## SHORT COMMUNICATIONS

# Disability, Geography and Ethics

## Introduction

ROB KITCHIN AND ROB WILTON

In recent years geographers have started to re-engage with issues of exclusion, social justice and moral philosophy, first explored by radical geographers in the 1970s. This re-engagement parallels the rapid growth in the 1990s of feminist and critical geographies. Geographers within these traditions have focused their attention on the intersection of issues such as identity, difference and space, and the ways in which socio-spatial processes reproduce material and non-material inequalities. Empirical and theoretical work has focused on a range of specific issues such as gender (patriarchy), race (racism), sexuality (homophobia) and class. To this list has recently been added disability (ableism). However, most critical geography research has concentrated on examining the production and maintenance of geographies of social exclusion. Only a small number of studies have engaged directly with these issues in the context of specific theories of social justice and moral philosophy, which are seemingly taken for granted (see Smith, 1994, 1997). One area where these ideas have been applied is in relation to data generation, where there has been a concern for research ethics and the power relationship between researcher and researched. For example, a number of articles have been published exploring issues such as production and situatedness of knowledge, representativeness, reflexivity, empowerment, emancipation, critical praxis and positionality, and how these might be best addressed (e.g. Katz, 1992; Robinson, 1994; Rose, 1997). In the collection of short position papers gathered here, the theme of ethics and moral philosophy is explicitly examined in relation to geography (as a research practice and institutional endeavour) and the lives of disabled people.

## Disability, Geography and Ethics

Geographers are not alone in their lack of consideration of ethical issues in relation to disability. Questions concerning normative ethics, what might be envisioned as a just

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society and how disability fits within different models of social justice, have been little explored, even within disability studies. There the consideration of ethics has largely been confined to research ethics and the social politics of research practice. As such, there have been on-going discussions on how disability research should be conducted (e.g. collections by Rioux and Bach, 1994; Barnes and Mercer, 1997), with debate centring on issues such as exploitation, alienation, misrepresentation, the development of emancipatory and empowering research strategies and the role of non-disabled people in disability research (see Oliver, 1992; Stone and Priestley, 1995). To an extent, these debates have also been rehearsed in the geographical literature, with exchanges concerning the nature and application of geographical practice (Golledge, 1993, 1995, 1996; Butler, 1995; Gleeson, 1996; Imrie, 1996). However, in geography whilst we still largely fail to address issues of normative ethics in relation to disability (although see Gleeson, 1999), we seem to have taken the research ethics debate to a new stage, questioning whether we should directly link research and activism into a single politicised process. The answer to this question from many geographers studying disability (e.g. Chouinard, 1997; Kitchin, 1999), and other critical geographers (see Kitchin and Hubbard, 1999), seems to be 'yes'. The theoretical and empirical practicalities of this 'yes', however, need to be more fully examined, and the papers collected here go some way towards this end, and towards considering research ethics in a more traditional context.

The first two papers, by Brendan Gleeson and Vera Chouinard, both examine the role of geographers in the emancipation and empowerment of disabled people. These authors contend that geographers need to be more proactive, both in their research and in their professional capacity as teachers and members of educational institutions, in seeking to improve the material and non-material conditions of disabled people. Gleeson, in his paper *Enabling geography: exploring a new political–ethical ideal*, calls for an enabling geography that is grounded in a social model of disability and which seeks to contribute something positive to disabled people. In particular, he is interested in promoting 'strategies of engagement' whereby geographers join with disabled people in their struggle against social exclusion and social injustice. He asserts that while there are dangers of paternalism and unconscious domination, geographers can be a valuable resource to disabled people. This resourcefulness, however, is not fully exploited purely through academic endeavour. Geographers, he suggests, need to find their way out of academic journals and into local presses and local politics. Moreover, their research should become political projects aiming to change socio-spatial arrangements through its focus and through its research design, where more inclusive and empowering research strategies need to be adopted: we must think and act politically.

These arguments are echoed by Chouinard, who argues that geographers need to both acknowledge their research positionality and become politically engaged in disability struggles. For her, the creation of an inclusionary academy is riddled with ethical and political challenges. These include implementing emancipatory research strategies that recognise and address issues of academic power and privilege in knowledge production, academic complicity in the exploitation and marginalisation of disabled people, the problems of detached observation and paternalistic approaches to political engagement. Like Gleeson, Chouinard contends that identifying these issues is not enough: they need to be acted upon; an enabling geography has to be consistently implemented. This then is her challenge to geographers working on disability.

In the next four papers, these ideas are explored in relation to empirical research practice. One of the most striking features of the accounts presented and arguments advanced is the contrast between the idealised enabled geographies advocated by

Gleeson and Chouinard, and the reality of trying to translate these ideals into practice (a task that they never envisioned as being easy). For example, Isabel Dyck, in her paper *Putting ethical research into practice: issues of context*, discusses the way in which the multiple contexts occupied by researcher and research participants complicate efforts to conduct inclusionary or action-led research. Whilst emancipatory and empowering research might be a desirable ideal, she argues that we have to recognise the institutional and professional context of our work (she works in a school of rehabilitation, dominated by the medical model of disability) as well as those contexts occupied by people participating in research. Disabled people are socially positioned not only as a result of their impairment but also by other intersecting power relations that need to be addressed for true empowerment/emancipation to occur. Moreover, many disabled people lack a collective identity around which political mobilisation might occur. They may be unable or unwilling to engage in overt political activity. Empowerment then is not easily bestowed. As Dyck notes, however, the difficulties of implementing inclusive research do not mean that geographers cannot make a difference to the lives of disabled people. An ethnography that recognises the positionality of both research subject and researcher, for example, can still contribute to an enabling geography.

Deborah Metzel, in her paper *Research with the mentally incompetent: the dilemma of informed consent*, implicitly acknowledges some of the same issues raised by Dyck. The people on whom her gaze focuses are unable to become politically active in their own future. She critically examines some of the ethical dilemmas of conducting research on a group unable to give informed consent for that research. She argues that whilst there are no simple solutions to these issues, this should not be an excuse for geographers to ignore the geographies of this group. To do so would be to leave its members further marginalised within academic discourses. She therefore advocates a professional approach to research that follows a code of ethics that safeguards the interests of the disabled people studied.

Rob Wilton, in his paper *'Sometimes it's OK to be a spy': ethics and politics in the geography of disability*, also discusses the issues of consent, and of conducting covert research. His discussion, however, does not relate to the deception of disabled people but rather to those people who seek to exclude disabled people. He describes the research strategy he used in studying the contested geographies of service provision in Los Angeles, and the ethical and political issues that arose out of his work. The crux of his dilemma concerned how to negotiate a political commitment to try to overcome the exclusion of disabled people and a need to interview people opposed to their inclusion. Revealing the true nature of the research project might have jeopardised his contact with service opponents. Further dilemmas were raised when he was asked to share the knowledge he gained through his interviews to provide a basis on which to fight service provision restrictions. Ultimately, he argues that his deception was justified by a commitment to social justice and by a need to understand how and why non-disabled people marginalise disabled people.

Eric Laurier and Hester Parr, in their paper *Emotions and interviewing in health and disability research*, also examine some of the social politics of research, focusing their attention on ethics and the role of emotion in interviewing. They suggest that more attention needs to be focused on understanding the role of emotions within interviews and the consequences of these emotions on participants, both researched and researcher. As such, researchers need to think not only about the power relations operating within an interview, but also about the emotional dynamic between researcher and researched and the consequences of the discussion. These issues they assert cannot be unproblematically managed. Their observations are informed by their own experiences of

conducting ethnographic and interview-based research where they became increasingly conscious of the role of emotion.

## Ways Ahead/Work to Do

The papers presented here are short position pieces designed to flag and initially explore important issues that are in need of discussion and further empirical research. Whilst they examine a number of substantive issues they also inevitably present a selective and partial view that focuses primarily upon research (although see papers by Gleeson and Chouinard). As was discussed in the panel session from which these papers originate, questions about ethics, politics and disability have as much to do with geography as an academic institution as they do with geography as a research process. The geographies we teach, the institutions we belong to, the departments and classrooms we occupy, the resources we use, the conferences and fieldtrips we organise, the *status quo* we maintain, all need to be examined through an ethical eye. As Carolyn Anderson (in press) describes, disabled students are excluded from geographical classrooms, fieldtrips and conferences, due to poor institutional facilities and arrangements. These are practices that need not only critical reflection but action. Indeed, as a discipline we have been slow to turn what we preach, in relation to social exclusion, social justice and moral philosophy, into practice (although the work of the Disability and Geography International Network, particularly in the context of the USA, is actively seeking to change geographical institutional practice). There is also little doubt that the links between the academy and activism (of varying forms) need further exploration (see Kitchin and Hubbard, 1999).

As the papers in this issue illustrate, whilst we might wish to engage in a critical praxis of emancipation and empowerment, reality is often more complicated. As we attempt to translate theory into practice, we need to consider what it means to think and act politically. We need to assess how and in what ways we can join with oppressed groups in their struggles for emancipation, and to consider the consequences of these unions for those involved. And we need to think through what a just landscape might look like. These are not easy questions, but they are important nevertheless. Collectively, the papers offer ideas and inspiration, encouraging us to critically engage with, rather than avoid, questions of ethics and politics as we work toward more inclusive geographies.

## References

Anderson, C. (in press) Claiming disability in the field of geography: access, recognition, and integration, *Social and Cultural Geography*.

Barnes, C. and Mercer, G. (eds) (1997) *Doing Disability Research*, Leeds: University of Leeds, Disability Press.

Butler, R. (1995) Geography and vision-impaired and blind populations, *Transactions of the Institute of British Geographers*, 19, 366–368.

Chouinard, V. (1997) Editorial: making space for disabling differences: challenging ableist geographies, *Environment and Planning D: Society and Space*, 15, 2–6.

Gleeson, B. (1996) A geography for disabled people?, *Transactions of the Institute of British Geographers*, 21, 387–396.

Gleeson, B. (1999) *Geographies of Disability*, London: Routledge

Golledge, R.G. (1993) Geography and the disabled: a survey with special reference to vision impaired and blind populations, *Transactions of the Institute of British Geographers*, 18, 63–85.

Golledge, R.G. (1995) A response to Ruth Butler, *Transactions of the Institute of British Geographers*, 19, 369–372.

Golledge, R.G. (1996) A response to Gleeson and Imrie, *Transactions of the Institute of British Geographers*, 21, 404–410.

Imrie, R.F. (1996) Ableist geographies, disablist spaces: towards a reconstruction of Golledge's geography and the disabled, *Transactions of the Institute of British Geographers*, 21, 397–403.

Katz, C. (1992) All the world is staged: intellectuals and the projects of ethnography, *Environment and Planning D: Society and Space*, 10, 495–510.

Kitchin, R.M. (1999) Ethics and morals in geographical studies of disability, in: Proctor, J. and Smith, D. (eds) *Geography and Ethics: Journeys through a Moral Terrain*, London: Routledge, 223–236.

Kitchin, R.M. and Hubbard, P.J. (1999) Research, action and 'critical' geographies, *Area*, 31, 195–198.

Oliver, M. (1992) Changing the social relations of research production, *Disability, Handicap and Society*, 7, 101–114.

Rioux, M. and Bach, M. (1994) *Disability is not Measles: New Paradigms in Disability*, North York, Ontario: L'Institut Roeher.

Robinson, J. (1994) White women researching/representing 'others': from anti-apartheid to postcolonialism, in: Blunt, A. and Rose, G. (eds) *Writing, Women and Space*, New York: Guilford, 197–226.

Rose, G. (1997) Situating knowledge: positionality, reflexivity and other tactics, *Progress in Human Geography*, 21, 305–320.

Smith, D.M. (1994) *Geography and Social Justice*, Oxford: Blackwell.

Smith, D.M. (1997) Geography and ethics: a moral turn?, *Progress in Human Geography*, 21, 596–603.

Stone, E. and Priestley, M. (1995) Parasites, pawns and partners: disability research and the role of non-disabled researchers, *British Journal of Sociology*, 47, 696–716.

# Enabling Geography: Exploring a New Political–Ethical Ideal

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## Introduction

There is now wide recognition of geography's prolonged failure to address the question of disability (Imrie, 1996; Chouinard, 1997). Equally, however, there is growing awareness of emerging new debates and published studies within the discipline that are rectifying this silence.

Amongst the rapidly proliferating geographies of disability, there appears to be broad support for a political–ethical approach that I term here 'enabling geography'.[1] This broad ideal seems to rest on two key normative aims. First, an enabling geography presumes a social model approach, requiring explorations of how social and spatial processes can be used to disable rather than enable people with physical impairments. Second, an enabling geography seeks to contribute something positive to disabled people: for example, knowledges that can be used to empower disabled people and disempower ableist structures, practices and institutions. A lot has already been written about the first aim, in the form of studies of how space has been manipulated in ways that disadvantage and marginalise certain forms of embodiment, including disability (e.g. Dyck, 1995; Pile, 1996). My interest in this short essay is in the second normative aim,

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and in particular, the need for geographers to develop 'strategies of engagement' in their research that can produce real benefits for disabled people.

## Can We Presume to Make a Difference?

Wanting to contribute to the improvement of disabled people's lives may be a noble enough sentiment, but it immediately raises some confronting political–ethical doubts centring on the dangers of paternalism and unconscious domination. It is an ideal that many might quietly aspire to but at the same time feel uncomfortable with or unwilling to discuss openly. To an extent, these anxieties are the products of recent critiques (e.g. Spivak, 1987; hooks, 1994) that have, quite rightly, questioned the authority of academics who in the past have claimed to speak for the 'subjects', or even 'objects', of their research.

There remains in the social sciences a vigorous, and by no means resolved, debate on the tendency of research to colonise, appropriate and generally misconstrue the experiences of individuals and groups, especially those whose voices are usually unheard in the discourses of power (Harding, 1992). In some quarters this has made researchers less willing to unfurl the banner of progressive social science over their research endeavours. However, this reticence is a relatively recent phenomenon in the social sciences, and does not therefore entirely explain geography's long avoidance of disability issues. To a large extent, this disciplinary silence reflects the exclusion of disabled people and their concerns from the realms of authoritative knowledge.

