

Walking on eggshells: Some ethical issues in research with people in vulnerable situations

Dóra S. Bjarnason

This article takes up some of the ethical issues at stake when qualitative inquiry involves people in vulnerable situations, such as the young, the very old, the sick or disabled or minority groups – people, in short, who are often labelled as “the other”. Ethical issues and dilemmas appear at every juncture of the research process and also when the researcher decides what to publish and why. The article starts with some of the issues and experiences the author brings to the table after working in the field of inclusive education and disability research for over three decades. Next it offers some notes on qualitative inquiry and then it moves on to explore the ethics, ethical issues and dilemmas inevitably part and parcel of all such inquiry. Then it applies examples from the author’s fieldwork to the discussion of ethical issues and dilemmas in qualitative encountered in qualitative research with people in vulnerable situations. Examples are in particular drawn from the authors recent study that involved interviews with Icelandic parents of disabled children. The ethical issues and dilemmas touched upon include those related to gaining access, the interview situation itself, including the building of rapport and the fine line between gathering the data, data analysis, ethical issues related to what to select from *privileged knowledge*, and other things that concern the writing up of sensitive data. Finally, some thought is given to publications, their interpretations by the reader and their use or abuse.

Key words: Ethical and methodological issues, researching vulnerable people

Dóra S. Bjarnason, Professor, University of Iceland
dsb@hi.is

Introduction

The chapter explores some of the many ethical problems that are likely to confront qualitative researchers, studying people in vulnerable situations, within the field of disability studies and special and inclusive educational research. Examples are taken from my own research, experiences gathered over the last 30 years in the field, but particularly from my current research into how parents of disabled children view their lives and the formal and informal supports made available to them over time. The examples include moral and ethical challenges, dilemmas and pitfalls one is likely to encounter as a researcher studying people in vulnerable situations in a small society where face to face interaction characterizes social encounters, or in local communities of larger societies, where people know or know of each other.

The chapter starts with some of the issues and experiences I bring to the table from my own work experiences. Next it offers some notes on qualitative inquiry. Then it moves on to explore ethics, and some ethical issues and dilemmas encountered in the context of qualitative inquiry. Then it applies examples from my own fieldwork, particularly the gathering of data through interviews, to the discussion of ethical issues and dilemmas encountered in qualitative research with people in vulnerable situations. The examples are in particular drawn from my recent study that involved interviewing Icelandic parents of disabled children (born 1974-2007) in a time of significant socio-political change in both Icelandic disability- and social policy and the society.

The ethical issues and dilemmas touched upon include gaining access, the interview situation itself including the building of rapport, and the ethical challenges found in the interview situation itself. Furthermore, ethical issues related to the data analysis will be discussed, and what to select from *privileged knowledge* (a concept given me by Dianne Ferguson 2009), if anything. The term *privileged knowledge* refers to the kind of things that the person being interviewed tells the interviewer, sometimes deeply private and personal matters they feel the need to share, which may not further the research. Finally the chapter will briefly touch upon other ethical concerns in the writing up of sensitive data and its publication.

Background: What do I bring to the table?

In my work as a qualitative researcher I have often used interviews to gather significant parts of my data combined with observations, participant observations and document analysis. I have interviewed teenagers and their parents, entrepreneurs, bureaucrats, government ministers, fishermen, teachers of all kinds, student teachers, health workers and therapeutic professionals, disabled youth, and family members of disabled children and young people.

Over the past 25 years I have researched issues related to disability, and inclusion and exclusion in schools and society (for example Bjarnason, 2002, 2003, 2004, 2009). My interests in those areas are fuelled by my concern with questions about inequality, marginalization and exclusion in modern schools and societies, and by a personal history of becoming a parent in 1980 to a son with significant impairment and an impressive string of labels (Bjarnason, 2003).

In my work I have often been amazed, humbled and even embarrassed by the intimate details people have been willing to share in semi-structured interview situations. Through successes, mistakes and failures I have become keenly aware of how delicate, but also deeply informative and rewarding, research with people in vulnerable situations can be. This chapter shares some of my reflections and lessons learnt in the field.

