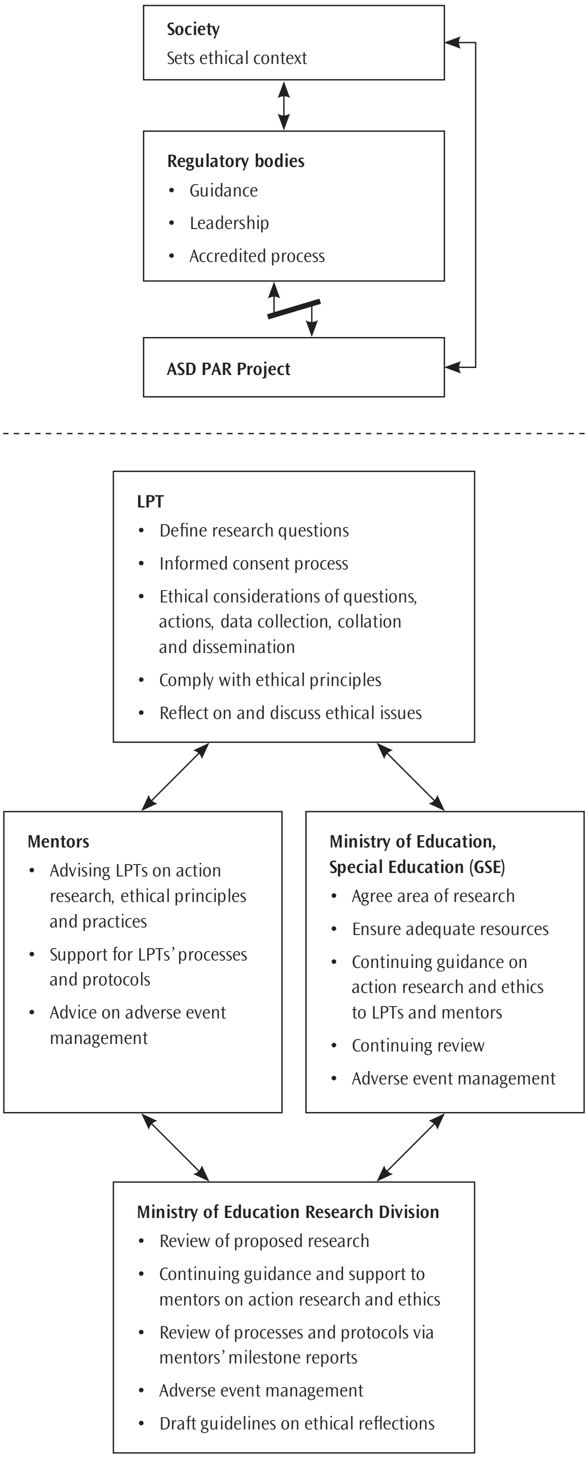

Figure 1. Ethical responsibility in the ASD PAR project (developed from Federman, Hanna & Rodriguez, 2003)

ETHICS IN ACTION

Within New Zealand, the principles and protocols of research ethics draw on the medical model developed in response to unethical experimentation on people (Tolich, 2001). Consequently, ethics focuses on active researchers doing research on passive participants for a clearly defined purpose and in situations where the risks are known. Emphasis is therefore placed on the rights of participants over the self-interest of researchers using, in the main, the following guiding principles:

- validity of research
- respect for persons
- informed and voluntary consent
- minimising risk of harm
- respect for privacy and confidentiality
- avoidance of unnecessary deception
- avoidance of conflict of interest
- social and cultural sensitivity to participants
- distributive justice.

(Ministry of Health, 2006).

Even when available, traditional ethics committees and their guiding principles do not sit comfortably with the active role of the participant/researcher in the PAR model. For the ASD PAR project, five of the above listed principles were particularly relevant and required careful reflection. The principles and challenges relating to the ASD PAR project are discussed below. It is acknowledged that the ethical challenges arising from the ASD PAR project were not unique, but are more a reflection of a wider international debate about ethics occurring amongst PAR participants/researchers from a range of disciplines. Williamson and Prosser (2002) suggest that political and ethical tensions arise in PAR as a result of the close relationship between researcher and researched, and the degree of "exposure" this brings. This is particularly the case for those working in their own organisations.