I argue that the long failure of geographers to engage with disability issues has denied to disabled people a valuable conceptual, professional and practical resource that might have aided them in their relations—very often, their struggles—with the various professional and institutional agencies that have shaped their environments, often in oppressive ways. As many geographers themselves have come to realise, space is a social artefact that is shaped by the interplay of structures, institutions and people in real historical settings. The historical production of space is a contested process where the exercise of power largely determines who benefits and who loses from the creation of new places and landscapes. Knowledge about how space is produced, and for whom, is, of course, a vital element in this constant power struggle. That disabled people in Western societies have largely been oppressed by the production of space is due in part to their exclusion from the discourses and practices that shape the physical layout of societies. Geography, as Imrie (1996) notes, is one such spatial discourse of power that has marginalised disabled people.

To eliminate oppressive spatial practices and knowledges, it is first necessary to explain how and why they occur. I therefore welcome the new geographies that seek to explain why the production of space has disadvantaged disabled people, both in the past and in contemporary societies. I argue, however, that new geographic work on disability needs to do more than simply describe the spatial patterns of disadvantage: it must contribute in a variety of ways to a broader political campaign that disabled people, and advocates, are waging in various struggles against the construction of oppressive environments. As Chouinard (1997, p. 380) has put it:

> there is a need for new spatial research on disability that not only unsettles ableist explanations of social processes and outcomes, but also considers how such knowledge can be used to further political struggles against environments that exclude and marginalize disabled people.

Thus the new and expanding understanding of how space conditions disability will

inform a broad political–theoretical project that can both resist the sources of spatial oppression and articulate new ways of creating inclusionary landscapes and places. As Harvey (1996, p. 326) writes, 'A renewed capacity to reread the production of historical–geographical difference is a crucial preliminary step towards emancipating the possibilities for future place construction'. I think that (non-disabled) geographers and other social scientists should not seek to direct that broader political–theoretical process, as this is properly the task of social movements rather than academic observers. Rather, I hope that our historical and contemporary studies will play some indirect role in the larger emancipatory struggles of disabled people.

## Research and Political Engagement

There has been growing awareness in recent decades amongst critical geographers that our work should seek an emancipatory role outside the academy, within the real social contexts where people and social groups experience everyday oppression. Chouinard (1997) puts this same demand for the emerging field of disability geography, arguing for approaches that contribute to the actual political struggles of disabled people. I would argue that published works—such as this article—can and should contribute indirectly to the struggles of disabled people, though even this role cannot be assumed and the challenge remains for geographers to make their work accessible, and therefore relevant, to disability communities. To this end, one obvious strategy is for geographers of disability to expose their work to critical scrutiny outside our own discipline, especially within the academic and political fora of disability movements. Indeed, I think it a very positive sign that one professional forum for (English-speaking) geographers of disability, the Disability and Geography International Network, has itself become increasingly drawn into the realms of disability studies and disability movements, especially within the USA.

Nonetheless, as Chouinard (1994, 1997) reminds us, geographers should not restrict themselves to the sort of formal and indirect engagement with disability politics that publications and conference papers represent. Chouinard (1994, 1997) has argued for a reconstructed and democratised radical geography that embraces the multiple political concerns of socially marginalised groups, including disabled people. For her, this new and expansive radicalism demands that geographers connect practically and politically with the experiences of marginalised social groups:

> This means putting ourselves 'on the line' as academics who will not go along with the latest 'fashion' simply because it sells, and who take very seriously the notion that 'knowledge is power'. It means as well personal decisions to put one's abilities at the disposal of groups at the margins of and outside academia. This is not taking the 'moral high ground' but simply saying that if you want to help in struggles against oppression you have to 'connect' with the trenches (Chouinard, 1994, p. 5).

This then highlights the most practical, and the most challenging, demand of an enabling geography: namely, that geographers must participate in the political struggle against the socio-spatial formations that oppress impaired people. There is a need within the discipline for a debate on how we can achieve the forms of direct engagement that Chouinard (1994, 1997) has in mind. In particular, there should be discussion on the sorts of research strategies that would be appropriate for an enabling geography. A number of commentators, including Chouinard herself (1994, 1997), Chouinard and Grant (1995), Dorn (1994), Hall (1994) and Kitchin (1997), have contributed to an emerging discussion on this issue. All commentators stress the need for empowering

research strategies; that is to say, engagements by geographers that contribute to the political needs of disability movements.

In a recent consideration of this issue, Chouinard (1997) has outlined a number of enabling research methods that prioritise power-sharing. Specifically, these methods involve the transfer of technical skills and information to disabled people, and the pursuit of inclusionary research processes that de-centre the priorities of the researcher. Similarly, Kitchin (1997, p. 2) advocates a 'participatory action research' (PAR) model that attempts to 'facilitate a moral geography of social action through the facilitation of studies *with* and *by* research subjects' (original emphasis). Echoing Chouinard's (1997) 'power-sharing' approach, the PAR model 'seeks to fully integrate research subjects into the research process from ideas to data generation to analysis and interpretation to writing the final report' (Kitchin, 1997, p. 2).

Of course, an enabling geography must do more than identify empowering research methods: it must also locate, and engage with, the political arenas of disabled people and their various movements. The task of engaging with disability is unavoidably challenging for researchers: it demands both that we think politically about our work and that we expose ourselves to direct political evaluation. However, the task of locating 'places of engagement' is not nearly as difficult: indeed, many of us are already situated within important domains of struggle for disabled people. In spite of the barriers to educational achievement that confront them, there are many disabled people in places of higher learning amongst our students and colleagues.

Hence, our own workplaces—universities, research institutes and bureaucracies—are probably the most appropriate starting places for the emancipatory engagements that Chouinard (1997) envisages. In many instances, these institutions are disabling places, presenting physical, intellectual and administrative barriers to the development of disabled students and staff (Harris *et al.*, 1995). In an earlier essay (Gleeson, 1997) I documented some of the problems facing disabled students at one New Zealand university, including physical inaccessibility and ableist teaching practices. Many such institutions have disability advocacy fora, usually attached to student organisations, which welcome involvement by non-disabled academic staff. My own participation in such groups has enriched my appreciation of disability politics: universities are in many ways microcosms of the broader arenas of struggle for disabled people. I also learned much about inclusive teaching methods, everyday access issues and the disabling practices of educational institutions.

Golledge (1993) calls for geographical research which can enhance the ability of impaired people to cope with the experience of disability. Whilst I appreciate his impatience with social science that offers little of value to the everyday lives of disabled people, I believe that an enabling geography should aim to do more than simply ameliorate the effects of disablement. Justice demands that we uproot the sources of inequality rather than simply help oppressed people to cope with their 'misfortune'. Radical disability commentators, such as Morris (1991) and Oliver (1996), have opposed the ameliorative approach, arguing instead for a transformative politics. The social constructionist analyses forwarded by many radical geographers (e.g. Dorn, 1994; Chouinard, 1997) argue that disability can and must be opposed at a deeper socio-political level; namely, at the level of processes that create social space and thereby shape the social experience of embodiment. In particular, structures such as the commodity labour market and the capitalist land economy can be identified as critical realms of emancipatory struggle, given their importance in creating landscapes that exclude many social groups, including disabled people.

Of course, these are grand political aspirations and I think that they could only

succeed ultimately as part of a broader progressive shift away from the oppressive and alienating relations that frame capitalist societies. Nonetheless, as the various national and regional disability movements have shown, there is much that can be done in the meantime to confront the sources of disability oppression. Geographic analyses could contribute to these emancipatory movements by suggesting strategies, policies and regulations that aim to counter core disabling relations. For instance, Oliver (1991) points out that Western governments have not attempted to regulate the demand side of disabling labour markets. Rigorous comparative analysis of alternative approaches, such as the German labour law (see Bundesministerium für Arbeit und Sozialordnung, 1997), might help to foster support for enabling laws and policies in Anglophone (and other) countries. This sort of research requires a scale of political engagement that extends beyond the university to the level(s) occupied by disability movements that aim to influence state policies and practices. Obviously, there are many other levels of engagement that lie between the workplace and the polity, including the large variety of community struggles waged by disabled people.

## Conclusion

Whatever our scale of engagement(s), there arises the need for a political–ethical outlook that can guide an enabling geography. Ultimately, disability movements themselves can only define this ideal. However, I believe that geographers can and should contribute to this process of political–ethical definition. I suggest that an enabling geography requires an inclusive, but not homogeneous, ideal of social justice, such as that proposed by Young (1990) and critically elaborated by Harvey (1993). More specifically, I argue that this ethical ideal would have material fairness, socio-cultural respect and socio-spatial inclusion as its central political objectives.

As Young's (1990) analysis implies, these objectives cannot be achieved through simply the promulgation of universal moral standards. Rather, they must be won through political engagements that presume social difference and seek thereby to articulate and satisfy the variety of human needs that exist in contemporary capitalist societies. The idea that engagement is the means to enablement is echoed in a call by Chouinard (1994, 1997) and others (e.g. Hall, 1994) for geographers to contribute to the movements organised by disabled people themselves. Political engagement is the most powerful way of ensuring that geographic research serves (i.e. empowers) disabled people and thereby avoids the tendency of much social science—even avowedly progressive forms—to appropriate without recompense the experiences of marginalised people. As Chouinard (1997, p. 384) puts it:

> Contesting privileged knowledges of disabling differences require[s] research methods that go beyond giving 'voice' to the experience of persons with disabilities, to actively empowering those with disabilities in the production of geographic knowledge.

It is surely this capacity to direct empowering knowledge against disabling practices and ideologies that will define an enabling geography.

## Note

1. Whilst most observers seem to agree that geography can play a role in improving the lives of disabled people, there are some important differences of opinion about the socio-political basis for this. Golledge (1993), for example, has expressed ambivalence about the social model of disability, and conceives enablement in largely functional terms.

# References

Bundesministerium für Arbeit und Sozialordnung (1997) *Ratgeber für Behinderte*, Bonn: Bundesministerium für Arbeit und Sozialordnung.

Chouinard, V. (1994) Reinventing radical geography: is all that's Left Right?, *Environment and Planning D: Society and Space*, 12, 2–6.

Chouinard, V. (1997) Making space for disabling differences: challenging ableist geographies, *Environment and Planning D: Society and Space*, 15, 379–387.

Chouinard, V. and Grant, A. (1995) On being not even anywhere near 'the project': ways of putting ourselves in the picture, *Antipode*, 27, 137–166.

Dorn, M. (1994) Disability as spatial dissidence: a cultural geography of the stigmatized body, unpublished M.Sc.thesis, Pennsylvania State University.

Dyck, I. (1995) Hidden geographies: the changing lifeworlds of women with disabilities, *Social Science and Medicine*, 40, 307–320.

Gleeson, B.J. (1997) The regulation of environmental accessibility in New Zealand, *International Planning Studies*, 2, 367–390.

Golledge, R.G. (1993) Geography and the disabled: a survey with special reference to vision impaired and blind populations, *Transactions of the Institute of British Geographers*, 18, 63–85.

Hall, E.C. (1994) *Researching Disability in Geography*, Manchester: School of Geography, University of Manchester, Spatial Policy Analysis Working Paper 28.

Harding, S. (1992) After the neutrality ideal: politics, science and 'strong objectivity', *Social Research*, 59, 567–587.

Harris, D.-R., Rowlands, M., Ballard, K., Smith, K. and Gleeson, B.J. (1995) Disability and tertiary education in New Zealand, unpublished report submitted to Ministry of Education, Wellington, New Zealand.

Harvey, D. (1993) Class relations, social justice, and the politics of difference, in: Keith, M. and Pile, S. (eds) *Place and the Politics of Identity*, London: Routledge, 41–66.

Harvey, D. (1996) *Justice, Nature and the Geography of Difference*, Oxford: Blackwell.

hooks, b. (1994) *Outlaw Culture: Resisting Representations*, New York: Routledge.

Imrie, R.F. (1996a) *Disability and the City: International Perspectives*, London: Paul Chapman.

Kitchin, R. (1997) Participatory action research in geography: towards a more emancipatory and empowering approach, unpublished paper, copy obtained from author.

Morris, J. (1991) *Pride against Prejudice: Transforming Attitudes to Disability*, London: The Women's Press.

Oliver, M. (1991) Disability and participation in the labour market, in: Brown, P. and Scase, R. (eds) *Poor Work: Disadvantage and the Division of Labour*, Milton Keynes: Open University Press.

Oliver, M. (1996) *Understanding Disability: From Theory to Practice*, London: Macmillan.

Pile, S. (1996) *The Body in the City: Psychoanalysis, Space and Subjectivity*, London: Routledge.

Spivak, G. (1987) *In Other Worlds: Essays in Cultural Politics*, New York: Methuen.

Young, I.M. (1990) *Justice and the Politics of Difference*, Princeton, NJ: Princeton University Press.

# Getting Ethical: For Inclusive and Engaged Geographies of Disability

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Geographers committed to empowering approaches to research on disability and space face significant ethical issues. In this paper, I argue that these can be effectively

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addressed if geographers are prepared to take responsibility for their own positionality and role in research and knowledge production, and to be politically engaged with disabled people's struggles for more inclusionary environments. Both challenges are difficult ones, and there is no single 'politically correct' way for researchers to address them. Differences between researchers, such as conflicting views on what the goals and strategies of disability activism should be, influence decisions on how research can be designed and used in support of disabled people's struggles. Researchers opposed to employment strategies associated with oppressive working conditions, such as sheltered workshops, for instance, may refuse to participate in projects which focus on ways of increasing employment in such environments. In short, researchers committed to empowerment through research must negotiate complex political tensions and contradictions that are part and parcel of struggles for social change.

This paper begins to grapple with such issues in the context of geographic research concerned with disability and space. It outlines some key ethical issues associated with such research, and then illustrates ways of addressing these in practice. My position on 'getting ethical' is informed by commitment to the radical, leftist goal of solidarity with and empowerment of oppressed groups in late capitalist societies, and by feminist concerns to challenge academic privilege and power in the knowledge production process.

## Ethical Issues in Radical Geographies of Empowerment

Geographers trained in traditions of inquiry which are self-consciously critical of oppressive modes of social organisation and of how knowledge about society is produced, such as political economy and feminist geography, believe that the point of knowledge is not just to understand the world, but to help change it for the better. Unlike rationalist views of knowledge, this perspective recognises that knowledges are never neutral: that they are riddled with assumptions about the way the world works and what we mean by concepts such as equality and justice, and that they often conceal as much as they reveal. And it admits that knowledges make a difference in whether and how societies change: that they can be used to legitimate the existing social order or promote fundamental changes in it. A key challenge for critical geographers is thus to find ways of producing and using knowledge that empower disadvantaged groups in struggles for social change.