Notes on qualitative inquiry

Qualitative inquiry aims at understanding the meaning of human action. It involves a variety of social inquiry which has its roots in hermeneutics, phenomenology and the tradition of *Verstehen*. It encompasses all forms of social research that involves data in the forms of words and gestures that form the basis for meaning making, and a broad base of methods, techniques and theoretical approaches applied to gather and interpret such data. Thus it may include ethnography, case studies, naturalistic inquiry, life histories and narrative inquiry (Schwandt, 2001). When qualitative inquiry involves people in vulnerable situations, it can be a way of giving the subjects a voice in matters concerning their own lives, furthering the understanding of difference, inclusion and exclusion in our schools and society and informing policy makers, professionals and the general public on matters involving diversity, social justice and lived experiences of people labelled as “the other”. In that sense there is a political aspect to such inquiry. Some such inquiry is done in partnership with the subjects involved, where the researcher is seen to be a facilitator, a critic, an advocate or a change agent, counter acting the disempowering dominant groups or structures in society. This is both a political approach aimed at empowering the research subject and those similarly situated, and a way of framing human relations in the research. Other such inquiry is carried out where the researcher is a marginal participant and the researched are seen to be informants for the research purposes. A bitter controversy about these two approaches has recently resulted in a fierce and somewhat ugly debate within the field of disability studies (Shakespeare, 2006; Vehmas, 2008; *Disability & Society*, 2007). On the one hand are those who want to stick with the British social model for its emancipator and political approach, respecting the slogan of British disability advocates “Nothing about us without us” (see O’Brien, 2000; Charlton, 1998; Oliver, 1990, 1996, 2007). On the other hand are those researchers in disability studies, like Tom Shakespeare, who want to be free from the dominant political implications of the British social model approach, favouring, what they argue as a more academic pursuit of knowledge. The argument put forward is that the epistemological approach to a research, not the subject matter should determine the appropriateness and usefulness of the researched as co-researchers (Shakespeare, 2006; Vehmas, 2008).

Most qualitative inquiry involves an ongoing relationship between the researcher and the researched. Such a relationship can be fairly detached and formalized, as when data is gathered by an outside (supposedly “objective”) expert who makes an a priori formal contract about the procedure and its ethical parameters with the subjects researched. An example of this is the evaluation of an institution such as a school, hospital or university. But more often the relationship is an ongoing one over a period of time, or intense as

in semi-structured interviews. In the field the relations between the researcher and the research participant or subject becomes substantial and subjected to changes in agenda, nuances and vested interests. This calls for heightened awareness of ethical dilemmas and possible pitfalls, and for the researcher's vigilant anticipation of these as the fieldwork unravels.

Before I move on to describe and explore some such ethical issues I have encountered in my work, I will briefly explain what I mean by ethics and ethical issues and dilemmas.

Ethical issues and dilemmas

Ethics is the branch of philosophy that explores the nature of moral virtue and evaluates human action. It seeks to study human action and morality through a rational, secular outlook that is based in notions of human happiness or well being. In the widest sense the subject matter of ethics is the justification of human actions, especially as those actions affect others.

There are basically two traditions in modern philosophical ethics regarding how to determine the ethical character of actions; the first is based on the argument that actions have one intrinsic ethical character but acquire their moral status from the consequences that flow from them. The second tradition is based on the argument that actions are inherently right or wrong. The former is called a *teleological* approach to ethics and the other *deontological* approach to ethics. The former is based in the utilitarian thinking of the British philosopher Jeremy Bentham and refined by John Stuart Mill. It claims that the moral character of action depends on the extent to which actions help or hurt people. Actions that produce more benefit than harm are "right", those that do not are "wrong" (White, 1993). This approach can be problematic based on for example who gets to decide what is or is not a benefit or a harm, and whether or not some harm or suffering to the few is justifiable if it brings benefits and pleasure to the many?