Validity of the ASD PAR

For research to be considered ethical it must also be valid (Snook, 1998). The validity of the ASD PAR project was at no time brought into question by those involved. The ASD PAR project was seen as significantly benefiting teachers, parents and especially the young people involved in this project, as well as contributing to wider knowledge about effective practice in education for young people with ASD. In essence, the ASD PAR project was seeking to narrow the gap between research and practice so that innovative practices validated in research could be adopted in education settings (Meyer, Park, Grenot-Schever, Schwartz & Harry, 1998).

The concept of validity also contains the notion that researchers must have appropriate qualifications and/or expertise to conduct the research. From the start, the Ministry of Education acknowledged the LPTs were "novice" researchers. The Ministry of Education built LPTs' capacity and capability by contracting mentors with a depth of ASD, PAR and education research expertise. All LPTs received resource packs containing relevant articles, papers and books on ASD and PAR. The Ministry of Education also funded "release time" for parents and teachers to work on the research and to take part in professional learning and development opportunities with a focus on methodology.

Informed and voluntary consent

Traditional ethics principles require that participation in any research project must be voluntary and based on understanding adequate and appropriate information about what participation will involve. PAR, by its very nature, makes it challenging to meet the criterion for informed consent. PAR's cyclic process of planning, action, observation and reflection means that much is unknown at the project's commencement beyond its overarching research questions. Thus, the researcher is unable to provide full and detailed information about what participation will involve, and the implications and risks of participation for the project's duration.

Further, traditional informed consent places the participant in a passive mode as the "subject" of research. In contrast, PAR expects participants to be active in the research design and at all stages of the research process. As a result, the boundary between researcher and participant is blurred. The latter, therefore, begs the questions: Who is the researcher? Who is the participant? Who is seeking consent from whom? And can participation be truly voluntary, given the strong inter-linked relationships and beliefs about friendship, reciprocity and power underpinning them?

To resolve these dilemmas, within most LPTs, participants sought informed and voluntary consent from one another during the early stages of the project. For most LPTs, informed consent was not a solitary activity at project commencement, but an ongoing and negotiated process throughout the project. The LPTs, mentors and the Ministry of Education recognised ongoing active involvement in the project as signifying members' willingness to continue. Although there was some variation between LPTs in the extent to which this occurred, on the whole informed consent was maintained throughout the project by reflection, open communications, negotiations and agreed actions within each LPT and at the overall ASD PAR project level.

Avoidance of conflict of interest

Parents, teachers and the young people with ASD in the LPTs had existing inter-related professional and personal relationships with each other. Unlike traditional researchers, members of the LPTs cannot be considered to be neutral, unbiased, and objective.

To resolve any potential conflict of interest, members of the LPTs had to recognise and share their positions, beliefs and values about the project and their relationships with other LPT members. They had to openly discuss with their team members how these factors might impact the research and their analysis of information collected. When researching one's own context, it is important to acknowledge the perspective one brings; however, the goal is not to overcome or change this perspective, but rather make known how it has affected the research (Kirsch, 1999).

Minimising risk of harm

Ensuring research participants are not exposed to unnecessary harm is a core ethical principle, and one of great significance to the ASD PAR project, given its focus on young people with ASD. Minimising the potential risk of harm required LPT members to negotiate the potential conflict of interest between their roles as parents/guardians and teachers of the child and their roles as researchers. For example, issues arose around parents who were members of the LPT giving consent for their children's involvement in the projects. In this instance, LPT parent members had to reflect on whether their consent for participation was in their child's best interest or more whether it reflected their expectations about the project. Through the process of reflection, LPT members had to acknowledge that they were active in the research process and as such there was the potential to do harm (no matter how unintended).

In minimising harm to the child and their family, LPTs had to recognise that harm can occur both during the project and years after its completion. Potential harm for the child and the family can arise inadvertently through casual communications about the project with non-members and other LPTs. This is especially pertinent with the involvement of children with ASD and their families as they are easily identifiable in their communities, and possibly not everyone would support their involvement in the project. In the long term, there was potential for information dissemination choices made about the findings from the LPT to have long-term repercussions for the child and their family, that is in 5 or 10 years, what impact will others' knowledge that the child was involved in this project have on them as a young person or adult?

Respect for privacy and confidentiality

Traditional research ethics principles contain the expectation that it is the role of the researcher to ensure the privacy and confidentiality of the participant. Within the context of the ASD PAR project, again the boundary issue arises of whose privacy and confidentiality is being maintained, by whom and whether confidentiality is, in fact, possible. Throughout the ASD PAR project, the LPTs had to recognise that neither the Ministry of Education nor the mentors could offer guarantees of confidentiality.

