222 Ethics and knowledge


16 Morals and ethics in geographical studies of disability

Rob Kitchin

We... are not interested in descriptions of how awful it is to be disabled. What we are interested in is the ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our... impairments by the way this society is organized to exclude us.

(UPLAS 1976: 4–5)

Introduction

Disabled people have long been labelled as Other. Across the globe, ableist prejudice, ignorance and institutional discrimination is rife (Barnes and Mercer 1995). As a consequence, disabled people generally occupy inferior positions within society, marginalized to the peripheries. Disabled people are more likely to be unemployed, occupy poorer housing, and have restricted access to education and transport than their non-disabled counterparts. As noted by Gleeson (1996), Imrie (1996) and Kitchin (1998) the oppressive experiences of disability are rooted in specific socio-spatial and temporal structures. Forms of oppression are played out within, and given context by, spaces and places. Spaces are currently organized to keep disabled people ‘in their place’ and places written to convey to disabled people that they are ‘out of place’. For example, urban space is implicitly and explicitly designed in such a way as to render certain spaces ‘no go’ areas. Implicit or thoughtless designs include the use of steps with no ramp, cash machines being placed too high, and places linked by inaccessible public transport. Explicit designs include the segregationalist planning including separate schools, training centres and asylums. Even within public spaces disabled people are separated and marginalized to the peripheries with separate and often shared-sex toilets and restricted access to theatres and other entertainment establishments. The messages written within the landscape by such designs are clear – disabled people are not as valued as non-disabled people. Finkelstein (1993) thus contended that disabled people occupy a ‘negative reality’.

This ‘negative reality’ has to a large extent been ignored by academia and other institutions. Moreover, as with poor people in relation to poverty discourse (see Bagguley and Craft, 1995), disabled people have largely been excluded from
disability discourse; marginalized from the political process and the media structures which influence public and policy discussion; and excluded from academic and institutional research, think tanks, charity and pressure groups. Instead, disability discourse has been, and to a large degree still is, overwhelmingly dominated by people who are not disabled.

In this chapter, two separate but related sets of moral and ethical issues are examined in relation to geographical studies of disability. In the first half of the chapter the moral responsibility of (non-disabled) academics to undertake critical emancipatory and empowering research concerning disability issues is examined. In the second half of the chapter the epistemological and ethical bases of conducting such research are explored. Central to, and linking, the two halves of the discussion are the questions: ‘Can academics representatively address the marginalization and marginalized life of disabled people within society?’; and ‘Can an academic adopt and enact an emancipatory and empowering position in relation to societal oppression and the research process?’ These questions have come to the fore in my own research as I have increasingly questioned my positionality and motivation as a non-disabled researcher studying issues of disability. In particular, I have two main concerns: first, to find an approach that is emancipatory and empowering, and which is representative of the disabled people taking part in my research; and second, the legitimacy of acting and writing on behalf of a group of which I am not a member. These reservations have currency beyond geographical studies of disability to include other excluded and oppressed groups within Western society and research on other cultures (see chapters by Deur and Rundstrom, and Gormley and Bondi, Herman and Mattingly, in this book).

Moral responsibility

Justice in modern industrial societies requires a societal commitment to meeting the basic needs of all persons.

(Young 1990: 91, my emphasis)

Academics must . . . be prepared to answer what they believe the role of the academy should be in promoting social change, and what they envision — in real, substantive terms — as the means to achieve a more just society.

(Nagel, Chapter 10, this book)

Smith (1994) and Sayer and Storper (1997) recently argued that geography tends to be positive in nature, avoiding questions about whether something is good or bad, right or wrong. As such, geography often focuses upon what actually exists and avoids normative ethics: the attempt to discover some acceptable and rational views concerning what is good and what is right. In relation to disability, normative ethics concerns social justice, the fair and equitable distribution of things that people care about such as work, wealth, food and housing, plus less tangible phenomena such as systems of power and pathways of opportunity, and specific moral issues such as how people should be treated (Smith 1994). Social justice, in essence, concerns human rights. A right is an ‘obligation embedded in some social or institutional context where expectation has a moral force’ (Smith 1994: 36). In other words, moral rights are those things that we as members of a society expect as members. In our society they include things such as freedom of expression, choice, access to accommodation, to vote in elections, full recourse to the law, and access to education and medical treatment.