The latter tradition, the *deontological* oriented ethics is based on the approach of Kant's universal moral law: that actions have an intrinsic moral value based on duty or what is the right thing to do. From that perspective some actions are inherently good, such as telling the truth or keeping a promise, others bad, no matter how much good may stem from them, for example lying, coercing or manipulating others. This approach is problematic in its inflexibility, and in who gets to determine whether or not an action is deemed right or wrong (White, 1993). Modern ethical theories include *deontological ethics*, *consequentialist ethics* which is based on the idea of an outcome achieving some good state of affairs, and *virtue ethics*, based on the qualities of character necessary to live well (Schwandt, 2001, p. 73).

In layman's terms, I think it is safe to say that ethics involves a set of customary principles and practices embodying some sort of a normative

moral code. Acting in an ethical way implies acting out that code in practice. These codes vary somewhat from culture to culture.

An ethical issue or dilemma arises when there's a conflict between two or more parties, here the researcher and the research participant or informant, if the researcher is benefiting at the expense of the research participant. In other words, when the researcher, using his or her power over the research situation and the research participant, uses the research participant as a *means* to his or her own scientific *end*, hurts or harms the research participant, breaks a promise, or otherwise undermines the trust which must be part and parcel of the relationship between researcher and the research participants. An ethical dilemma can also arise when there's a conflict between moral rules or when one is violated.

As I am neither a philosopher nor ethicist, I dare not dive deeper into this particular theoretical jungle, but all of us involved in educational and disability scholarships, working with people in vulnerable situations, need to take stance to and reflect upon ethical issues in our work. We need to recognize at all times, that ethics, epistemology and politics are intrinsically linked in our every day work.

When the research participants are people in vulnerable situations, we the researchers, must be extra vigilant. People in vulnerable situations can be old people, children and youth, people of all ages with special needs, illness or disability labels and their families, people from minority groups and other disempowered people within our communities.

Sometimes we make errors of judgment or actions and face the painful problem of learning from our mistakes. More often we are just not sure whether or not we managed to live up to our ethical standards, and simultaneously stayed with what constitutes legitimate warranted knowledge of social life, our personal experiences, political commitments, and our responsibilities as students of meaning making. Some such errors may do damage to our academic portrayal, but in the case of people in vulnerable situations, such errors can irrevocably harm the lives of our research participants, people often already vulnerable, disempowered and socially excluded. The doing of qualitative research with people in vulnerable situations can at times be captured by the metaphor of walking on eggshells.

Capturing meaning without doing harm

Most ethical concerns in the literature and practice of qualitative research revolve around issues of harm, consent, deception and privacy (de Laine, 2000; Punch, 1998; Christians, 2000). As stated above, in qualitative research the researcher enters into a relatively close relationship with the research participants, for example in the participant observer or interview situation. Participation is grounded in trust. Bad mistakes may do harm and

close the door for further research. But too much concern with the possible pitfalls can reduce the flexibility of the fieldwork situation and reduce the quality of the data to platitudes of little use for analysis.

Ethics issues are thus always present in qualitative research which is filled with unanticipated occurrences, feelings, lies, unexpected revelations, and unequal roles and power balance. In qualitative research the researcher is himself the research instrument. The researcher, with his or her research participant, creates the text of the research material, interviews, observation, field notes and the research reports. The readers engage with the text of the final report and carry out the final interpretations by engaging with the finished document. Their interpretations may be different to the researcher's own interpretations and may carry unintended consequences, personal, political and economic.

There are different stances regarding ethical issues in qualitative research. Two of those are of particular concern here. They are the *absolutist stance*, which addresses the following four ethical concerns: protection of participants, prevention of deception, protection of privacy, and informed consent. Those who adopt this stance argue that social scientists have no right to invade the privacy of others because such invasion may cause harm to research participants. The *relativist stance*, by contrast, states that investigators have absolute freedom to study what they see fit, but they should study only those problems that flow from their own experiences. Agenda setting is most often determined by the personal biography of the researcher. Thus the only reasonable ethical standard is one directed by the researcher's conscience. No single ethical standard can be developed because each situation requires a different ethical stance. From this point of view the researcher is advised to build open sharing relationships with his or her research participants and involve them as much as possible in each and every state of the research process and interpretations (www.sahealthinf.org/ethics/ethics-qualitative.htm).