Of particular note, LPTs grappled with the issue of confidentiality around information dissemination, particularly as the project came to a close. Some LPTs wanted to share findings from their projects with wider audiences so others could learn from their experiences of what worked or did not work in their educational settings. This disclosure met the ethical requirement of distributive justice, though it raised concerns about confidentiality. However, others did not want to share the findings from their projects, as doing so would clearly identify the child and the family, and had potential to create harm for them. This approach denied the family and other LPT members recognition of their participation and their valuable contribution to educational strategies and wider knowledge in this field. As is often the case with ethics, there was no one right answer but differing defensible positions. Consequently, each LPT collectively agreed on a position regarding information dissemination that all members of that LPT, including the young person and their family, accepted.

CONCLUSION

The ASD PAR project was unable to access an accredited ethics committee to review and approve the project in its entirety. Although the HRC committee advised formal ethics approval was not required, the ASD PAR project teams and the Ministry of Education ensured ethical consideration was a strong and consistent thread weaving through the project. Consequently, all members of the ASD PAR project became more sensitive to the inherent ethical dilemmas of a PAR project, and had greater awareness and appreciation of their own ethical responsibilities. It may be surmised, therefore, that the lack of an avenue to gain accredited ethical approval serendipitously resulted in richer and more robust ethical self-reflection throughout the life cycles of the ASD PAR project.

As demonstrated, there are underlying tensions between a traditional ethics top-down researcher driven model, which views participants as passive, and the PAR model where participants are actively involved in the process. Key tensions noted include the challenges of obtaining informed consent, given the iterative and action-focused nature of PAR, and issues of confidentiality, validity, minimisation of harm and conflict of interest, owing to the active role of participants as researchers.

These tensions required ASD PAR stakeholders to be more reflective throughout the project, and for the LPT members, in particular, to self-reflect on how their positions, beliefs and values influenced the project. Mason (1996) calls this an 'active and self questioning approach' (p.167) and goes on to say, '[it] is because of the complexities of research ethics, and because there is unlikely ever to be one clear ethical solution, that a practical approach to ethics which involves asking yourself difficult questions – and pushing yourself hard to answer them – is particularly appropriate' (p. 29).

In conclusion, the ASD PAR project emphasised the responsibility for behaving ethically remains with the researcher and the wider project team, regardless of the formal ethical approval process applied.

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APPENDIX 1:
Questions to guide self-reflective ethics in PAR

Further insight and practical guidance on a self-questioning and self-reflective approach to ethics in PAR is offered by Jane Zeni (2001) who details the "hard questions" requiring reflections, if not answers, at each stage of the PAR cycle.

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I. Overview of the Study

1. Briefly describe your project as you see it today.
2. What is your time frame? Is this a one shot project or do you anticipate several cycles? Have you done a preliminary study?
3. What problem does your research address? Is it a problem in your own practice? Or is it a problem with your students or with your administrators? Who owns the problem?
4. What (initial) action will you take? What do you hope to accomplish?
5. List your research questions as they appear at this time. (Questions will be revised or refocused during your project.)

II. Location

1. Are you, the researcher, also a participant in the setting where this research will take place? Specify your role (teacher, supervisor, principal, counselor, social worker, and so forth)

2. Map your position on such dimensions of culture as gender, race, age, region, ethnic heritage, education, class, and family.

III. Methods

1. For this research, will you gather data on your normal educational practice and on changes in curriculum, instruction, and assessment that you could make in your role according to your own professional judgment?
2. List the kinds of data you plan to collect (e.g., fieldnotes, taped interviews, writing samples).
3. How is this plan different from the way you normally document your practice? Consider two or three alternative ways you could gather data for this project. What are the ethical implications of choosing your preferred method?
4. At this time in your research, what do you aim to understand? What do you aim to change?