This challenge poses difficult ethical dilemmas. And despite substantial attention to ethical matters in literatures such as sociology and women's studies, there continues to be relatively little discussion of ethical issues in the geographical literature. With exceptions, such as England's (1994) reflections on the dilemmas of difference in feminist research, few geographers seem prepared to wrestle (at least in print) with what counts as ethical research, and perhaps more importantly, what doesn't. There are promising signs that this situation is changing, including the conference session on ethical issues in research on disability and space which led to this collection.

In what follows, I reflect on ethical dilemmas in doing radical and 'activist' research on disability and space. These are not unique to this area of inquiry, but are in some ways thrown into especially stark relief by the extremely disempowered positions of disabled persons in our societies, and in the production and use of knowledge about their lives.

### Academic Power and Privilege in Knowledge Production

I was reminded of how difficult it is to even begin to name the ethical dilemmas

academics face when one reviewer reacted impatiently to my claim that academics enjoy power and privilege by scrawling 'not so privileged' and 'it's bloody hard work' in the margins of an earlier draft of this paper. There is something about trying to name the ethical issues that we face as academic researchers that makes us want to divert the discussion to something else: to debating just how privileged academics really are or whether we deserve those privileges because, for example, we work hard. Perhaps talking about our own positionality and the privileges and ethical obligations associated with it hits us a little 'too close to home', threatening to unsettle our views of our place in the world and of the differences our work makes.

Still, the fact remains that as academics we exercise a great deal of power over what counts as knowledge, how it is created and *for whom*. We decide what topics are worthy of investigation and what questions need to be asked about phenomena such as homelessness and poverty. We decide who will be included in the research process and, significantly, who will not. Academic researchers, rather more arguably today as post-secondary institutions and researchers are increasingly forced to seek private sector funding, continue to enjoy the privilege of independent thought and inquiry. This gives us the power to draw our own conclusions about research findings, to decide who will have access to those findings (and again significantly, who will not), and within the context of institutional ethics review processes to establish the terms and conditions of participation in our research. At a personal level, we are privileged to be able to do work that we care about and are intellectually stimulated by. In societies troubled by high rates of unemployment, especially among younger workers, and the concentration of job growth in the low-paying service sector, these privileges are very significant ones.

In the past geographers have sometimes addressed issues of power and privilege in rather naive ways: for example, trying to minimise differences between themselves and those they 'research' by temporarily experiencing aspects of their daily lives or by choosing to conduct research on people relatively similar to themselves in terms of characteristics such as race/ethnicity (Rose, 1997). Such approaches incorrectly conflate difference and power, and are ethically problematic insofar as they prevent researchers from acknowledging and taking responsibility for their power within the research process. Naming academic power and privileges for what they are makes it possible to begin imagining ways of doing research that include those normally excluded from knowledge production, and which use academic power in ways that empower others.

### Complicity in the Exploitation and Marginalisation of the Disabled

If it is difficult to name our power as academic producers of knowledge, it is even more difficult to admit that we are sometimes complicit in societal processes of exploiting and marginalising the disabled. If, for example, we conduct research by appropriating the life stories of disabled persons, by using contacts with research participants to gain access to data and personal knowledge but otherwise excluding participants from the production and use of research results, we are arguably complicit in constructing persons with disabilities as oppressed and marginalised 'others'. Research practices that use the disabled as a primary information source but fail to address related issues of disempowerment in the production of knowledge about disability, including direct exclusion from the research process and indirect exclusion from institutions of higher learning, help to legitimate and reinforce the oppressed position of persons with disabilities in the production of knowledge. Indeed, such practices can arguably be seen as a violent and exploitative theft of one of the few resources that disabled people have in late capitalist societies: knowledge and insights about what it is like to be disabled.

Even if one allows for possible 'unintended' benefits of research, such as raising awareness of the poverty in which most disabled people live, an exchange in which the researcher receives information essential to producing 'their' knowledge and participants receive only a possibility that the research will make a positive difference in their lives is a highly unequal one. It is an exchange that devalues the contributions of disabled participants to knowledge and thus reinforces their marginalised positions in society. It is perhaps not surprising that researchers are reluctant to take responsibility for this complicity, since it requires us to admit that our research practices may in certain respects be highly unethical and that we ought to consider measures such as more inclusive research designs in order to 'give back' something equally valuable to those who make our research (and indeed careers) possible.

Researchers involved in projects that do not require direct participation by persons with disabilities also need to consider the complicity issue. For oppressed groups have other stakes and claims in the knowledges we produce. A quantitative study of state restructuring and its economic impacts on disabled persons, for instance, might not involve direct participation of persons with disabilities but still indirectly draw on studies produced in part by disabled activists and benefit from the fact that disability struggles have helped prompt the state to keep better statistical records of the socio-economic status of the disabled. One can go further and argue that a study which details conditions of life that cause misery to others and fails to contribute to changing those conditions by working to empower the persons whose lives are at stake is a kind of intellectual trafficking in human suffering. Is this too harsh a judgement? Maybe. But it does pose the moral issue of the extent to which researchers should assume that the knowledge they produce is, in and of itself, beneficial to society in general and its disadvantaged members in particular.

The use of 'expert' models of knowledge (implicitly or explicitly), in which the only authoritative voice in the presentation and interpretation of research results is that of the academic researcher, is another form of complicity in the cultural oppression of persons with disabilities. Even if the researcher is disabled, their particular, situated experiences of disability are not sufficient to enable them to speak for disabled persons more generally or to negate the privilege of their position as an academic researcher (albeit probably one at the margins of academic power). Exclusionary research practices and the retention of authority by academic researchers are often experienced as significant barriers to creating and using knowledges in ways that advance disabled persons' struggles for empowerment, political voice and action. The Disabled Women's Network (Canada) recently expressed its frustration with participation in academic research by stating bluntly that 'We are tired of being "researched". We want research by and for disabled people' (personal communication).

## Detached Rather than Engaged Research Gazes and Practices

Although many geographers, and philosophers of science, reject conventional notions of scientific objectivity and neutrality, remnants of positivistic, rationalist models of science persist and inform our research practices. Nast and Kobayashi (1996) remind us how visual metaphors and ways of knowing are privileged in social scientific research and how such practices emerged from Enlightenment models of the scholar as a detached and rational observer of events. This model persists, for example in recent geographic research on identity and difference, which, despite trying to understand the situated, shifting and emotive facets of our experiences of spaces of life, often presents research results through a detached, neutral and non-invested (in emotional terms) academic gaze.

This has significant consequences for how research results are interpreted and used. The feminist geographic literature on performative or transgressive acts, for example, tends to examine those acts in and of themselves (to objectify them). This in turn makes it difficult to raise political and personally 'invested' questions about what's at stake in such acts: for instance whether such performances promote greater respect for differences in sexuality within spaces dominated by heterosexual cultural norms (see for example Bell and Valentine, 1995).

Critical and engaged research gazes and practices, in contrast, recognise, nurture, celebrate and critically assess our political and emotional commitments to causes such as the elimination of socio-spatial barriers to the inclusion of the disabled. By rejecting problematic assumptions that research focused on marginalised groups is necessarily empowering to them, this approach helps focus our attention on how we can realise political solidarity in research practice.

*Privileged, Paternalistic Approaches to Political Engagement*

Historically, critical approaches to social research have tended to share conventional views that knowledges produced through academic research are inherently superior to other forms of knowledge. Since these traditions also imply a critique of existing societies and a concern with possibilities for progressive change, this tendency brings with it the related danger of privileging academic viewpoints on issues such as what counts as political engagement by researchers and the societal changes needed in order to empower disadvantaged groups.

For example, geographic studies of disability and space which conflate personal encounters between researcher and researched with engagement in struggles for empowerment run the risk of placing researchers in the ethically problematic position of privileged intellectual and political leaders (c.f. Routledge, 1996). This is particularly true if the researcher regards her or his role as that of the expert or radical who unsettles the world views of disabled participants by imparting knowledge and thus inspiring them to resist their oppression. Such conceptions of the academic's role and positionality have led to lengthy debates in the Marxist literature over whether members of the working class are 'falsely conscious' of their societal position and thus in need of intellectual leaders who can 'reveal' their true position and interests to them. It is important to recognise that such 'working models' of the links between intellectual work and political practice privilege academic standpoints and thus fail to fully respect alternative ways of knowing or resisting. This in turn can translate into exclusionary political practices, such as devaluing or dismissing proposals for collective action which are judged to be inconsistent with the collective interests of the disabled as defined by academic knowledge. Ethically, such exclusionary political views and practices arguably make academics complicit in the oppressions they claim to challenge.

The way we interpret and represent our research findings can also help to place us, often unintentionally, in ethically problematic and paternalistic positions with respect to groups such as the disabled. For instance, an authoritative 'expert' writing style can cause speculative interpretations of inconclusive research findings to appear to be more convincing than they are. I recently read an article on disabled persons' lives in a particular locality which remarked in passing that it was 'curious' that none of the study participants reported being involved in political action. Implicit in this statement was a privileged and paternalistic judgement that, whatever the reasons for inaction, the disabled *ought to be more active*. What this narrative didn't convey was that the researchers weren't in a position to make an informed judgement on this matter (not

having investigated why the disabled people in question were not politically active), and that other possible reasons for inaction needed to be considered, such as the impacts of cutbacks in government programmes and services to the disabled on opportunities to engage in activism.

## Getting Ethical: Ways of Addressing These Issues

If a first step in getting ethical is naming the dilemmas we face, the second and crucial step is to do something about them in research practice. How, then, can we help to ensure that critical geographic research on disability is more ethical and empowering to persons with disabling differences?

### Challenging Academic Power and Privilege in Knowledge Production

As indicated above, *naming academic power and privileges for what they are* involves recognising that access to resources such as research grants, computer networks and library resources, resources sometimes taken for granted, is a privilege of position and not an individual right. Similarly, the opportunity to reflect upon the causes of social injustices and ways of struggling for more just societies is a privileged albeit often difficult role. If we acknowledge this and are politically committed to empowering research, then we have a responsibility, a moral obligation, to challenge this privilege and the socio-spatial inequities in the production and use of knowledge associated with it.

But before we can act on this obligation, we need a clear map of what these inequities are and how they are reproduced. At the local scale, cultural constructions of academic knowledges as 'expert' and more valuable than other ways of knowing are perpetuated through a complex web of daily practices: from job advertisements equating academic credentials with knowledge and skills, to the use of academic experts as witnesses in court disputes, and deference to academic judgements in places such as planning offices and classrooms. If we try to challenge these constructions of what 'counts' as knowledge as academic individuals, for example by emphasising direct quotes from participants in our narratives about research results or using film to create a virtual presence of other knowers in exclusionary spaces such as conference sessions, we are likely to come to the frustrating conclusion that although we may have virtually validated other knowledges, prevailing relations of power in knowledge production remain intact. Our efforts to situate ourselves in opposition to exclusionary knowledge is further complicated by the fact that opportunities to produce and use knowledge are geographically uneven and that knowledge produced in Western nations has greater influence than that produced in other parts of the world. At the global scale, researchers located in Third World nations often lack access to basic resources such as journals and find their work neglected by Western academics (Slater, 1992). At regional and local scales oppression on the basis of differences such as disability complicates these geographies of cultural exclusion, finding expression in the relative absence of disabled scholars and students within academic institutions, systemic discrimination within such institutions and multiple physical and social barriers to participation (e.g. the design of academic environments and the 'print barrier'; see Golledge, 1997).

What sorts of research practices can we use to challenge such exclusionary mappings of power within the production and use of knowledge? Research designs which share access to resources with disabled participants and/or disability organisations are one such practice. Research partnerships between academic researchers and community-based

organisations of the disabled can create opportunities for shared involvement in the research process and in determining how research results will be used to promote social change. I was involved in such a partnership through a collaborative research project on positive work environments for persons with disabilities (Zeytinoglu *et al*., 1996). Data collected through focus groups with disabled workers were summarised by researchers and then discussed in follow-up focus groups which considered matters such as how initial results should be interpreted, the steps government and other agencies should take to encourage more positive work environments for persons with disabilities and how research results should be used to help promote social change. Local organisations of the disabled were involved in the project as research partners. They helped to oversee the research process and to interpret results, and provided input on using the results to promote action on local employment and workplace issues. The study included follow-up partnership events, such as a forum on project results at a local employment fair for persons with disabilities.

In contrast to practices such as quoting research participants, partnership research projects actually share academic power over matters of research design, conduct, interpretation and use. They are thus more likely to ensure that the knowledge produced has user value to disadvantaged groups, and they also redistribute resources and decision-making power in the production and use of knowledge itself. In the study discussed above, follow-up discussions of initial focus group results allowed participants to correct researchers' interpretations of their comments and to elaborate on new, related issues (such as frustration with the lack of pro-active job creation strategies for the disabled at local and provincial levels of the state). In short, this partnership project was able to validate alternative ways of knowing in the actual research process itself and allowed a collaborative approach to determining how knowledge would inform social action.

Study designs can incorporate opportunities for empowerment in other ways. Disabled co-researchers can be invited to share and discuss research results in places from which they are often excluded: university classes, conferences and meetings with research funding agencies and interested politicians, for instance. Research can thus help to facilitate networking amongst disabled activists and between the disabled and those in positions of power. My most recent research project, concerned with the impacts of state restructuring on the disabled and disabled activism, includes networking opportunities through a local community forum which will focus on *how barriers to well-being and collective action can be addressed.*

Including persons with disabilities in the research process is a small but significant step toward empowering the disabled in the production of knowledge about their lives. More radical initiatives could relinquish final control over the issue of what counts as knowledge by 'making space for' alternative and even competing interpretations of research results. For example, the differences that emerge in situated knowledges within a partnership study of barriers to participation of the disabled in local communities could be shared, not with the aim of arriving at a 'consensus' explanation or eliminating difference, but in order to encourage discussion of the sorts of differences in knowledge found, and the insights different vantage points provide. A recent initiative at my university to promote such discussions are 'diversity lunches', at which members of marginalised groups share diverse knowledges about what it's like to be 'different' on campus, and what changes in the university environment would promote inclusion. Participants draw on a variety of academic and non-academic knowledges in these discussions.