The difference between these two stances is not clear cut in practice. For example there is no clear cut distinction between the public and the private in research that aims at understanding disability in the family, school or society, partnership between parents of children with special educational or other needs and professionals, formal and informal support as experienced by families of children and youth with special needs, the building or erosion of individual or group social capital in schools or out of school activities to mention just a few research areas. Punch, discussing what can be taken as public and what as private, summarizes the kind of questions that are asked in the research literature on ethical standards in qualitative research as follows:

What is public and what is private? When can research be said to be “harming” people? Does the researcher enjoy any immunity from the law when he or she refuses to disclose information? In what way can one institutionalize ethical norms –such as respect, beneficence, and justice (Reiss, 1979) – to ensure accountability and responsibility in the use and control of human subjects? And to what extent do betrayal of trust, deception and invasion of privacy damage field relationships, make the researcher cynical and devious, enrage the “participants” in research, harm the reputation of social scientific research, and lead to malpractice in the wider society? (Punch, 1998, p. 169)

Obviously there are no simple answers to any of these questions, but I argue that that should not stop us from considering them very seriously at every juncture of our research work, but not so seriously that we intimidate ourselves and our work and render ourselves incapable of taking risks and being flexible in how we apply our trade.

Both feminist (Oakeley, 1979, 1981) and disability studies scholars (Barnes, Mercer & Shakespeare, 1999) further muddied the water of what can be seen as the ethical dimension in qualitative research by claiming its political nature. Feminist and disability studies research is carried out not only to develop “new knowledge” or open up new perspectives, but also to give voice to groups that are normally not heard or listened to, unmask injustice, oppression, exploitation and exclusion with the stated aim of improving life for oppressed or people in vulnerable situations. Feminist scholars for example emphasize identification, trust, empathy and non-exploitive relationships in all their research (Finch, 1984; Oakeley, 1981). As Punch reminds us:

Feminist research by women on women implies “a standpoint epistemology” that not only colours the ethical and moral component of research related to power imbalances in a sexist and racist environment, but also inhibits deception of the research “subjects”. Indeed, the gender and ethnic solidarity between researcher and researched welds that relationship into one of cooperation and collaboration that represents a personal commitment and also a contribution to the interests of women in general (e.g. in giving voice to “hidden women,” in generating the “emancipatory praxis” , and in seeing the field settings as “sites of resistance”). (ibid. p. 169)

Disability scholars attempt much the same thing in their work. Disabled scholars such as Colin Barnes, Michel Oliver and Tom Shakespeare have contributed much to the field by opening up new research venues and theoretical perspectives, asking new questions, and applying new and emancipating methods of inquiry. Their work is inspired by them being both *insiders* and *outsiders* in the world of disability. The same applies to thoughtful work by scholars who are also parents or siblings of disabled people (Ferguson, D. L. and Ferguson, P. M, 1993, 1995; Ferguson, P.M. 2001; Turnbull, A and Turnbull, R., Skrtic, 1995).

Examples from the field

My current research project focuses primarily on four groups of parents of disabled children (born 1974-2007), in all 75 families of one or more children diagnosed with significant impairments, and their experiences of formal supports (by the welfare state including health, education, disability and social services) and informal supports given by members of the family social networks. The data base is 135 semi-structured open ended interviews, with one or both parents, and with 5 couples who selected to abort a foetus with a difference (10 interviews), and 12 interviews with professionals. I also used 3 focus group interviews with staff and professionals and document analysis. I will use examples from that research here to illustrate some of the ethical dilemmas I encountered. These involve selecting the sample, the interviewing process, the data analysis and in reporting the findings.