Social commentators universally agree that disabled people suffer social injustice. They are systematically denied their moral rights to social relations and interactions that ‘able-bodied’, ‘mentally competent’ people take for granted. Given that scholars of disability studies recognize the social injustice that disabled people face, the mechanisms by which it is perpetuated, and appreciate that disabled people are largely marginalized and excluded from positions of power and influence to change their own conditions, two questions arise. First, do academics have a moral responsibility — an obligation — to disabled people to expose ableist practices and seek social change? Second, should academics become politically involved in disability issues (or other aspects of societal oppression relating to gender, race, sexuality, etc.) and engage with direct action? The answers to these questions are contested and five basic positions adopted.

In the first position are academics who view their role as voyeurs, objectively and neutrally studying society. They argue that it is not the role of academics to try and influence decision- and policy-making. Instead it is for others, in democratically elected or institutional positions, to interpret research findings and influence future policies. Academics occupying the second position recognize their own subjectivity and positionality in relation to a researched group, but also believe it is not their place to be suggesting and seeking societal change. A third group recognizes the need for change but seeks alternative futures through implicit means such as raising consciousness. Here, discourse is itself seen as an action, and writing and lecturing as mediums in which to engage fellow members of society and alter world views. As such, traditional research methods are still adopted and no explicit action is taken. Academics occupying a fourth position recognize the power imbalances in their own research and seek research strategies that will empower their research subjects either to be able to seek justice themselves or to seek justice through the research (see Herman and Mattingly, this book). The fifth group comprises academics who recognize the need for change and who explicitly seek change through their own political and social actions.

Those occupying the fourth and fifth positions argue that by not actively seeking change through empowerment or emancipation that will improve the human condition, academics are guilty of averting their gaze from oppression and human suffering. Not actively engaging with the group which is oppressed or their respective politics would be the academic equivalent of what Dickson (1982, cited in Mohan 1995), in relation to student education, termed ‘systematized selfishness’ — the study of a subject without giving anything in return. He suggested that unapplied knowledge is knowledge shorn of its meaning. Oliver (1982) contended that this has been the common model of disability research.
He described this model as ‘the rape model of research’ because whilst the researchers benefit from respondents’ knowledges or experiences, the research subjects remain in exactly the same social situation. As a consequence, Routledge (1996) has questioned what current marginal, social responsibility of academics, given their training, access to information, and freedom of expression. He suggested that by not joining their work with political practice or impinging their knowledge to empower oppressed people academics are complicit in oppressive practices. Mohan (1996) has similarly lamented that the current focus upon identity, culture and difference is failing the research subjects and there is a need for critical geography to become more critical.

In other words, geographers should be engaged in an emancipatory project aimed at improving the lives of disabled people (and other groups) in both practical and political ways. This involves bridging the chasm that still exists between radical, academic theorists and ‘on the ground’ activists (Pfaff 1994) and engaging with what Touraine (1981) termed ‘committed research’, Katz (1992) a ‘politics of engagement’, and hooks (1994) described as an ‘ethics of struggle’ both within the academy and beyond. Here, there is a recognition that people are not merely subjects to research ‘but lives to be understood in the interests of working for a redistribution of wealth and justice’ (Deur and Rundstrom, this volume).

Routledge (1996) has demonstrated that there is a ‘third space’ between academic and activist that researchers can occupy. An uneasy space where respective roles have to be balanced and negotiated through a dialectical relationship, but nonetheless a space from where committed research can be practised. He does not, however, envisage that this space should necessarily be occupied by all academics. Indeed, it can be argued that the occupancy of this ‘third space’ does not necessarily make a project any more emancipatory although it may provide more insights through social interaction and personal experiences than might be gained from formal research strategies.