IV. Subjects, Subjectivity, and Relationships

1. Describe the individuals, groups, or communities you expect will be touched by your project. List their roles (student, parent, resource teacher, and so forth). Which participants are minors?
2. Analyze the power relations in this group. Which people (e.g., students, parents) do you have some power over? Which people (e.g., principals, professors) have some power over you?
3. What shared understandings do you have with these people? Do you have personal bonds, professional commitments? Will your research strengthen this trust or perhaps abuse it?
4. Will your study attempt to read and interpret the experience of people who differ from you in race, class, gender, ethnicity, sexual orientation, or other cultural dimensions? How have you prepared yourself to share the perspective of the “other” (coursework, experiences, other sources of insight)?
5. Will an insider review your questionnaires or teaching materials for cultural bias? Have you provided for consultation by adult members of the community? How will you reduce or correct for your misreading of populations who differ from you?
6. Does your inquiry focus on people with less power than you? Children in classrooms are always vulnerable – especially if their families have little money or education … How does your project demonstrate mutual respect and justice?
7. What negative or embarrassing data can you anticipate emerging from this research? Who might be harmed (personally, professionally, financially)? What precautions have you taken?
8. Might your research lead to knowledge of sensitive matters such as illegal activities, drug and alcohol use, or sexual behaviour of participants? How do you plan to handle such information?

V. Consequences

1. Describe the possible benefits of your research – to students, teachers, or other participants; to society or to the profession.
2. Describe any risks to participants. For example, might your current students be disadvantaged for the possible benefit of future students? What steps are you taking to minimize risks?
3. Explain how you will protect the people from whom you collect data through surveys, interviews, or observations.
4. Describe how you will obtain informed consent. Do you need permission from students, parents, or both? How will you work with any students who refuse to be interviewed or to allow their materials to be quoted?
5. Are different kinds of consent needed at different stages in the project? (a) A blanket *consent to participate* from all students at the start of each year (with parent signatures of minors). (b) An individual *consent to publish* from selected students, giving you access to writing samples, videotapes, photographs, or fieldnotes that describe recognizable people.
6. Do you wish to protect the anonymity of students, teachers, parents, and other participants? If so, it is wise to use pseudonyms even in your fieldnotes. If your report is eventually published, you can also interchange physical description, age, gender, and so forth or develop composite rather than individual portraits. What are the gains and losses of anonymity?
7. On the other hand, instead of anonymity, it may be wiser to seek full participation and credit for students and colleagues. Research by an educator in his or her own classroom is rarely anonymous. Even if names are changed, students can be recognised in a well-written case study or classroom scene. What are the gains and losses of open acknowledgment?

VI. Publication

1. What data will be contributed by others? Will you record student writing, oral histories, or other documents that may be considered someone’s intellectual property? How have you arranged with colleagues or students for credit in your manuscript?
2. If your study is collaborative, how are you negotiating authorship and ownership? University researchers, colleagues, students, and parents may interpret their stake in the research in quite different ways. Who owns the videotape of a classroom writing group, the dialogue journal between teacher and mentor, the transcription of talk by teacher-researchers in a college seminar?
3. Who is responsible for what is said in the final report? Will other stakeholders (teacher, principal, school board) review your report in draft? Will this (a) improve your accuracy or (b) compromise your candour? Which participants (students, colleagues) might be embarrassed if they were to read your report?
4. You will inevitably gather more data than you “need”. Consider why you choose some data to report to a wider audience and why some is left in your files. (On what basis do you select?) Consider the politics of the way you focus your story.

5. How will your report recognise the perspectives of participants who disagree with some of your interpretations? For example, you may revise your views; quote their objections and tell why you maintain your original view; or invite them to state alternative views in an appendix.
6. Have you decided on anonymity or on full acknowledgment of other participants in your report? Perhaps you will identify teachers but use pseudonyms for students. If you began your study with a blanket consent form, have you now requested consent to publish specific material from specific people?

VII. Ethical questions specific to "insider" research

1. [Is there] a formal review procedure for [the] research? If you are collaborating with people at a university or research institute, you may need approval from the institutional review board (IRB) in both settings.
2. Which participants at your school or college have read your research proposal? Which ones have been informed of the research orally in some detail? Which ones know little or nothing of this project? Reflect on the decisions behind your answers.
3. What do your students know of your research? Who told them? What are the risks to them or their families of their knowing (or not knowing) what you write or collect?
4. How do your school [board/principal] view your work? Is action research under suspicion or is it mandated from the top in a drive for organizational quality control? How safe do you feel in this institutional setting pursuing this research? Would you be free to report your findings and interpretations to a wider audience?
5. Who is sponsoring this research through grants, contracts, released time, course credit, and so forth? Will you evaluate the sponsor's program, textbook, or method? Do you anticipate pressure to report what the sponsor wants to hear?
6. Does your study evaluate your own effectiveness or a method to which you are committed? How will you handle the temptation to see what you hope to see? How will you obtain other perspectives – for example, classroom observation or analysis of student work by people who do not share your assumptions?

(Zeni, 2001, pp. 156-164).

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