The research applied theoretical (social constructionist) and purposive strategies in choosing the sample. The parents came from all socio-economic groups, lived in different parts of the country, and had in common that they had given birth to or raised one or more child diagnosed with significant impairment (but various diagnostic labels) in a period of massive changes in social policy, law and the society. The sample was chosen because of its relevance to my research questions on parents' experiences of supports due to a disability in the family over time, and how the analytical framework and the explanations and narratives developed in the research.

In Iceland with its population of 319.000 people, like in any small community, it is inevitably hard to disguise any research informants. This can be almost impossible when researching the lives of disabled people and their families. This poses all kinds of ethical challenges related to trust and the protection of the identities of research participants.

Further, geographic and social proximity within such a small society invites other concerns like role conflicts both for the researcher, research assistants and the research participants. A number of times either I or my research assistant who came along to the interviews, had to turn away because one or the other of the parents to be interviewed turned out to be old friends or even in case of the research assistants, relations. In such cases either I or the research assistant, depending on which one of us did not know the people took over the interview situation, or we dropped that family from the sample. Over identification of the researcher with his or her research participants is another problem I was keenly aware of in this particular research and in the process of the data analysis, much of the data was coded independently by me and one of three research assistants. We then compared codes and notes and triangulated across and within cases.

Access

Much has been written about problems researchers have had with gaining access to their field and getting past gatekeepers (e.g. Wolcott, 1994, 1995). I have had problems getting access to research participants in the past, and was almost barred from a school by a powerful gatekeeper, who half way through the fieldwork, felt that the research was impinging upon the power relationships within the school. She was probably right. The research approach was action research. I did not have much experience in that nor did I realize the hegemony held by me in the eyes of the preschool teachers and other staff. My field notes from that study are filled with comments of stress and despair. The gate-keeper played me like a musical instrument, changing her tune, her rules and our agreement. I did manage to finish that research, after altering the research design several times, but my memories of that work are filled with pain, anger, surprise and more. This was amongst my most valuable lessons as a researcher, but I do not look back on the experience with pride.

In my more recent work including the family study referred to above, I have found it surprisingly easy to gain access. I am known in my society as both a parent of a disabled child, for a time active in the parents' movement, and as an academic. My university is also well known and respected. To gain access I simply called key people in the practical field of teaching or services for disabled people, explained in general terms what my research was about and enlisted their help to find suitable research participants. My contact people then contacted individuals, who might be willing to talk to me, and after gaining their consent, sent me a list of names and phone numbers. I phoned these people, explained what I was doing and why and asked for interviews. We decided on a time and a place. In this study only one mother refused to give an interview. Two families had heard about my study. They contacted me and volunteered their stories. The willingness of parents (particularly the mothers) to participate in this research is gratifying but it also causes me concern. Many of the people I enlisted to help did so because they wanted to contribute their experiences in order to inform and enlighten professionals, politicians and the general public about the fate of their children, and thus combat stigmatization and prejudice. Each story is a unique gift. By accepting it, blurring individual details in the writing up process, publishing articles in academic journals, often in English, and using them in teaching, I must ask myself if I am taking these valuable gifts and applying them for my own ends? I am even more concerned when I learn that some of these parents have over the years been swamped with requests for interviews by students from upper secondary schools and universities, collecting material for their assignments, often with no preparation in interviewing technique.

Sigrun, a mother of a child with an unusual syndrome said, when I asked for an interview:

It is OK; you can come because I know who you are. But I am getting a little tired of telling our story. Only this year I have contributed to at least nine or ten essays. I have never seen any of them...students just come with their questions about difficult aspects to our lives, tape my answers and leave. I never know what they do with the stuff. I want to help ...and I do it because I want young people to understand...but sometimes it is very difficult.