Even if the academy is willing to accept that it has moral responsibilities (whatever they might be) to engage in social and political action on behalf of, or with, oppressed groups, new questions concerning the positioning of the academic and the situatedness of knowledge are encountered. Here, two forms of ethics identified by Proctor in the Introduction to this volume, become entwined:

In science, ethics typically involves reflection upon moral questions that arise in research, publication, and other professional activities... yet philosophical usage is broader than this prevailing scientific interpretation. Ethics, also known as moral philosophy, is commonly understood as systematic intellectual reflection on morality in general, or specific moral concerns in particular.

Questions concerning the ethical nature of research practice become enmeshed in questions concerning whether the researcher should be trying to change societal relations. By trying to bridge the gap between academic and activist a tightrope is walked in relation to whether an oppressed group is gaining the representation it seeks (or in some cases does not seek). Indeed, as recent debates in the disability literature have illustrated, some critics would be dubious about non-disabled academics forwarding visions for disabled people, questioning both the motivation and positionality of researchers. Given that academic research has perpetuated, reproduced and legitimated the marginalization of disabled people, justifying segregation, eugenics, and the denial of civil rights, it is little wonder that disabled people are suspicious of research by non-disabled researchers including those who claim to be allies (Rioux and Bach 1994). As such, there is a need to seek paths that allow societal oppression to be tackled, but are also representative of these people potentially being liberated. It is to finding such a path that the discussion now turns.

Emancipatory and empowering research strategies

Central to finding a path that is emancipatory, empowering and representative are epistemological debates concerning how knowledge is derived or arrived at; and the assumptions about how we can know the world (what can we know? how can we know it?). Such debates are currently taking place in the disability literature, particularly in respect to how we gain knowledge. As noted, debates within the disability literature have increasingly questioned the relationship between (non-disabled) researcher and (disabled) research. Protagonists on one side of the debate (predominantly academics who are disabled) have argued that it is only disabled people who can know what it is like to be disabled. They question the legitimacy of (non-disabled) experts to draw conclusions about disabled people’s lives and experiences. They argue that research concerning disability is invariably researcher-oriented, based around the desires and agendas of the (non-disabled) researcher and able-bodied funding agencies rather than subject(s) of the research (disabled people). Indeed, Oliver (1992) argued that current expert models of research are alienating, and disempower and disenfranchise research participants by placing their knowledge into the hands of the researcher to interpret and make recommendations on their behalf; that researchers are compounding the oppression of disabled respondents through exploitation for academic gain.

Hunt (1981) illustrated, in a much cited critique, the experiences of being a ‘victim of research’. He described how as a resident at Le Court Cheshire Home he and other residents became disillusioned with ‘unbiased social scientists’ who followed their own agenda and ignored the views of the people they consulted. Oliver (1992) suggested that continued academic ‘abuse’ is leading to a growing dissatisfaction amongst disabled research subjects who view academic research as unrepresentative. Indeed, disabled activists and organizations have declared that existing research has largely been a source of exploitation rather than liberation (Barnes and Mercer 1997); that current expert models of research, where disabled people are the subjects and academics the experts, controlling all aspects of the process from initial ideas to the contents of the final report, reproduce
current social relations. As such, critical research adopting an expert model is paradoxically seeking change at one level, while at the same time reproducing exploitation at another.

Drawing on work within feminism in particular, these disabled academics argue that power relations within the research process need to be destabilized and the research agenda wrested free from academic researchers still using traditional research methodologies. Indeed, Finkelstein (1985 – cited in Barners and Mercer 1997) has called for ‘no participation without representation’. Such a reformulation, they argue, will close the emerging credibility gap between researchers and researched, provide a ‘truer’ picture of the experiences of disability and strengthen policy-making formulation whilst moving away from a social engineering model (Oliver 1992; Sample 1996). Stone and Priestley (1996: 706) suggested that the core principles of a new research agenda should be:

- the adoption of a social model of disablement as the epistemological basis for research production;
- the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation;
- the willingness to undertake research only where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers;
- the evolution of control over research production to ensure full accountability to disabled people and their organizations;
- giving voice to the personal as political whilst endeavouring to collectivize the political commonality of individual experiences;
- the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.