Geographies of exclusion in the cultural construction and representation of knowl-edges can also be challenged in creative ways. As a feminist colleague recently

suggested, traditional, individually performed academic roles, such as acting as a discussant at geography conferences, can be modified so that marginalised 'others' (e.g. Third World and disabled women) are included in a collaborative assessment of critical geographic knowledge about issues affecting their lives. More global strategies aimed at challenging geographic biases in the representation and assessment of knowledges about oppression could complement such local actions. Research forums or conferences could be designed to focus on 'who and what's missing' in Western accounts of the causes and consequences of disabling environments. A related aim of such events could be to promote inclusion of those normally excluded from such discussions: disability activists in general and activists and scholars from non-Western nations in particular. Careful strategic planning, through use of low-cost accommodation, volunteer support and targeting of financial assistance to marginalised groups, for example, could help to reduce physical and financial barriers to participation. Other initiatives, such as establishing research institutes based on partnerships with diverse marginalised groups, could also help to create more inclusive and empowering spaces of knowledge production and use.

## Challenging Our Complicity in the Exploitation and Marginalisation of the Disabled

At a personal level, challenging academic complicity in the oppression of the disabled requires researchers to accept a moral obligation to avoid research practices that perpetuate or exacerbate the marginal position of disabled persons in society and space. More pro-actively, it requires commitment to research practices that challenge this oppression. Ensuring that disabled participants are economically compensated for their time and contributions, for instance through honorariums, and that their situated knowledges are respected (as outlined above), are ways of valuing and affirming their participation in research projects. Participants' contributions can be acknowledged not only through citation in academic publications, but also in places that benefit and empower the disabled: for example, within local community organisations and in discussions with agencies in positions to support research and other initiatives by and for the disabled. Researchers can relinquish some of their privilege and power in such contexts by allowing disabled participants to present their own interpretations of research results, even if these conflict with academic accounts in significant ways.

Researchers committed to political engagement in struggles against the oppressions they study arguably have an obligation not only to 'validate subjugated knowledges' but also to compensate disabled partners or participants for their contributions to knowledge by conducting and using research in ways that further disabled people's empowerment goals. There are various practical ways to fulfil this commitment. Disabled partners can be encouraged to provide input on how the research process can be adjusted to meet their needs and goals. Supportive spaces, such as local forums on disability issues, can be created so that disabled persons can share views on the research and its implications. Including disabled persons in decisions about how research results will be used and what future research will be conducted also provides opportunities for empowerment. In the positive work environments project, disabled participants and partner organisations helped to decide which local decision-makers would be informed about research results, how the results would be used to encourage local government and employers to promote positive employment opportunities and work environments, and what further research was needed. Such practices recognise disabled persons' stakes in research about their lives and rights to expect that it will be designed, conducted and used in ways that make positive differences in their lives. Clearly, strategies like these help to place researchers

in positions of practical, political solidarity with the disabled in ways that conventional strategies, such as circulating summaries of results to participants, do not.

*Promoting Engaged Research Gazes and Practices*

Although recent post-positivist philosophies of science reject notions that the social scientist is a detached, neutral and purely objective observer of events, elements of this image persist in our research practices. One example of this is our tendency to regard the research process as a primarily intellectual exercise, rather than as a set of activities that emotionally engage and politically situate researchers within the production and use of knowledge about social issues. Acknowledging the latter has important ethical implications. Recognising that we are emotionally and politically invested in the research that we do implies that we cannot 'opt out' of addressing how we are personally and politically 'situated' within the production and use of knowledge. Further, it implies that we must take responsibility for the partiality of the knowledges we produce: for example, by reflecting on how the 'personal' informs our research efforts and by making our political commitments explicit in conducting and sharing our research.

Taking on such responsibilities can be a difficult, contradictory experience (see for example Routledge, 1996), forcing us to grapple with how we help to perpetuate academic privilege in our day-to-day practices within institutions such as universities and within social movements (e.g. through cultural practices which construct academics as 'experts'), and more generally with how to engage in acts of political solidarity with grass-roots struggles in which we are at least in part 'outsiders'. In short, it forces us to ask how the social and geographic situatedness of our lives as academics shapes and perhaps limits our capacities to understand oppression and to contribute to resistance to it. In what ways, for instance, does spending our working lives within information-rich environments limit our abilities to understand the everyday barriers to information faced by disability activists? Do our proposals for political action take adequate account of barriers to collective struggle, such as grinding poverty and spatial entrapment within the home, particularly if we do not experience such facets of ableist oppression in our own lives? Do our experiences as 'experts' within the academy encourage us to accept roles as privileged 'knowers' and decision-makers in disability struggles too readily, perhaps limiting opportunities to build more inclusive, grass-roots leadership?

Being an engaged researcher is thus more than simply being politically active: it involves learning to appreciate the situated nature of our own understanding of and political responses to social issues, and the implications of this for knowledge production, political action and social change. Grant (1996) discusses how her attempts to combine academic and activist roles in her study of women's struggles against male violence enriched the knowledge produced, by allowing her to experience political discipline and resistance directly, but also created difficulties such as sometimes situating her in opposition to other activists (who were also co-researchers) on matters of political strategy. This added to the emotional intensity of the research experience, complicated relationships within the research process and made collective review of her interpretations of findings particularly important.

Engaged research gazes and practices thus challenge us to work through some of the dilemmas of using academic and other knowledges of oppression to inform collective political action. They encourage us to face up to the partialities of academic knowledges, and to explore more inclusive ways of applying various knowledges in collective

struggles against oppression. They challenge us to create spaces of research which 'unsettle' academic authority in knowledge production and use: spaces that are simultaneously more inclusive, collective and contested.

### Inclusive Approaches to Political Engagement

Bringing the spaces of academic life and grass-roots activism together is a difficult challenge. Cultural constructions of academics as 'expert knowers' permeate spaces of political action and make solidarity with groups such as the disabled difficult. Cultural deference to 'experts' may encourage submission to their political judgements as well thus helping to marginalise grass-roots leadership. Disabled persons with negative past experiences of oppression within conventional academic research may be sceptical of and even hostile toward efforts to bridge academia and activism. So while engaged research gazes and practices may help set the stage for negotiating academic and activist spaces in more inclusive and empowering ways, they by no means guarantee that this will occur.

What can academic researchers do to challenge their cultural privilege within spaces of grass-roots activism? One strategy is to take advantage of opportunities to defer to other ways of knowing: to point out, for example in discussions of organising strategies, when non-academic knowledges of disability are needed to understand and advance political struggles. Notions that devalue non-academic knowledges, for instance the idea that 'hard' quantitative facts are the best means of swaying powerful groups such as politicians, can be challenged by showing how personal accounts of disabled lives enrich our understanding of disability issues (e.g. identifying the human and social costs of current policies). Activist researchers can help to nurture grass-roots leadership by positively reinforcing creative and credible suggestions for political action. Perhaps most importantly, activist researchers can insist that the situated knowledges they produce are an incomplete basis for political action and solidarity, and that by sharing different knowledges struggles for social change can become more inclusive and effective.

Strategies such as these can help to create spaces in which non-academic knowledges are valued and used as bases for action. These need to be 'safe spaces' in which academic knowledges and political prescriptions can be openly questioned and assessed, and alternative ideas presented. And they need to be spaces in which new relations of reciprocity, rather than privilege, are negotiated. In a culture still often mesmerised by expert opinions, this is both an urgent and a difficult challenge.

### Conclusions: Ethics in the 'Real' World

As geographers are well aware, it is one thing to propose ways of 'getting ethical' in academic print and another to realise this in the messy, often unruly realm of 'real world' research. Everyday circumstances often frustrate efforts to be more inclusionary. Community-based disability organisations, starved of funding, time and personnel, may be reluctant to commit to partnership research projects. Negative past experiences of working with academic researchers, such as failed promises to share or discuss research results, often make activists sceptical of future collaborative research. Deadlines for reporting on project results or the desire to get results published can encourage researchers to 'cut corners' when it comes to participation by non-academic groups. Researchers who wish to 'get ethical' may find that colleagues do not appreciate the benefits or special challenges of inclusionary research and thus devalue their work.

These are the daunting realities of academic research. Should we then conclude that efforts to develop more ethical and empowering research strategies are 'too hard' or even naive? No. Yes, translating principles into practice is an imperfect process. And yes, we may sometimes fail. But when what is at stake is creating knowledges that make a difference—that empower and perhaps even advance social justice—these are small risks to take.

## References

Bell, D. and Valentine, G. (1995) The sexed self: strategies of performance, sites of resistance, in: Pile, S. and Thrift, N. (eds) *Mapping the Subject: Geographies of Cultural Transformation,* London: Routledge, 145–157.

England, K.V.L. (1994) Getting personal: reflexivity, positionality, and feminist research, *Professional Geographer*, 46, 80–89.

Golledge, R. (1997) On reassembling one's life: overcoming disability in the academic environment, *Environment and Planning D: Society and Space*, 15, 391–409.

Grant, A. (1996) Geographies of oppression and resistance: challenging the heterosexual regime, unpublished doctoral dissertation, Department of Geography, McMaster University, L8S 4K1.

Nast, H. and Kobayashi, A (1996) Recorporealizing vision, in: Duncan, N. (ed.) *Body/Space*, London: Routledge, 75–93.

Rose, G. (1997) Situating knowledge: positionality, reflexivity and other tactics, *Progress in Human Geography*, 21, 305–320.

Routledge, P. (1996) The third space as critical engagement, *Antipode*, 28, 399–419.

Slater, D. (1992) On the borders of social theory: learning from other regions, *Environment and Planning D: Society and Space*, 10, 307–327.

Zeytinoglu, I., Westmoreland, M., Denton, M., Chouinard, V. and Pringle, P. (1996) *Positive Work Environments for Persons with Disabilities*, Research Report, McMaster Centre for the Promotion of Women's Health, McMaster University, Hamilton L8S 4K1, Canada.

# Putting Ethical Research into Practice: Issues of Context

## ISABEL DYCK

## Introduction

Debate about how disability research should be approached is well rehearsed in the literature, particularly within sociology. As a social model of disability has been proposed, critiqued and modified, the theoretical as well as political links between conceiving research and its mode of practice with persons differently disabled have also been interrogated (Barnes, 1992; Morris, 1992; Oliver, 1992; Stuart, 1992; Zarb, 1992; Sample, 1996; Shakespeare, 1996; French and Swain, 1997; Stalker, 1998). Feminist

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scholarship, critical 'race' theory and poststructuralism all carry implications for what might be considered ethical disability research, in terms of not just the more traditional model of 'protecting the subject' but what the outcome of that research should be, what it should 'look like' and to whom and how it should be made accessible. Certainly in this discussion, there is consistency along the lines of making space for absent voices and attempting to include 'the researched' into the research process through participatory and emancipatory research methods and paradigms that focus on the concept of oppression. There is less consensus over the participation of 'able-bodied' researchers in disability studies research as standpoint epistemology is critically engaged (Stone and Priestley, 1995; Vernon, 1997).

Geographers discussing the use of qualitative methodology have been particularly sensitive to the cultural and social contexts of the voices to be included in constructing knowledge that is intended to enhance understanding of embodied research participants in particular places (Nast *et al.*, 1994; Dyck and Kearns, 1995). Sensitivity to such contexts includes not only analysing how experiences are constructed and given meaning in particular socio-spatial contexts, but also a politics of methodology which derives from such socio-spatial contexts and their cultural shaping (Parr, 1998). Yet, there is relatively little explication of the day-to-day struggles in doing geographical field research which seeks to see the person and society in a context of recursive, ongoing constitution of each other.

In this paper, I address two dimensions of my research that have not received much attention in this otherwise well rehearsed discussion. These take account of some of the complexities of context as they relate to my positioning as a white, feminist, largely able-bodied geographer affiliated with a university and occupying a faculty position where most of the students I teach are destined to be health professionals. One dimension concerns institutional mandates and the admission of knowledge from 'different voices'—not in this case those of people categorized as 'disabled', but those of social scientists, such as geographers, in a curriculum heavily packed with educational materials and ways of learning that are intended to produce a thinking, flexible, client-centered health professional. The second dimension I discuss is that of the possibilities of research, in part directed toward this audience, to make a difference when this is conducted with population groups not well positioned to be involved in action-oriented research. These, for example, include minority group women with little connection with the community organizations that might represent their interests, and women with debilitating chronic illness with little energy or interest in becoming politically involved. How might research practice and associated knowledge production in this context affect the 'social change' disability studies researchers see as essential if the lives of the (dis)abled are to be improved? Can challenging dominant discursive constructions of disability—one output of academic endeavor—readily be translated into material change? If such is likely to contribute to only slow, incremental change is it to be valued in the same way as the work of those finding ways of working with particular groups in making specific, more immediate practical or policy change? Furthermore what can geographical perspectives bring to this type of contribution?

## Inclusionary Strategies for All? Some Tensions and Problematics

I have thought about my own research in terms of the above questions, where the ambiguities of addressing two different audiences—health and disability geographers and health professionals—bring a tension to how I do research and negotiate the presentation of the knowledge produced through that research. One aspect of my research concerns

the effectiveness of the biomedical health care system for first generation Canadian women who have immigrated from non-English speaking countries and, in the context of Canada's multiculturalism, are commonly referred to as from 'visible minority' groups. The other concerns the everyday realities for women living with disabling chronic illnesses, including the ways in which they restructure their home, community and work environments. In this work I focus on the sociospatial and discursive structuring of the women's experience. The studies I have engaged in are collaborative, and interdisciplinary.[1]

While one aspect of my research speaks directly to issues of treatment intervention by health professionals, the other emphasizes the daily negotiation of disability and a disabled identity by women as they go about their everyday lives. Both strands of research point to the complex interactions between health, gender, 'race' and place. They are not studies, though, that have involved disabled people in setting the agenda of the research, or acting as partners in the sense of achieving 'empowerment' as advocated in participatory and emancipatory models of research. There are two issues I want to raise in this connection, particularly in pursuing the notion that such models advocate a process that supports people in speaking for themselves and defining their own issues. First is the difficulty of making space for absent voices that Morris (1995) refers to, when those absent voices are not politicized around a collective identity. Second is the problematized distinction between impairment and disability (French, 1993; Crow, 1996; Oliver, 1996), and its implications for the action-oriented model of participatory research. For example, as pointed out in critiques of the social model of disability, pain or other debilitating symptoms (such as chronic fatigue for many of the women in our studies) may preclude the action required in commonly understood ways of involving the disabled in participatory research. These considerations suggest that ethical disability research, while centrally concerned with inclusionary strategies and moral obligations around the issue of social justice for disabled people (the latter a term itself that needs careful scrutiny in use), can take more than one form for its outcome to have implications for its participants as individuals, as well as collectives, whether through influencing discursive constructions of 'disability' or through social practices affecting the lives of those categorized as disabled.