I found it somewhat more difficult to get some of the fathers to talk to me. But I tried to interview them without their wife or partner present. Typical explanations were: “I cannot find time”, “I work away from home”, “ask the wife, I know much less about what happens around my (disabled) child, she sees to all that and tells me if there is something I need to do”. Sometimes a father has made an appointment to talk to me, but when I turned up he had gone to work or out on an errand, but his wife told me that I could always try later. This was problematic, particularly if the couple lived in a village or on a farm far away from the capital. This avoidance can mean a lot of things. It can be genuine, as many men feel compelled to work long hours, or because these fathers really believed they did not know enough about what was happening in their child’s life, or did simply not want to talk about their experiences. The mothers seemed to trust in our shared experience, and many welcomed the opportunity to talk about their experiences to an insider. Some of the fathers may have found it difficult to talk to a woman and a stranger about experiences they did not talk about with friends or workmates and sometimes not even with their spouses. However, many appeared glad to talk to me. The fathers’ stories were different from the mothers’, and added important dimensions to my research. Some of these fathers, once agreeing to the interview were putting words to experiences and feelings they had bottled up for a long time, and not even talked about with their partners. The role of the interviewer is not and should not be that of a therapist. But there is a fine line between listening to peoples experiences and becoming their therapist. That line should not be crossed between the interviewer and the research participant. However listening to the parents narratives my eyes sometimes blurred. I learnt to keep a box of tissue within reach for the interviewees, but there is also a lot of smiley voices and laughter recorded and registered in the transcripts.

The interviews

The interviews took place either in my office or in the families’ homes, depending on their preferences and the practicalities. The research had been certified by The National Bioethics Committee of Iceland and reported to The National Committee on the Protection and Processing of Personal Data.

This is standard procedure under Icelandic law and the parents were reminded of this at the beginning of the interview when they co-signed a statement with me to that effect.

Building rapport

I always began by explaining what I was doing without going into a great detail. I talked about what the research was about, explained that I had a list of topics to talk about but not pre designed questions, promised confidentiality, asked permission to record the interview, and answered any questions they had. I also told them that it was up to them what they chose to tell me and that we could stop the interview at any time. Further, that if they regretted what they had said later, I would erase the interview and not use it for the research purpose. Then we signed a paper of consent and confidentiality. All this is standard procedure.

I started the interview by asking about the family: “Tell me about the people in your family?” This question provided information on the family structure, number of children, the parents work, education and previous marital status if applicable, the children’s schooling and more. Most respondents found it easy to sketch out a brief description of their families and the interview could move on.

The interview

Next I asked the parent to describe their child (or in some cases children) labeled with disability, the child’s strengths, personality, charm and needs. Most, but not all the parents used this question to draw up the strengths, abilities and charm of their child. The father of Peter, a 9 year old boy with Down syndrome said:

Peter is our eldest. He is absolutely delightful. He has developed a lot in the past three to four years... kind of taken a big leap forward. He is good and gentle, and a surprisingly thinking human being... and he is almost able to read...He loves swimming and music and he loves people. He really is the sunshine in our lives...

A few parents however, answered my question by giving a detailed medical account of everything that was seen to be wrong with their child. One mother, Gudrun went as far as explaining to me using a Latin medical term which of her daughter’s chromosomes was irregular, how that might have happened, and what the future prognoses might imply. She seemed surprised when I stopped her and asked her about her daughter’s strengths and interests. She said with tears in her voice: “She is lovely, of course, but nobody wants to know that. All people ask about is her problems.”

I asked why she thought that might be so. She could not get a word out for a while, just cried. She said she did not know why she was crying, and I,

handing her a tissue offered to stop the interview, she declined and said she wanted to go on, but that she did not know why she was crying. Then she explained that when her daughter was born at the local hospital, she was unable to suck, Gudrun feared that maybe there was something wrong with her baby, but that the midwife blamed her and did not take her concern seriously. They were sent home, but when the baby was a few months old, it became undernourished. Gudrun had noticed that her baby did not move normally and became more and more frightened. Nobody believed her except her mother, and the midwife spread a story of Gudrun's incompetence as a mother. She was sent with her baby daughter, by plane to the large University hospital in Reykjavík, and from there from one paediatrician to another. It was finally detected that her daughter had a regressive muscular disease. Once the expert had diagnosed the problem, she lost contact with him. She said:

He was very busy. I do not blame him, but everything stopped. You are interesting while the diagnosis is being carried out, then when they have found out what is the matter, you are instantly forgotten.