French and Swain (1997: 31) suggested that one way to approach these issues is for researchers to ask themselves three principal questions before undertaking work on disability:

1. Does the research promote disabled people’s control over the decision-making processes which shape their lives?
2. Does the research address concerns of disabled people themselves?
3. Does the research support disabled people in their struggle against oppression and the removal of barriers to equal opportunities and a full participatory democracy for all?

Consequently, disabled academics argue that there needs to be a change in the way that we research and come to understand the world; a shift to emancipatory and empowering approaches. Not surprisingly, not all researchers agree on the path to emancipatory and empowering studies and three alternative approaches have been forwarded. The first seeks to retain the expert model of research but to enforce a strict code of

ethical practices that are designed to try and make the research process fair and non-exploitative. These are usually designed and enforced by professional bodies whose members are meant to comply with the ethical codes adopted. For example, The Council for Exceptional Children (CEC) has developed the CEC Code of Ethics for Educators of Persons with Exceptionalities, which states that special educators should:

- adopt procedures that protect the rights and welfare of subjects participating in the research;
- interpret and publish research results with accuracy and a high quality of scholarship;
- support a cessation of the use of any research procedure which may result in undesirable consequences for the participant;
- exercise all possible precautions to prevent misapplication or misutilization of a research effort, by self or others.

Guidelines within research manuals, and those issued by representative bodies, generally advocate a professional approach to research and focus upon issues such as privacy, confidentiality, and anonymity. They suggest that the researcher should carefully weigh the potential benefits of a project against the negative costs to individual participants. Such individual costs might include affronts to dignity, anxiety, embarrassment, loss of trust, loss of autonomy and self-determination, and lowered self-esteem (Kidd 1986). This is clearly a subjective exercise, but one that can be approached in an informed manner. As a general rule a deontological approach is advocated which judges actions according to whether the researcher would wish them upon herself/himself, whether the participants are treated with the respect due to them, and seeks to adopt a non-parasitic position (see Stone and Priestley 1996). The basis of such an approach is the development of genuine trusting relationships, where researchers respect the situated nature of their interpretation and their authorial power (see Cragg 1992). Here, a system of relational ethics is adopted:

where (the researcher) is/are committed to working with the differences between (them)selves and those with whom (they) interact, without seeking either to erase difference – that is to presume similarities or identifications that do not exist – or to treat difference as representing something essential and exotic.

(Gormley and Bondi, this book, p. 252)

Feminist analyses in particular have highlighted the situated and produced nature of research accounts, the asymmetrical power relations at play between researcher and researched, and the authority expressed in research accounts (see WGS 1997). Feminist reassessment of conducting research has led to the formulation of a feminist methodology which is characterized by a search for a mutual understanding between researcher and researched (Katz 1992). This methodology
focuses thought upon four issues: ways of knowing; ways of asking; ways of interpreting; and ways of writing. Within each of these issues researchers are encouraged to reflect upon their own position, as well as that of the researched, and to acknowledge and use these reflections to guide the various aspects of the research process (Dyck 1993). For example, Robinson (1994) in discussing white women representing 'others' in post-apartheid and postcolonial times, contends that there is a need for researchers to continually question their social location (gender, class, ethnicity), their political position, their disciplinary stance, and the physical location of the research. Each is key in shaping the research and the relationship between the researcher and researched. The same is true for those conducting research on disability. This includes non-disabled and disabled researchers alike. Academics who are themselves disabled do not occupy privileged positions where they can speak on behalf of their fellow disabled people. Admittedly, the disabled academic has the benefit of personal experience but this does not provide him or her with the platform to speak for all disabled people — their knowledge is also situated and they should pay similar respect to their research subjects. Reflexivity is particularly important when researching and writing upon a group that is unable to represent itself adequately (such as severely mentally impaired people).