## Discursive Interrogation, Absent Voices and Politics of Knowledge Construction

Although the emphasis in my work on the discursive and material construction of the 'deviant' body does not constitute direct social action affecting the lives of the study participants, it does have the potential for influencing the theoretical constructs underpinning models and modes of health professional practice. While the ableist world of most geographical knowledge is being challenged by geographers working with issues of disability (Chouinard, 1997), disability studies are strangely absent from the curricula of schools of rehabilitation. Despite the philosophy of rehabilitation professionals of working with clients in a client-centered and holistic manner, and taking account of the environment in intervention strategies, an individual model of disability prevails (Abberley, 1995). My research then, for that audience, aims to influence the building concepts and theoretical frameworks within which rehabilitation is practiced. Exploring the social and spatial structuring of disability and chronic illness experience through qualitative research approaches challenges the medical model as the dominant discursive construction of disability, together with its translation into the material practices of health care institutions and practitioners of health care. I attempt to unravel the taken-for-granted and universalizing discourse of the medical model as a culturally produced discourse,

and emphasize its limits in addressing the most pressing issues for people living with impairments and chronic illness in an ableist society.

The idea in the social model that rehabilitation professions collude in producing disability is novel and challenging for students. It does, however, and through its reaffirmation (and modification) by the study findings that inform my teaching, suggest ways of conceptualizing 'disability' and 'environment' that directly influence what rehabilitation intervention will 'look like'. Rather than 'adjusting' the individual to the environment, other modes of addressing the needs of clients are suggested by an understanding of the complex ways in which society and space shape disability experience. That this complexity is revealed by research using qualitative field methods and analysis is a further lesson for students who in the future, as practicing health professionals, may conduct their own research. As the teaching of qualitative research methodology, which includes discussion of ethical issues and models of participatory research, is part of the overall education program of the students there is some reinforcement of the theoretical–epistemological–practice–action links of research. In this sense, there is potential for effecting discursive change from within the structures and institutional organization of health service provision. Is this ethical research? Perhaps not in the terms of emancipatory models that aim to produce social action around an issue of concern for study participants/collaborators. However, its outcome enters a body of knowledge that is influential in affecting how some immediate needs of disabled people may be conceptualized and addressed, whether this is through assistive technology and changes to living and working environments, or shaping the form and delivery of disability related services. Such research may also influence how 'client-centered' practice is interpreted. In the context of this intended audience of health professionals a different way of conceptualizing disability, informed by materialist accounts, can pave the way for the improvement of services for disabled people and bring into discussion the inclusion of an advocacy role in professional practice.

My greater concern is with how knowledge is produced in my research. When research does not fulfill the criteria of participatory or emancipatory models, how is space created for absent voices? What power relations are in play when generating knowledge about disadvantaged groups? These questions have been of issue both in my research with predominantly white, and often middle class, women, and in work concerning minority, immigrant women with chronic illness. There is no shortage of discussion of the in-depth interview in interpretive research, following the postmodern turn that has emphasized the multiple positioning and multiple perspectives of those engaged in producing knowledge, whether as researcher, research assistant, subject participant or any other player in a research project. A primary goal of decreasing the hierarchical positioning of researcher and 'researched' is, of course, central to any participatory research models. Yet, such power relationships and associated dynamics permeate all research and its chosen field techniques. In-depth interviews, a primary strategy in qualitative research, have been found to encompass unanticipated and complex dynamics of power, particularly as rehearsed in an extensive feminist literature on methodology. Our research studies with women with chronic illness suggested that women wanted to share their experiences and make their voices heard and, furthermore, found benefit to themselves in feeling themselves to be contributors to knowledge and having value placed on their stories of living with disability and chronic illness. Interestingly, gate-keeping by a local activist group, as well as more anticipated resistance by medical personnel, at first precluded access to such voices and stories in one study, raising the issue of whose voices are given space in research processes (Dyck, 1996).

The research with immigrant women, mainly from China, Hong Kong, India and Fiji, sometimes long resident in Canada, but speaking little English and with little experience of white institutions and spaces, including Western, or any other, research practice, raised other issues. My concerns with this research are on two levels, one epistemological and the other regarding the involvement in the research of the study participants. A primary concern is that of the ways in which research about the health and health care of people from cultural minority groups is implicated in the ongoing construction of understandings of 'difference'. As is pointed out in feminist geographical research in particular (for example, Nast *et al*., 1994), the field needs to be problematized. Researchers and study participants are in a relationship in which they are actively constructing knowledge about themselves and others in ongoing processes of cultural and place identity formation (Dyck *et al*., 1995; Dyck, 1997). How does our 'gaze', as researchers holding legitimacy and authority through our institutional base and 'expert' knowledge, construct images of others? In choosing to study populations identified according to particular, broad ethnocultural communities such as the Chinese-Canadian and Indo-Canadian groupings in Vancouver, do we contribute to processes of racialization and inscription as a 'subordinate other' by using homogenizing categories of ethnic identification? While such issues about research of the 'other', whose bodies are not the white, male, middle class bodies that the universalizing discourse of biomedicine is constructed around, are raised in anti-racist health and feminist research (see for example Mohanty, 1988; Sheldon and Parker, 1992; Ahmad, 1993; Bannerji, 1993; Stubbs, 1993), there has been little scrutiny of the actual experiences of conducting research with such racialized 'others'. Awareness of the need not to reproduce cultural racism in interpreting health problems is crucial, but is only one part of a cautionary story. What actually happens in the power dynamics of research that attempts to be sensitive to such issues is complex. Ethical research needs to include a reflexive accounting of the investigator's part in influencing research aims, the research process and what is inevitably a co-construction of a story about illness or disability. In our studies this has been an important part of the research and has allowed us to reflect back on problematic issues in the research.

In an early study, although we felt that ethical procedures in the conventional sense adequately protected the participants, concerns remained. Recruitment was a first issue. Because we wanted to explore the women's experiences of clinical encounters and their subsequent use of Western health professional knowledge in the management of their illness/disability, it was necessary that the women were currently engaged in some treatment. We therefore recruited through the clinics the women attended. In the white space of the institutional setting, with a physical structure and organizational practices encoded with biomedical knowledge with its dominance in defining health care issues, the women may have felt pressured into agreeing to be part of the study. Consent procedures are an ongoing issue in research with minority, marginalized groups, with the formality bestowed by the language and format required by universities sometimes intimidating. Although research assistants were chosen from the same ethnocultural groups of the participants in order to defray to some extent the hierarchy and power differential of the research relationship, the vulnerability of the women study participants has to be seriously considered. Fear and suspicion may attend recruitment in the unfamiliar space of the clinic and exposure to research reflective of dominant institutions and interests (Dyck *et al*., 1995). Yet, resistance to research is possible and it is mistaken to consider study participants as necessarily passive. For example, a few women cancelled interview appointments, or reconfigured usual interviewing methods by having family members in attendance and choosing public locations for meeting with the interviewer.

And what of the study participants' involvement in the research? While their accounts may lead to improved health care and rehabilitation practice, and better understanding of the links between cultural meanings and disability or chronic illness in particular places, what benefits does the research have for them? The women did not set the research agenda, nor did they take part in the analysis. Particularly for elderly women with little education, the idea of research is unfamiliar. The women were observed by a research assistant in their sessions with a variety of health professionals, and then interviewed at home about their understanding of what was imparted and how they were using that knowledge. The barriers to women's understanding of and following of advocated management procedures were identified during this process, as consistent with the research aims, but did the women gain anything from this participation? On an individual level some did. For example, the research assistant became a resource for some of the women, answering questions about the clinical and management procedures both at the clinic and at home interviews. In some instances the research assistants gave moral support during lengthy and confusing days of assessment, and shared information about issues pertinent to the women's lives that were unrelated to their health. At the home interviews, if it became apparent that women were having difficulty in understanding procedures or acquiring information about resources important to their health, the research assistant was able to reciprocate through clarification or referral to appropriate services. Here, in the space of the home away from institutional power, some return to study participants was possible.

## Contextual Contingency and Enabling Geography

Experience shows that research with and about vulnerable groups necessarily must engage with ethical and political issues. Kitchin (1999) talks of the tight association between politics and ethics in research that geographers doing disability related research need to consider. He suggests that 'exposing the disabling nature of society and its spatialities' is an important part of an interdisciplinary endeavor to have research positively affect the lives of disabled people in 'practical and political ways'. In this paper I suggest that different forms and aims of research, for example whether research is action-oriented or with a primary intent of influencing discourses about, and cultural representations of, disability in society, will affect its specific attendant ethical and political issues. The various research projects with which I have been involved show that these issues are also inherently geographical. Geography makes a difference to experiences of illness and disability, and health service delivery. It also makes a difference to what research is possible, how it is conducted and what questions have particular relevance. Everyday worlds of disability experience—and research about this—are deeply connected to the playing out of wider social, economic and political relations and distributions of power in particular places.

Each research approach and the context of a study will suggest different political and ethical issues, rather than universal applicability of particular principles. The interlinkages among various aspects of research, including the interactions between study participants and researcher, are complex and located within interacting narratives and institutional practices. In producing knowledge the relationship between researcher and researched can be constructed in different ways, with no single model of social action necessarily appropriate for different situations. Much of my research concerning disability issues has been constructed within a mandate of rehabilitation practice committed to improving client-centered services in a social climate and geographical locale where increasing cultural diversity raises new practice issues for service providers. Yet, as a

researcher looking from outside the professional paradigm typically framing the 'problem of culture' and conceptualization of the (dis)abled body in rehabilitation, this research raises questions for me as to its potential for 'social action'. I attempt to expose the social and spatial structuring of disability and explore rehabilitation and other health care services in terms of their value to people with impairments and chronic illness, but this may well be a slow route to policy change and influencing thought about ableist society. Research set within issues of rehabilitation practice, however, contends with a context of the power of institutionalized biomedicine in framing and naming the 'deviant other', and study participants who may not be in a position to, or want to, be involved in social action research. Ethical research must primarily be concerned with centering the 'subject' in knowledge production. This, however, is not enough. Spaces for 'absent voices' and 'disabling differences' can only become present if research is also sensitive to the cultural and social contexts of those individuals' everyday worlds.

## Note

1. The studies referred to in this paper have been variously conducted with Lyn Jongbloed, University of British Columbia (women with multiple sclerosis), with Joan Anderson and Judith Lynam, University of British Columbia (minority, immigrant women), and with Pamela Moss, University of Victoria (women with chronic fatigue syndrome and rheumatoid arthritis). Researchers and research assistants included self-identified cultural minority women and one with a chronic illness.

## References

Abberley, Paul (1995) Disabling ideology in health and welfare—the case of occupational therapy, *Disability and Society*, 10, 221–232.

Ahmad, W.I.U. (1993) Making black people sick: 'race', ideology and health research, in: Ahmad, W.I.U (ed.) *'Race' and Health in Contemporary Britain*, Buckingham: Open University Press, 11–33.

Bannerji, H. (ed.) (1993) *Returning the Gaze: Essays on Racism, Feminism and Politics*, Toronto: Sister Vision.

Barnes, Colin (1992) Qualitative research: valuable or irrelevant?, *Disability, Handicap and Society*, 7, 115–124.

Chouinard, Vera (1997) Guest editorial: making space for disabling differences: challenging ableist geographies, *Environment and Planning D: Society and Space*, 15, 379–504.

Crow, Liz (1996) Including all of our lives: renewing the social model of disability, in: Morris, J. (ed.) *Encounters with Strangers: Feminism and Disability*, London: The Women's Press, 207–226.

Dyck, Isabel (1996) Whose body? Whose voice? Contradictory cultural constructions in the politics of research, *Atlantis*, 21, 54–62.

Dyck, Isabel (1997) Dialogue with difference: a tale of two studies, in: Jones III, J.-P., Nast, H.J. and Roberts, S.M. (eds) *Thresholds in Feminist Geography: Difference, Methodology, and Representation*, New York: Rowman and Littlefield, 183–202.

Dyck, Isabel and Kearns, Robin A. (1995) Transforming the relations of research: towards culturally safe geographies of health and healing, *Health and Place*, 1, 137–147.

Dyck, Isabel, Lynam, Judith M. and Anderson, Joan M. (1995) Women talking: creating knowledge through difference in cross-cultural research, *Women's Studies International Forum*, 18, 611–626.

French, Sally (1993) Disability, impairment or something in between?, in: Swain, J., Finkelstein, V., French, S. and Oliver, M. (eds) *Disabling Lives: Enabling Environments*, London: Open University Press, 17–25.

French, Sally and Swain, John (1997) Changing disability research: participatory and emancipatory research with disabled people, *Physiotherapy*, 83, 26–32.

Kitchin, Rob (1999) Morals and ethics in geographical studies of disability, in: Proctor, J. and Smith, D. (eds) *Geography and Ethics: Journeys in a Moral Terrain*, London: Routledge, 223–236.

Mohanty, Chandra (1988) Under Western eyes: feminist scholarship and colonial discourses, *Feminist Review*, 30, 60–88.

Morris, Jenny (1995) Creating a space for absent voices: disabled women's experience of receiving assistance with daily living activities, *Feminist Review*, 51, 68–93.

Nast, Heidi J., Katz, Cindy, Kobayashi, Audrey, England, Kim V.L., Gilbert, Melissa R., Staeheli, Lynn A. and Lawson, Victoria A. (1994) Focus. Women in the field: critical feminist methodologies and theoretical perspectives, *Professional Geographer*, 46, 54–102.

Oliver, M. (1992) Changing the social relations of research production, *Disability, Handicap and Society*, 7, 101–114.

Oliver, Mike (1996) Defining impairment and disability: issues at stake, in: Barnes, C. and Mercer, G. (eds) *Exploring the Divide: Illness and Disability*, Leeds: The Disability Press, University of Leeds, 39–54.