Gudrun cried all through the interview, but declined my repeated offers to stop. She felt angry, betrayed by the midwife, the doctors, her husband, family and friends except for her own mother who supported her. She needed to get all this off her chest. Interviews can be abusing. Was I opening a can of worms? For whom and to what end?

I am still not certain whether or not I should have gone on with the interview. My probing caused Gudrun to have to revisit some of the most difficult moments of her life. These were things she had not talked about for years, but when the memory came flowing back, it caused her a lot of pain. Was I using her trust and her story as a means to my research ends? How can I be sure she really wanted to do this? I think she felt my empathy and saw my tears reflect hers, but did that help or harm?

As mentioned in the introduction, the term *privileged knowledge* (Dianne Ferguson 2009) refers to some of the things the person being interviewed tells the interviewer, things that may be deeply private and personal; this knowledge is not asked for and does not further the research. The researcher then has the privilege of that knowledge and the ethical dilemma of what to reveal and what to filter out in the analysis and the writing up. I have often been given the uneasy privilege of such knowledge. In the parent study, the husband told me he was cheating on his wife with a woman in their circle of friends, that the marriage bed was getting cold because the wife was always too tired for making love, or that he was unable to visit his wife. I have even had to stop the car to cry or be sick after some such revelations. Knowledge of this kind is difficult to handle, especially if the re-

searcher has to interview the other spouse, knowing what had been revealed. I chose to filter this kind of knowledge out before analyzing the data.

The data analysis and the writing up of findings

In reading and rereading the data (in this example both the interviews and the research notes made at various stages of the analysis), it begins to speak to the researcher or the team of researchers in a new way. Themes begin to emerge within and between data bits. Triangulations have to be made both within and between cases, looking for similar and opposite examples. The research participants may have to be contacted for clarifications or verifications (Bogdan & Biklen, 2003).

In this process ethical issues creep in at every stage. What did he or she really mean, why did they skip this bit, lie about that, and what of all this can be written up, how and why? What is the researcher's big story about all these individual stories? The researcher must be cognizant that according to the interpretive (hermeneutic) social science there is a general acceptance that present experiences shape who we think we are and who we become. How we read our experiences and those reported by others is never what happened but an outcome of a transaction between ourselves and the text. In the writing up and the publishing of the big story of the research there are more ethical issues. Questions such as: is this really respectful of the gifts you received from your research participants, is it trustworthy, and how will the readers eventually interpret this piece of research, are they likely to use it, and if so, how and for what ends?

Conclusion

I have shared some of the many ethical issues and dilemmas confronting a qualitative researcher working with people in vulnerable situations. Many of these apply in all such research work, but call for extra care when the research participants are people whose voices are not generally heard or if heard not taken seriously. I believe that it is the responsibility of the researcher in such cases to make as sure as possible that the research participants feel empowered through having shared their stories. It is also important to take the bigger story, the new knowledge, to the venue of policy makers, professionals, and the public, in the hope that new perspectives and new voices can throw a beam of light on the debate on how to use resources, and build for the future. If our work is to be taken seriously, it may well be controversial, but it has to be clear, ethical and open to scrutiny.