The second approach seeks to alter the expert model of research so that it becomes more representative. Here, feedback (empathetic) loops are inserted into the research process so that the whole process is monitored by the research subjects who provide constructive criticism at all stages (see Barnes 1992; Oliver 1992; Sample 1996). As such, the academic retains control of the research process and the questions being asked but the participants get the opportunity to correct misinterpretations and influence the direction of the research. By using such feedback loops the researcher aims to make her/his research more representative of the subjects’ views and experiences. This is the approach advocated by Deur and Runstrom in Chapter 17 of this book, in relation to cross-cultural studies.

The third approach, and the one I am currently using in a study of the measurement of disabling environments, seeks a radical departure from the expert model of research, forwarding a partnership approach. This approach seeks to integrate research subjects more fully into the research process so that they take on the role of co-researchers (see Lloyd et al. 1996; Kitchin 1997). Here, the research process is 'collectivized amongst its participants' (Priestley 1997: 89) with disabled people taking an active role in the whole research process from ideas to hypotheses to data generation to analysis and interpretation to writing the final report. In this approach, the role of the academic is not as expert but as enabler or facilitator. As such, the academic takes an emancipatory position which seeks to inform and impart her/his knowledge and skills to the disabled people who are co-researchers in the project, and provide an outlet to inform the policy-makers. The academic’s role is primarily to provide specific technical advice to co-researchers to help them make informed choices. Second, it is to provide a relatively privileged position through which it
for self-organization, independent living and anti-discrimination legislation (Beresford and Wallcraft 1997).

As I have argued elsewhere (Kitchin 1997), involving disabled people in the research process is important academically for two principal reasons. In the first instance, participation by disabled people is the only mechanism by which disability research can truly become emancipatory and empowering. Zarb (1992) described emancipatory research as being defined by two principles: reciprocity and empowerment. Whilst many methodologies might claim to fulfill these two principles, in general, reciprocity is a by-product of research aimed at increasing knowledge rather than directly addressing a real-world problem and empowerment is largely illusory as the researcher ultimately designs and controls the study (Sample 1996). Empowerment is not something that can just be bestowed by those in power (researcher) to those who are disenfranchised (subject) (Lloyd et al. 1996). Empowerment is a process of gradual change which, although they might be instigated by the researcher, must be accepted and built upon by the subject. To be fully empowering, the study needs not only to be designed in conjunction with the research subjects but to be conducted with them in such a fashion that they learn from the process and gain some semblance of power, either politically through the research results or through the learning of research skills.

In the second instance, an inclusive research approach allows the research to become more representative and reflexive by addressing the issue of unequal power arrangements within the research process and recognizing the ‘expertise’ of disabled people in their own circumstances. Inclusion acknowledges and signifies a respect that the contributions of disabled co-researchers are valuable and worthwhile. Here the co-researchers’ expertise is acknowledged as equal but from a different frame of reference than the academics’ (Elden and Levin 1991):

- Disabled people occupy insider positions. Their knowledge on a particular subject is often individual, tacit, practical, led, from first-hand experience;
- Academics occupy outsider positions. They have specialized skill, systematic knowledge, are theory led, and based upon second-hand experience.

Here there is the development of a mutual sharing of knowledge and skills (Lloyd et al. 1996). This is not to say that an expert/lay-person relationship between researchers and co-researchers does not exist but rather that such a position can be re-worked into a more favourable, emancipatory position. Emancipatory studies thus address some of the problems of representativeness, reciprocity and reflexivity that plague both interpretative and positivist studies. As Routledge (1996) suggested, it is all too easy for academics to claim solidarity with the oppressed and claim to act as relays for their voices. Inclusive studies are designed to negate such criticism and allow disabled people to speak through the research rather than have voices in it.