Parr, Hester (1998) The politics of methodology in 'post-medical geography': mental health research and the interview, *Health and Place*, 4, 341–353.

Sample, Pat L. (1996) Beginnings: participatory action research and adults with developmental disabilities, *Disability and Society*, 11, 317–332.

Shakespeare, Tom (1996) Rules of engagement: doing disability research, *Disability and Society*, 11, 115–119.

Sheldon, Trevor and Parker, Hilda (1992) The use of 'ethnicity' and 'race' in health research: a cautionary note, in: Ahmad, W.I.U. (ed.) *The Politics of 'Race' and Health*, Bradford: University of Bradford and Bradford and Ilkley Community College, 55–78.

Stalker, Kirsten (1998) Some ethical and methodological issues in research with people with learning difficulties, *Disability and Society*, 13, 5–19.

Stone, E. and Priestley, M. (1995) Parasites, pawns and partners: disability research and the role of non-disabled researchers, *British Journal of Sociology*, 47, 699–716.

Stuart, O.W. (1992) Race and disability: just a double oppression?, *Disability, Handicap and Society*, 7, 177–188.

Stubbs, Paul (1993) 'Ethnically sensitive' or 'anti-racist'? Models for research and service delivery, in: Ahmad, W.I.U. (ed.) *'Race' and Health in Contemporary Britain*, Buckingham: Open University Press, 34–47.

Vernon, A. (1997) Reflexivity: the dilemmas of researching from the inside, in: Barnes, C. and Mercer, G. (eds) *Doing Disability Research*, Leeds: Disability Press, Leeds University, 158–176.

Zarb, Gerry (1992) On the road to Damascus: first steps in changing the relations of disability research production, *Disability, Handicap and Society*, 7, 125–138.

# Research with the Mentally Incompetent: the Dilemma of Informed Consent

DEBORAH METZEL

This paper examines the conundrum of conducting research in the USA with people who are unable to give informed consent, and because they are adults without legally appointed guardians, no one else has clear authorization to give consent on their behalf. Here I focus specifically on people with severe or profound intellectual handicaps while acknowledging that there are many other people with other limitations, such as advanced Alzheimer's disease, that prevent them from understanding the concept of informed consent. This paper does not deal with the issue of establishing competency to

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give informed consent, but rather, crosses the threshold into the nebulous arena that contains the issues of exclusion from research agendas, information, consent and permission.

## Perpetuating Exclusion: Should Research Wait?

This issue is neither new nor discipline-specific. Indeed, the *Washington Post* published an article in its series 'Science on the ethical frontier' in which a similar question in medical science was posed: 'When, if ever, is it appropriate to conduct research on minors or the mentally incompetent, who are by definition unable to give consent?' (Weiss, 1998, p. A12). This question was characterized as one which has been unanswerable for years.

Geographical research with people who have any degree of intellectual handicap has been scant and to continue to exclude people with intellectual handicaps from geographical research is to compound the extant omission. Social geography and disability studies in geography have been concerned with exclusion and inequalities, yet these sub-disciplines, with few exceptions, have excluded people with intellectual handicaps from research agendas. This is possibly due to the fact that people with intellectual handicaps, and among them people with severe and profound intellectual handicaps, have not had an audible voice in establishing research agendas. This latter speculation makes a compelling argument for assuring that geographical research includes them.

Geographical research that has focused on people with intellectual handicaps, such as that by Golledge (1979, 1991) and Walker (1996), identifies its participants as having mild or moderate intellectual handicaps and they are more likely than people with severe or profound intellectual handicaps to understand the nature of the research and the concept of informed consent. But what about people with severe or profound intellectual handicaps?

I take the position that it is appropriate to include people with severe or profound retardation in geographical research since their absence deprives them, and those who work on their behalf, of the knowledge gained by their participation to whatever degree possible. Appropriateness must be balanced by as many safeguards as possible, which is admittedly more easily said than done.

## Who is Informed?

It would seem likely that the probability of protecting the rights of participants would correspond to the number of people who are informed about the research. At administrative levels, universities and sometimes individual departments require proposals to identify the study populations, procedures, risks, interview questions and data collection forms to be approved by institutional review boards. Service provider agencies have human participant oversight committees that also review study protocols before approving such projects. Parents and other involved family members, friends and advocates should also be informed and this may be done in cooperation with a service provider agency, if one is involved. However, in my experience in conducting survey interviews, families are not always informed in advance of a survey or study. Furthermore, people with severe or profound retardation do not always have interested family, friends or advocates outside the service system, and if an aspect of the service system is under study, there may be conflict of interest.

### Whose Consent? Whose Permission?

In the *Consent Handbook*[1] published in 1977 by the American Association on Mental Deficiency, Turnbull (1977, p. 13) advised:

> In such a situation (where the person's consent is legally ineffective because of his or her incapacity to understand) it is prudent to obtain his consent and the consent of persons empowered to act for him if he were adjudged incompetent, such as his parents, natural guardians, or persons *in loco parentis*.

There is no disputing the fact that this is a prudent action, but is it legal? A few pages later he pinned down the true dilemma: when there is no legal statute identifying who is entitled to give substitute consent, then who is authorized to give informed consent (Turnbull, 1977, p. 16)?

A generation later, the question of who may give consent for people with severe or profound intellectual handicaps remains. Although now there are situation-specific, temporary or otherwise limited guardianships available, they are more suited to health, medical, financial or legal situations, and likely to be impractical or unfeasible when applied to geographical research.

Practically and traditionally we look at other disciplines and topics for their experiences in problematic areas. Researchers who study people with Alzheimer's disease have encountered similar ethical and legal issues and some guidelines have been proposed (e.g. Melnick *et al.*, 1984; High, 1992). For example, pre-arranging for durable power of attorney or other legally recognized proxy authorization while the person is still competent is a pro-active and anticipatory approach, but not a possibility for people with severe or profound intellectual handicaps.

One of the foremost responsibilities of the researcher is to assess each potential participant's competency for involvement in a particular study (Dell'Aquila (1996, p. 5), citing Turnbull (1977) and Parkes (1995)). The competency or incompetency of the participants should not be assumed or unconditionally accepted based on others' professional or personal assessment of the potential participants, since there is great variation in the degree of intellectual handicap and the label of severe or profound may pertain to general level of ability while masking other abilities and competencies.

But once a person is deemed incompetent, then the tricky task is to determine *who* can give permission, but not consent, on behalf of the person. Dell'Aquila (1996, p. 4) refers to the convention of consent and permission: only the individual is legally entitled to give consent; others give permission on the individual's behalf. This shifts but does not resolve the underlying question of who is entitled to give permission. In ideal circumstances, family or friends would be approached for permission, but as noted previously, this is not always possible. A representative from the service provider agency may be next in line after the question of possible conflict of interest is settled. Or perhaps a separate general oversight agency or administrative office in the service provision hierarchy is appropriate.

### Considering the Risks in the Research

Unlike behavioral, health and medical studies where new practices, treatments or medicines are tested, geographical research does not contain elements that are as risky or potentially harmful. Geographical research would more probably fall into the category of minimal risk, if indeed there were any risk at all. In my experience, most but not all of the people with severe and profound intellectual handicaps have been unable to

understand the interview questions: thus even a minimal risk of emotional distress is unlikely.

More probably, informed consent is sought so that the researcher can collect data through interviews or observations, and through such secondary sources as records and case-histories. As usual, all such data would be kept confidential and all measures to protect identities would be maintained.


## Conclusion

What are the recommendations when one has decided to undertake research with people who are mentally incompetent? First, if they have not already done so, it would be advisable for geographers to take a course in the ethics of research. While it seems safe to assume that people who go into disability studies have sensitivity and integrity regarding disability studies, a course in ethics of research could help anticipate some difficult points in designing and conducting the research. Secondly, during the study design, a procedure should be developed, but opened to modification, that explicitly outlines how consent or permission will be obtained when the researcher has concluded that the potential participant is not able to understand the concept of informed consent.

This paper has pointed out several but certainly not all of the difficulties inherent in research with people whose disabilities preclude informed consent. Until there are formal guidelines in performing research with people who are mentally incompetent, we should proceed with caution and respect, but we should definitely proceed. The lack of clear procedures for obtaining informed consent and permission is a distinct disincentive for doing research with people for whom informed consent is incomprehensible, but unless research is done, forcing the development of guidelines in the process, these people will remain on the margins of research.


## Note

1. Since this paper was written, the American Association on Mental Retardation has published *A Guide to Consent* (Dinerstein *et al*., 1998). While it is a more thorough treatment of the issues of consent and choice, informed consent for research other than health care is not specifically addressed.


## References

Dell'Aquila, S. (1996) Consent for research: dangers of presuming either capacity or its lack, *The Newsletter of the Network on Ethics and Intellectual Disabilities*, 2, 4–5.

Dinerstein, Robert D., Herr, Stanley S. and O'Sullivan, Joan L. (eds) (1998) *A Guide to Consent*, Washington, DC: American Association on Mental Retardation.

Golledge, R.G. (1979) An experimental design for assessing the spatial competence of mildly retarded populations, *Social Science and Medicine*, 13D, 291–295.

Golledge, R.G. (1991) Special populations in contemporary urban areas, in: Hart, J.F. (ed.) *Our Changing Cities*, Baltimore, MD: Johns Hopkins University Press, 146–169.

High, D.M. (1992) Research with Alzheimer's disease subjects: informed consent and decision making, *Journal of the American Geriatrics Society*, 40, 950–957.

Melnick, V., Dubler, N., Weisbard, A. and Butler, R. (1984) Clinical research in senile dementia of the Alzheimer type: suggested guidelines addressing the ethical and legal issues, *Journal of the American Geriatrics Society*, 32, 531–536.

Parkes, C.M. (1995) Guidelines for conducting ethical bereavement research, *Death Studies*, 19, 171–181.

Turnbull, H.R. (1977) *Consent Handbook*, Washington, DC: American Association on Mental Deficiency.

Walker, Pamela M. (1996) The social meaning of place and people with developmental disabilities, Ph.D. dissertation, Syracuse University.

Weiss, R. (1998) *Washington Post*, 1 August, p. A12.

# 'Sometimes it's OK to be a Spy': Ethics and Politics in Geographies of Disability[1]

ROBERT D. WILTON

## Introduction

Within the social sciences, there is a well-established tradition of critical reflection on the ethical bases for, and implications of, social research (Sjoberg, 1967; Bell and Encel, 1978; Punch, 1986; Rees, 1991). From this reflection has come the recognition that a vast majority of social researchers face one or more ethical questions during the course of their academic endeavors. While these dilemmas range in scope and magnitude depending upon the research in question, the way that scholars acknowledge and respond to them holds significant consequences for the outcome of research projects and, more importantly, for the well-being of those involved.

At the same time, there has been a growing recognition of the politics of social research. In recent decades, critiques of scholarly claims to objectivity and neutrality have emerged, coupled with admonitions to explicitly acknowledge the position of the academic community within a broader social and political context (for example, Nicholson, 1990; Haraway, 1991). The implications of this discourse for social research have been manifold, but notable among them is the idea that researchers can and perhaps should allow an explicit political commitment to guide their work.

In this paper, I discuss the implications of these two traditions for an evolving geography of disability. In particular, I am interested in the ways that ethical considerations and political commitments may coexist and/or conflict in work on the social exclusion of disabled people. As both Chouinard and Gleeson argue (in this issue), where research involves disabled people it may be possible to address ethical concerns about their representation and treatment while maintaining an explicit political commitment to challenge their continued exclusion. However, this same balance may not be possible when research involves those individuals and institutions responsible for exclusion. In these instances, how are competing ethical and political considerations addressed, and with what implications? The specific focus of the paper is recent doctoral research on the social construction of disability during a conflict over the siting of human service facilities. In the research, I interviewed residents and business owners engaged in opposition to understand more about their motivations to exclude. In the paper, I look first at recent discussions concerning ethics and politics, and their intersection in social research. Secondly, I examine the reasoning behind my choice of research topic. Thirdly, I look at the resolution of two related ethical/political dilemmas that arose during the course of the research. Finally, I offer a brief conclusion.

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## Ethics and Politics in Social Research

What does it mean to talk about ethical issues in social research? Barnes (1979, p. 16) offers a useful definition of ethical questions as those:

> that arise when we try to decide between one course of action and another not in terms of expediency or efficiency, but by reference to standards of what is morally right or wrong.

These questions might conceivably concern the honesty of the researcher in recording and reporting information, the use of research results, the issue of confidentiality and informed consent for research participants, and the impacts of research upon participants more generally (Bell and Encel, 1978; Patton, 1990; Rees, 1991). Implicit in this definition is an understanding that it is impossible to know what kinds of ethical questions or dilemmas will arise in the course of a research project *a priori*. As Rees (1991, p. 147) notes, ethical issues, like research themes, often emerge from one's experience in the field. As such, answers to those ethical questions must also emerge from one's own position/perspective at the time and place they arise. This does not mean that a researcher begins research without an ethical framework. Instead, the framework itself must necessarily be dynamic, evolving with the researcher's understanding of the study, the context, the participants and her/himself.

Alongside ethical considerations, political concerns also increasingly influence how and why we conduct social research. We might usefully conceptualize political questions as those concerned with the exercise of power. This is true in the sense of those power relations that exist both within the immediate research process, and also more broadly within and between the academic community and the surrounding social context (Nast, 1994). Scholars have argued that these power relations must be acknowledged if we are to understand the way in which knowledge is produced (Haraway, 1991). Others have argued that an active engagement with the politics of social research is in fact essential if we are to satisfactorily address issues of ethical import. Van den Berghe (1967, p. 196), for example, writing about his research in South Africa, makes a direct link between ethics and politics:

> The distinction between ethics and politics in an actual research situation is analytical rather than empirical. Once more, the South African case is extreme in that … the ideology and practice of apartheid conflict with virtually all religious or secular systems of ethics evolved over the last three thousand years of human history. In that context, *the injunction to be apolitical thus becomes a precept of amorality* [emphasis added].

Middleton (1978) expresses a similar viewpoint when describing her fieldwork with Australian Aborigines. She argues that the ways in which research results are used raises

> the searching questions of the peoples of the third world and others: namely 'What has been the effect of your work among us? Have you contributed to the solution of the problems you have witnessed? Have you even mentioned those problems? If not, then you are part of those problems (Middleton, 1978, p. 263).