References

- Barnes, Colin, Mercer, Geoff & Shakespeare, Tom (1999). *Exploring disability: A Sociological introduction*. Cambridge, Policy Press.
- Bogdan, Robert C. & Biklen, Sari K. (2003). *Qualitative research for education: An introduction to theory and methods*. 4th ed. New York, Pearson Education grp.
- Bjarnason, Dora S. (2002). New voices in Iceland: Parents and adult children juggling supports and choices in time and space. *Disability and society*, 17(3), 307-327.
- Bjarnason, Dora S. (2003). *School inclusion in Iceland: The cloak of invisibility*. In: B. T. Peck (Ed) *Education: Emerging goals in a new millennium*. New York, Nova Science Publishers.
- Bjarnason, Dora S. (2004). *New voices from Iceland: Disability and young adulthood*. New York, Nova Science Publishers.
- Bjarnason, Dora S. (2009). Parents and professionals: An uneasy partnership? In J. Allan, J. Ozga and G. Smyth *Social capital, professionalism and diversity: New relations in urban schools*. Rotterdam: Sense Publishers.
- Charlton, James (1998). *Nothing about us without us: Disability, oppression and empowerment*. Berkeley, CA, University of California Press.
- Christians, Clifford G. (2000). Ethics and politics in qualitative research. In N. K. Denzin, & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd Ed) (pp. 133-155). Thousand Oaks. Sage publications.
- De Laine, Marlene (2000). *Fieldwork, participation and practice: Ethics and dilemmas in qualitative research*. London, Sage publications.
- Disability & Society* (2007). A review symposium. 22(2), 230-234.
- Ferguson, Dianne L. (2009). Personal communication.
- Ferguson, Phil M. (2001). Mapping the family: Disability studies and the exploration of parental responses to disability. In G. L. Albrecht, K. D. Seelman and M. Bury (Eds.), *Handbook of disability studies* (pp. 372-395). Thousand Oaks: Sage Publications.
- Ferguson, Dianne L. & Ferguson Phil M. (1993). *The promise of adulthood*. Columbus OH, Macmillan.
- Ferguson, Dianne L. & Ferguson Phil M. (1995). The interpretivist view of special education and disability: The value of telling stories. In T. M. Skrtic (ed.) *Disability and democracy: Reconstructing special education for postmodernity* (pp. 104-122). New York, Teachers College Press.
- Finch, Janet (1984). "It's great to have someone to talk to": The ethics and politics of interviewing women. In C. Bell & H. Roberts (Eds.) *Social researching: Politics, problems and practice* (pp. 70-87). London, Routledge and Kegan, Paul.
- Oakeley, Ann (1979). *Becoming a Mother*. Oxford: Martin Robertson.
- Oakeley, Ann (1981). *Subject Women*. Oxford: Martin Robertson. New York, Pantheon.
- O'Brien, Ruth (2001). *Crippled justice: The history of modern disability policy in the workplace*. Chicago, University of Chicago Press.
- Oliver, Mike (1990). *The politics of disablement: Critical texts in social work and the welfare state*. Basingstoke, Macmillan.

- Oliver, Mike (1996). *Understanding disability: From theory to practice*. Basingstoke, Macmillan.
- Oliver, Mike (2007). Review symposium, *Disability and Society*, 22(2), 232-234
- Punch, Maurice (1998). Politics and ethics in qualitative research. In: N. K. Denzin & Y. S Lincoln (Eds), *The landscape of qualitative research: Theories and issues* (pp 156-184). Thousand Oakes, Sage Publications.
- Schwandt, Thomas A. (2001). *Dictionary of qualitative inquiry* (2nd Ed). Thousand Oakes, Sage Publications.
- Shakespeare, Tom (2006). *Disability rights and wrongs*. London, Routledge.
Homepage: www.sahealthinfo.org/ethics/ethicsqualitative.htm. Retrieved 15th April 2009.
- Skrtec Thomas M. (Ed) (1999). *Disability and democracy: Reconstructing special education for postmodernity*. New York, Teachers College Press: 104-122.
- Turnbull, Ann & Turnbull, Rud (Eds) (2005). *Families, professionals and exceptionality*. New York, Prentice Hall.
- Vehmas, Simo (2008). Philosophy and science: The axes of evil in disability studies? *Journal of Medical Ethics*, 34, 21-23.
- White, Thomas (1993). *Business ethics: A philosophical reader*. New York, Macmillan
- Wolcott, Harry F. (1994). *Transforming qualitative data: Description, analysis, and interpretation*. Thousand Oakes, Sage Publications.
- Wolcott, Harry F. (1995). *The art of fieldwork*. Walnut Creek, Alta Mira Press.