Whilst emancipatory studies are demanding, it is suggested that the shared benefits to researchers, policy-makers and disabled co-researchers outweigh costs in terms of time and organization. Involving disabled people in disability discourse as controllers or partners then offers practical and social gains for disabled people. It is only with their active involvement that disability discussions will reflect their needs, concerns and interests. Through participation and partnership, research will become more reflexive, reciprocal and representative. It will provide a platform from where disabled people can speak for themselves, to seek the services and support they want, explicitly to influence social policy, and fight for disabled rights. In short, research will become enabling and empowering.

Conclusion

Whether an academic feels (s)he has a moral responsibility to address issues of social suffering, injustice and oppression is a personal issue. When researchers do, however, make the decision to fight for civil and material rights through their research and writings, a new set of problems are encountered concerning research ethics, positionality and representativeness. In this chapter I have discussed these new problems in relation to geographical studies of disability issues. Recent debates within the disability literature have led some researchers to question the ethical basis and validity of traditional expert models of research. Instead, they suggest that research should become more reflexive and, where possible, inclusive in design. Such a reformulation of research design, they contend, will lead to empowering and emancipatory research that will improve the social position of disabled people both within academic studies and society. I am currently trying to use one particular reformed approach, namely participatory action research, to address some of the concerns raised. In this study disabled people from Belfast and Dublin are designing and undertaking their own research into measuring disabling environments. They have complete autonomy and control over the process, deciding on the topic to be investigated, the methods of data collection and analysis, and writing the final report. My role is one of advisor or facilitator. The projects are action-led, aimed at confronting ableist practices (e.g. inaccessible public transport) and seeking change. Although the study is in its preliminary stage, early indications suggest that the projects will be a success and vitally the arguments of many disabled academics calling for a change in the social relations of research.

Note

1 http://www.ccc.sped.org/home.htm
References


Kitchin, R. M. (1997) ‘A geography of, for, with or by disabled people: re-conceptualising the position of geographer as expert’, SARU Working Paper 1, School of Geosciences, Queen’s University of Belfast.


17 Reciprocal appropriation

Toward an ethics of cross-cultural research

Robert Rundstrom and Douglas Deur

For most people, serious learning about Native American culture and history is different from acquiring knowledge in other fields. One does not start from point zero, but from minus ten.

Michael Dorris (1987: 103)

“Enjoy yourself, and never, never be an embarrassment to the administration.” Anonymous faculty advisor.

(Clinton 1975: 199)

Peoples of the Northwest Coast of North America speak of sisiutl, the two-headed sea serpent, guardian of supernatural beings – one head masculine, the other feminine; one head hot, the other cold; one head good, the other evil. If you flee the sisiutl charging from the fjord you will be devoured, but if you stand firm before it, some say, its two heads will see one another at the very last moment as it lunges at you. Opposing forces collide: good will meet evil. The sisiutl will achieve a form of enlightenment and back off into the water. You will not be eaten. And you will find a form of enlightenment yourself, a spirit power of great magnitude.

The sisiutl story serves as a metaphor for the task before us in this chapter, the articulation and reconciliation of what often appears as two opposing forces: the abusive, colonizing academic gaze and the institutional apparatus out of which it peers; and the world of colonized peoples on which that gaze is frequently trained. Cross-cultural geographic researchers have long served as “cultural brokers,” translating across cultural divides, representing — intentionally or otherwise — each group to the other (Szasz 1995). Particularly during the late twentieth century, these cultural borders have been subject to perpetual renegotiation, as non-Western peoples challenge the authority of European institutions and question the veracity of past scholarly depictions of themselves (Deloria 1995). Today, geographers must confront the colonial legacy directly, interacting with people who often define their identities in opposition to the colonial world (a world of which, more often than not, the researcher is a part). In the process, geographers encounter alternative views of the world which must be recognized