In both of these perspectives, there is a sense that to be ethical scholars *must* commit to challenging forms of social injustice encountered during the course of their research. But what is the nature and extent of the commitment required by a scholar to make good on this commitment? To what extent should this commitment guide research design and

objectives? And is a balance between ethics and politics always possible? Efforts satisfactorily to answer these questions remain a central concern of feminist scholars and other progressive researchers within geography and the social sciences more generally (Rees, 1991; also Gottfried, 1991; Nast, 1994; Kitchin, 1999). While many acknowledge the importance of a connection between research and social change, the precise nature of this link and its implications for social research remain topics of considerable debate.

These ongoing discussions linking ethical decision-making to an understanding of the power relations that structure the lives of research participants have produced two related developments that are of particular significance for this paper. First, there has been a growing recognition of the need to complement research on the experiences of marginalized groups with studies that examine those individuals and institutions responsible for their marginalization. In other words, there is a need to study 'up' to comprehend how those in power are able to sustain their positions, as well as 'down' to understand how those in subordinate positions deal with and respond to injustice and inequality (Wax, 1982; Messner, 1996). At the same time, there is some willingness on the part of scholars to classify those individuals, groups and institutions involved in research based on their relative position within an existing set of social relations. Put more simply, all research participants are no longer the same (Galliher, 1982). When socially marginalized groups are directly or indirectly involved in research, one's political commitment demands an explicit sensitivity to issues of representation and the potential impact of the research process on the people involved. Conversely, when research involves individuals and institutions responsible for the continued marginalization of others, political commitments may modify the researcher's ethical framework, and in so doing, justify research practices that would be untenable elsewhere. One such modification that has produced considerable debate has been the use of covert research (Bulmer, 1982; Wax, 1982; Rees, 1991). Punch (1986, p. 39) has identified two questions he considers key in justifying the use of deception in research:

> First, are there areas where some measure of deception is justified in gaining data (yet while bearing in mind, and respecting, privacy, harm, identification, confidentiality)? And, second, are there some institutions which deserve what they get so that devious means are legitimate and, crucially, it is our intention to expose them?

I am interested in the implications of these developments for geographies of disability. Within geography, there is an established understanding of disabled persons as a minority group, economically, socially and politically marginalized by ableist norms and attitudes (re)produced by a disabling spatiality (Chouinard and Grant, 1995; Imrie, 1996). In this sense, there is an explicit recognition of the social injustice faced by people with disabilities and the concomitant need to challenge that injustice. But what does this mean for the practice of research in geography? More specifically, to what extent should we be concerned with studying up as well as down to understand the social marginalization of disabled groups? In the same way that scholars have recognized the importance of studying whiteness and heterosexuality to understand how racism and heterosexism are reproduced (Katz, 1995; Lipsitz, 1996), I argue that we need to understand more about the 'non-disabled' and their efforts to exclude disabled persons. An understanding of *non*-disabled geographies constitutes an important correlative to work on the social and spatial experiences of people with disabilities. Mapping the contradictions and inconsistencies inherent in 'abled' bodies, identities and places will help undermine the bases for the continued exclusion of disabled people.

At the same time, what ethical and political challenges does an upward emphasis raise that might differ from those emerging from studies involving disabled people themselves? As Punch (1986) asks, are there individuals and institutions that 'deserve what they get' because they contribute to the continued marginalization of disabled people? And how does a political commitment to uncover the causes of marginalization conflict with one's ethical commitment to those people who participate in research? In the remainder of the paper, I examine my own doctoral research on the social construction of disability during facility siting conflicts to illustrate one way in which these concerns were negotiated.

## Studying up on Disability

My original plan for doctoral research had been to work with disabled people living in group homes to look at how their use of space within everyday neighborhood environments might challenge neighbors' perceptions of disability and difference. However, several factors combined to shift my research focus.

First, I was concerned about conducting qualitative research with persons with disabilities because I doubted my ability, as a relatively able-bodied person, to accurately represent the people I was working with. I do not subscribe to any kind of essentialism, but it is not necessary to treat identity as given in order to understand the value of embodied or experiential knowledge, nor to recognize the potential for misrepresentation and appropriation of knowledge (England, 1994). In addition, I was unsure what, if anything, I would be able to offer in return for people's assistance with the project. I was also conscious of the need to complement studies of disabled people's experiences in community space with research on the motivations of those individuals and groups opposed to their presence. Finally, I thought research on the exclusion of disabled people from communities might have more of an immediate political value. I was concerned about the growing trend towards exclusion of a wide variety of socially defined 'problem groups'. This trend can be seen in the growth of anti-homelessness ordinances, local restrictions on the location of group homes and service facilities, and the continued criminalization of people with mental disabilities and alcohol and drug addictions among others (National Law Center on Homelessness and Poverty, 1994; Mitchell, 1997). I wanted to critically examine the arguments used to justify these types of exclusion.

Together, these considerations led me away from what we might consider as studying 'down' towards research that was distinctly upward in its orientation. In this case, the focus was on a 'non-disabled' population seeking to exclude disabled and disadvantaged people from their community. Initially, it seemed that this focus would allow me to satisfactorily resolve a number of ethical and political concerns. While I did not take direct contact with people in the study community lightly, I anticipated that concerns about representation and being in the field would be less pronounced. The people whom I planned to interview were not socially marginalized.[2] In fact, they were themselves acting to exclude others. In addition, their identities were not dissimilar to my own, being primarily white, middle-class and relatively able-bodied.[3] Theoretically, the work seemed worthwhile because it would allow me to probe the taken-for-granted nature of able-bodied identities and places. Finally, the research was motivated by a political commitment to understand and problematize efforts to exclude people with disabilities.

Despite the apparent validity of these arguments, two issues arose during the course of the research that forced me to re-examine my research design and the balance between ethics and political commitment therein. The first concerned my honesty and openness with research participants. The second concerned the dissemination of research results.

**Not Quite the Whole Truth**

The purpose of the research was to understand more about why people organize to oppose and exclude human service clients and facilities. As such, I needed to talk to individuals engaged in opposition about their motivations, but in such a way that they would be willing to talk to me. I also wanted to talk to service providers about the people opposing them. How then should I represent myself to potential participants? How should I describe the project to them?

When asking for interviews, I told people I was a geography student interested in problems concerning facility location. A frequent response was 'geography?', whereupon I proceeded to briefly explain urban geography and its similarities with urban planning. I then told them that I was interested in talking to residents, business owners and service providers to obtain a variety of viewpoints on the siting conflict. Speaking to service providers I explained my interest in community opposition and my concern that people's perceptions of human service client groups were often unfavorable. I was actively constructing myself as a service-friendly researcher interested in the problems that confronted providers—*a fairly accurate description*.

By contrast, when speaking to residents involved in the opposition group, I felt this persona would simply not have worked. Instead, I still told them that I was interested in gaining as many different viewpoints on the conflict as possible. This was not a statement of overt sympathy, but suggested I was open to hearing their side of the story (whether they believed me or not is another question, but the vast majority consented to interviews). Several residents involved with the opposition group asked for my opinion on the conflict during interviews. I told them that the more people I talked to, the more complex I realized the issue to be. This was true in the sense that the volume of data I acquired did not offer any easy interpretation, but it was also a deliberately neutral statement designed to deflect further questions.

In fact, I was not entirely open and honest with facility opponents about the motives for my study. I wasn't so much seeking to understand the complexity of the siting issue as trying to understand what it was that bothered *them* about the facilities and their clients. *It was thus the opponents themselves who were the focus of the research,* something that was not made clear before or during interviews with participants. The decision not to reveal this fact was made with three reasons in mind. First, I felt that there was no potential for harm to respondents by not telling them.[4] I made clear my own identity as a student researcher, and it was clear to people that they were participating in a research study. Secondly and more pragmatically, had I told them, I felt that the research would have been unfeasible. Thirdly, I felt that my own commitment to greater social justice for people with disabilities, and a belief that community opposition is motivated by negative stereotypes of disability and difference, justified this approach.

**Biting the Hands that Feed?**

A second issue concerned the use of research results. Shortly after completing fieldwork, I was approached by the Coalition to Preserve the Fair Housing Act. The coalition was formed by lawyers and advocates as a response to a House of Representatives bill (HR3206) that seeks to repeal elements of the Fair Housing Act (FHA) (1988) protecting persons with disabilities. Among other things, the bill would make it easier for community members to express exclusionary sentiments as an 'expression of an opinion' without fear of prosecution. It would also make it much harder to effectively use the FHA enforcement procedures. Thirdly, it would seek to tighten the definition of a family,

facilitating the exclusion of non-family households from certain residential neighbor-hoods.

The community in which I conducted my research lies within the constituency of one of the three primary co-sponsors of the HR3206 House bill. Members of the opposition group in the community had been effective in lobbying for this bill. The chair of the coalition asked me to provide a briefing on the community so coalition members might better understand the origins of this politician's support for the bill and identify ways to challenge her stance. This briefing was given via conference call to about 40 members of the coalition in April 1998. Again, however, it was necessary to confront a number of ethical questions. If the people I interviewed had known that I was going to speak to the Coalition to Preserve the Fair Housing Act, would they have declined to speak to me? When I was approached by the coalition, should I have asked participants for their permission? Of course, I did not refer to, or name, any individuals in the course of the briefing. However, the summary of events presented to the coalition contained insights about the opposition group's motivations and strategies, for example, obtained from interviews with the group's members and supporters. Again, my decision to present information to the coalition was based on two related consider-ations. First, the only threat posed by the briefing was to the political agenda of the opposition group, and not to any individual's psychological and/or physical well-being. Secondly, the passage of the bill would have constituted a serious threat to the FHA, and by extension, to the quality of disabled people's everyday lives. Therefore not offering assistance to the coalition would have directly contradicted my own political commitment.

## Conclusion: Ends and Means

In the current project, I resolved (1) to employ a measure of dishonesty in interactions with facility opponents and (2) to disseminate research results to a third party politi-cally opposed to the aims of the opponents. These decisions were based on deliberations about what constituted a basic level of honesty and ethical behavior during research. They were also based on a political analysis of the issue at hand. In community opposition to human service facilities, opponents are typically in positions of relative power and privilege when compared with those they are seeking to exclude. In addition, opponents often restrict their arguments to the location of individual facilities and do not address larger issues concerning the rationale for their existence (e.g. excluding the homeless, rather than asking *why* they are on the streets). Thirdly, opponents typically draw upon and reproduce popular stereotypes that stigmatize dependency and disability. Thus while I sympathized with some residents who were concerned with the changing character of their community, an understanding of oppo-sition as an inherently exclusionary process justified the research design and use of research results.

This discussion also carries a broader significance. I have argued that critical work on 'able-bodied' geographies constitutes an important part of an overall research agenda for geographies of disability. However, this research raises new ethical and political concerns. While studies with disabled people demand an explicit sensitivity to issues of representation and reciprocity among other things, research with non-disabled populations may require a sensitivity of a different kind. In particular, studying 'up' on disability may require researchers to negotiate a delicate balance between ethical considerations and political commitments.

## Notes

1. I am indebted to Dr Devva Kasnitz at the World Institute on Disability for the title of this paper. I would like to thank Cynthia Cranford, Rob Kitchin and two anonymous referees for their comments and suggestions on this paper. Errors and omissions are mine alone.
2. This statement oversimplifies the situation. My point is that most people engaged in community opposition were white and middle-class. *In this immediate context*, they were not socially marginalized. In a broader sense, they are enmeshed in a complex network of power relations that render them neither all-powerful nor completely powerless.
3. In addition, the fact that I was suitably foreign provided an ideal measure of what Lofland and Lofland (1995) term 'acceptable incompetence'. I use the term 'suitably foreign' for obvious reasons. I am from the United Kingdom. Particularly in states like California, with high rates of immigration, discrimination and racism against Latino immigrants are commonplace.
4. I carefully consulted the guidelines of the human subjects review board on this issue.

## References

Barnes, J. (1979) *Who Should Know What? Social Sciences, Privacy and Ethics*, Harmondsworth: Penguin.

Bell, C. and Encel, S. (eds) (1978) *Inside the Whale: Ten Personal Accounts of Social Research*, Oxford: Pergamon Press.

Bulmer, M. (ed.) (1982) *Social Research Ethics: an Examination of the Merits of Covert Participation Observation*, New York: Holmes and Meier.

Chouinard, V. and Grant, A. (1995) On being not even anywhere near 'the project': ways of putting ourselves in the picture, *Antipode*, 27, 137–166.

England, K. (1994) Getting personal: reflexivity, positionality, and feminist research, *Professional Geographer*, 46, 80–89.

Galliher, J. (1982) The protection of human subjects: a re-examination of the professional code of ethics, in: Bulmer, M. (ed.) *Social Research Ethics: an Examination of the Merits of Covert Participation Observation*, New York: Holmes and Meier, 152–165.

Gottfried, H. (ed.) (1991) *Feminism and Social Change: Bridging Theory and Practice*, Urbana, IL: University of Illinois Press.

Haraway, D. (1991) *Simians, Cyborgs, and Women: the Reinvention of Nature*, New York: Routledge.

Imrie, R. (1996) *Disability and the City: an International Perspective*, London: Paul Chapman.

Katz, J. (1995) *The Invention of Heterosexuality*, New York: Dutton.

Kitchin, R. (1999) Morals and ethics in geographical studies of disability, in: Proctor, J. and Smith, D. (eds) *Geography and Ethics: Journeys in a Moral Terrain*, London: Routledge, 223–236.

Lipsitz, G. (1996) *The Possessive Investment in Whiteness: How White People Benefit from Identity Politics*, Philadelphia, PA: Temple University Press.

Lofland, J. and Lofland, L. (1995) *Analyzing Social Settings: a Guide to Qualitative Observation and Analysis*, Belmont, CA: Wadsworth.

Messner, M. (1996) Studying up on sex, *Sociology of Sport Journal*, 13, 221–237.

Middleton, H. (1978) A Marxist at Wattie Creek: fieldwork among Australian Aborigines, in: Bell, C. and Encel, S. (eds) *Inside the Whale: Ten Personal Accounts of Social Research*, Oxford: Pergamon, 238–269.

Mitchell, D. (1997) The annihilation of space by law: the roots and implications of anti-homeless laws in the United States, *Antipode*, 29, 303–335.

Nast, H. (1994) Opening remarks on 'women in the field', *Professional Geographer*, 46, 54–66.

National Law Center on Homelessness and Poverty (1994) *No Homeless People Allowed: a Report on Anti-homeless Laws, Litigation and Alternatives in 49 United States Cities*, Washington, DC: National Law Center on Homelessness and Poverty.

Nicholson, L. (ed.) (1990) *Feminism/Postmodernism*, New York: Routledge.

Patton, M. (1990) *Qualitative Evaluation and Research Methods*, Beverly Hills, CA: Sage.

Punch, M. (1986) *The Politics and Ethics of Fieldwork*, Beverly Hills, CA: Sage.

Rees, T. (1991) Ethical issues, in: Allan, G. and Skinner, C. (eds) *Handbook for Research Students in the Social Sciences*, London: The Falmer Press, 140–151.

Sjoberg, G. (ed.) (1967) *Ethics, Politics and Social Research*, Cambridge, MA: Schenkman.

Van den Berghe, P. (1967) Research in South Africa: the story of my experiences with tyranny, in: Sjoberg, G. (ed.) *Ethics, Politics and Social Research*, Cambridge, MA: Schenkman, 183–197.

Wax, M. (1982) Research reciprocity rather than informed consent in fieldwork, in: Sieber, J. (ed.) *The Ethics of Social Research: Fieldwork, Regulation and Publication*, New York: Springer-Verlag, 33–48.

# Emotions and Interviewing in Health and Disability Research

## ERIC LAURIER AND HESTER PARR

## Introduction

This paper opens out a discussion of the emotional intersubjectivity which occurs during and after interviews in disability and health related research. It should be noted that *disability* constitutes the social responses towards people with differing mind/body characteristics, some of which can be termed *impairments* (a functional limitation of the body or mind) and some of which can be termed *illness* (a temporary or ongoing 'condition' which usually incurs biomedical or psychological intervention). Our arguments here are informed by ethnographic and interview-based research with people who experience mental health problems (Parr, 1998a, b) and with people suffering from various smoking related illnesses (Laurier, 1999). The necessarily modest purpose in this brief position piece is to signpost and to begin to problematise the interweaving of ethics, emotions and interviewing in research concerned with illness, impairment and disability. Although we do not provide precise definitions (deliberately so), we need to represent schematically the key terms in this paper. Ethics can be understood as the need for intellectual reflection on *good practice* in a particular research context. Emotions can be understood as complex manifestations of corporeal and psychological aspects of human beings which are simultaneously felt and performed as relations between self and world. And in this context interviewing can be ideally conceived of as a ritualised, yet intersubjective encounter which reveals something of such relations (and how they are spatially constituted).

The intersection of human feelings and scholarly research has been documented within geography by writings from humanistic geography perspectives (Buttimer, 1974; Ley and Samuels, 1978; Rowles, 1978) and writings on methodology and positionality (Cornwall, 1984; Herod, 1993; England, 1994; Cook and Crang, 1995; Dyck and Kearns, 1995; Goss, 1996), but more particularly by writers applying psychoanalytic principles to different interviewing situations (Burgess *et al.*, 1988a, b; Pile, 1991). A key point for our discussion is that these latter writers argue that interviewing and therefore the emotions which are encountered within them can be 'managed' much like in a therapeutic alliance, what Pile has called a *research alliance* (Pile, 1991, p. 461). Although these arguments have been criticised as problematic in that they overly *manage* uncontextualised emotional exchanges (McDowell, 1992; Parr, 1998b), these writings still do say something useful about the psychodynamics between the interviewer and interviewee, the transference, repression and suppression of emotion and feelings, and the good practice (or ethics) which should accompany such intimate investigations. However, there are many other questions, processes and situations still to be analysed, in what we consider to be the undertheorised and underacknowledged state

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of emotion in the discipline of geography, and this is particularly the case when considering the investigation of geographies of impairment, health and illness. Relatively recent work on the sociology of the emotions (Hochschild, 1983, 1989; Harre, 1986; Kemper, 1990; James, 1992; Wouters, 1992; Fineman, 1993; James and Gabe, 1996; Bendelow and Williams, 1998) could be useful for geographers since it offers several different approaches to interpreting, analysing and understanding the social aspects of emotion.

## Emotions in Disability, Health and Illness Research

We have turned toward emotion as an analytical frame in our own research because it is a fundamental component of our orientation with the subjects of our research. Masculinist discourse in the social sciences (Bordo, 1986; Rose, 1993) has lent a suspicion of emotion as contrary to the rational tenets of Enlightenment thinking and as contrary to the distanced objectivity required in gathering impartial information during interviews (a problem also documented by many feminist writings on methodology, e.g. Oakly (1993)). However, we have both found that acknowledging emotions and emotional exchanges orientates us *differently* within our research interviews. Anxiety (the classic interviewer's emotion) can tell us something more than that we are nervous about the interview potentially 'going wrong'. Since disability, health and illness research often concentrates on embodied and embodying differences, experiences of anxiety may tell researchers something about our own maps of mattering (Grossberg, 1992) and how these position the interviewer/interviewee before any intersubjective account has been negotiated (Radley and Billig, 1996). To use an example here, one of Hester's first Ph.D. research interviews was with a man who had been diagnosed as schizophrenic. Upon starting the interview, the man's leg started twitching violently. Hester felt fear and anxiety because of what appeared to her to be the 'performance' of the condition with which she knew her interviewee had been diagnosed. In fact, his own nervousness at being interviewed had been activated by what he went on to explain was his 'stelazine kick', a common reaction to strong psychiatric medication, and one aggravated by stress. By acknowledging and analysing her emotional (mis)interpretation and situating it beside her interviewee's account, Hester learnt something of how our intimate emotional responses to different corporealities can lead to othering within the interview.

Wilton (1998) has argued that proximity to difference (such as impairment or illness) involves experiences of *unheimlich*, a Freudian term for feeling 'unsettled', especially when concerned with a threat to what is known about the self/body (the presence of difference reminding the same of its other and the potential to become 'other'). Although Wilton has discussed this with reference to urban facility locations for people with physical disabilities, it is perhaps possible to reorientate this focus to think about *unheimlich* as an 'emotional clue' (Hochschild, 1983) within the interview situation. Researching changed, changing or dying mind/bodies can reveal such processes of separation and constructions of difference, although this has not been acknowledged all that fully by geographers. However, it is also recognised that such research can lead to deep emotional attachments between interviewer and interviewee, especially in longer term research projects where interviewees may experience significant alterations in their mental or bodily status (Rowles, 1978; Dyck, 1995; Wilton, 1996; Brown, 1997). In this sense, ways of responding to calls for the embodying of geography (Dorn and Laws, 1994; Longhurst, 1994, 1995) may usefully include further acknowledgement and analysis of emotions and how they can play a vital part in situating geographical research

'which is not merely *about* bodies but *from* bodies' (Williams and Bendelow, 1998, p. xvi). This entails recognising that we, as researchers, are always corporeal, and our understandings of emotional exchanges within the interview are felt, not just observed, and hence it is important to realise that the intersubjectivity of illness, impairment and disability is not just *about* verbal meanings, but also *from* bodily engagings.

We sense (we feel) that these points raise important questions about emotions such as fear, anxiety, sadness, shock, grief, joy or happiness when research is focused on people with different mind/body characteristics (often differing from pre-given characterisations of ordinariness). We are not assuming here that interviewers are always able-bodied and able-minded, or even all that ordinary. We hope instead realistically to acknowledge that a range of different, often unfamilar, states-of-being, 'conditions' and impairments are encountered within this research area by a diverse collection of researchers. There is concern about the management of emotional exchanges and responses (Burgess *et al.*, 1988a, b): the suppression of feelings of shock, embarrassment and joy in this research area, ironically, may end up repressing the experience of socially divisive emotions and the normative rules that produce and contain emotional performances. Nevertheless we do also have to be wary about emotional engagings, about 'being moved' and that somehow registering an emotion is enough in itself. And we also have to be cautious over the powerful readings of responsibility and trust (emanating from both interviewer and interviewee) which can accompany emotional exchanges. One of the purposes of this position piece is to raise questions about emotional exchange and interviewing and to request more work which considers whether researchers should develop 'management strategies' as Burgess *et al*. (1988a, b) seem to advocate or whether we can develop other, less prescriptive agendas for 'good' ethical practice in this area.

## Ethical Dilemmas

While we would urge researchers to include emotions as empirical material to reflect upon during their analysis and indeed as a (sometimes misleading) guide in orientating themselves during interviewing, this recognition has to be tempered by critical reflections on its links with medical and social discourses, some of which construct emotion in very particular ways. Research in the sociology of the emotions suggests that discursive constructions of disability, health and illness carry with them figurations of appropriate emotional comportment, judgements of emotional competence and narratives of emotional 'progress'. Mental illness is perhaps the clearest example of this since its medicalised definitions often involve measures of inappropriate emotional displays (crying in the street, joyful talking to trees, etc.), or a decline in knowing and showing the appropriate emotional response to social events. Critiques of the social and medical aspects of psychiatric diagnosis and institutionalisation (Goffman, 1961; Szasz, 1961) point to the ways in which emotional 'display' can easily be coded as, and (always) seen as constitutive of, 'illness', decline, acceptance or recovery. Such 'expert' judgements have also been made about the emotional states and stories of people with physical impairments. Given the powerful and often medicalised interpretations of emotional states and performances, to which many people experiencing illness or embodying impairment may be subjected to, researchers need to be careful of 'emotional analyses' within and beyond the interview.

There are other representational dilemmas in further acknowledging emotions in geographical research: how do we write emotion? Can we and should we justifiably represent often fleeting corporeal/psychological moments experienced within research encounters? By seeking to capture emotion do we inappropriately and excessively

rationalise it by attempting to incorporate it into the dry emotional logic of our analyses? By what authority and form of agreement can we characterise others' emotional states? Are there confidential emotions? In practical terms, what kind of emotional and ethical space should the interviewer work toward if not a managerial one? These difficult questions are ones which we feel should be highlighted in work which deals with disability and health issues, particularly as geographers are increasingly turning to qualitative and interpretative research strategies in this area. Critical and empirical notice now needs to be paid to the neglected area of 'emotions' in future research on illness, impairment and disability, and further work should clarify whether it is possible, or indeed desirable, to have an 'ethics' of emotional research.

## References

Bendelow, G. and Williams, S.J. (1998) *Emotions in Social Life: Critical Themes and Contemporary Issues*, London: Routledge.

Bordo, S. (1986) The masculinisation of Cartesian thought, *Signs*, 11, 433–457.

Brown, M. (1997) The cultural saliency of radical democracy: moments from the AIDS quilt, *Ecumene*, 4, 27–45.

Burgess, J., Limb, M. and Harrison, C.M. (1988a) Exploring environmental values through the medium of small groups. Part one: theory and practice, *Environment and Planning A*, 20, 309–326.

Burgess, J., Limb, M. and Harrison, C.M. (1988b) Exploring environmental values through the medium of small groups. Part two: illustrations of a group at work, *Environment and Planning A*, 20, 457–476.

Buttimer, A. (1974) *Values in Geography*, Washington, DC: Association of American Geographers, Resource Paper 24.

Cook, I. and Crang, M. (1995) *Doing Ethnographies*, London: Institute of British Geographers, Catmog Series 58.

Cornwall, J. (1984) *Hard-earned Lives: Accounts of Health and Illness from East London*, London: Tavistock.

Dorn, M. and Laws, G. (1994) Social theory, body politics and medical geography, *Professional Geographer*, 46, 106–110.

Dyck, I. (1995) Hidden geographies: the changing lifeworlds of women with multiple sclerosis, *Social Science and Medicine*, 40, 307–320.

Dyck, I. and Kearns, G. (1995) Transforming the relations of research towards culturally safe geographies of health and healing, *Health and Place*, 1, 137–147.

England, K. (1994) Getting personal: reflexivity, positionality, and feminist research, *Professional Geographer*, 46, 80–90.

Fineman, S. (1993) *Emotions in Organisations*, London: Sage.

Goffman, E. (1961) *Asylums*, Harmondsworth: Penguin.

Goss, J.D. (1996) Introduction to focus groups, *Area*, 28, 113–114.

Grossberg, L. (1992) *We Gotta Get Out of This Place: Popular Music and Conservatism*, London: Routledge.

Harre, R. (1986) *The Social Construction of the Emotions*, New York: Blackwell.

Herod, A. (1993) Gender issues in the use of interviewing as a research method, *Professional Geographer*, 45, 305–317.

Hochschild, A. (1983) *The Managed Heart: the Commercialisation of Human Feeling*, Berkeley, CA.: University of California Press.

Hochschild, A. (1989) *The Second Shift: Working Parents and the Revolution in the Home*, London: Piatkus.

James, N. (1992) Care = organisation + physical labour + emotional labour, *Sociology of Health and Illness*, 14, 488–509.

James, V. and Gabe, J. (eds) (1996) *Health and the Sociology of the Emotions*, Oxford: Blackwell.

Kemper, T.D. (1990) *Research Agendas in the Sociology of the Emotions*, New York: State University of New York Press.

Laurier, E. (1999) Talking about cigarettes: conversational narratives of health, *Health* (in press).

Ley, D. and Samuels, M.S. (eds) (1978) *Humanistic Geography: Prospects and Problems*, London: Croom Helm.

Longhurst, R. (1994) The geography closest in—the body … the politics of pregnability, *Australian Geographical Studies*, 32, 21–23.

Longhurst, R. (1995) The body and geography, *Gender, Place and Culture*, 2, 97–105.

McDowell, L. (1992) Doing gender: feminism, feminists and research methods in human geography, *Transactions of the Institute of British Geographers*, 17, 399–417.

Oakly, A. (1993) *Essays on Women, Medicine and Health*, Edinburgh: Edinburgh University Press.

Parr, H. (1998a) Mental health, ethnography and the body, *Area*, 30, 28–37.

Parr, H. (1998b) The politics of methodology in 'post-medical geography': mental health research and the interview, *Health and Place*, 4, 341–353.

Pile, S. (1991) Practising interpretative geography, *Transactions of the Institute of British Geographers*, 16, 458–469.

Radley, A. and Billig, M. (1996) Accounts of health and illness: dilemmas and representation, *Sociology of Health and Illness*, 18, 220–240.

Rose, G. (1993) *Feminism and Geography*, Cambridge: Polity.

Rowles, G. (1978) Reflections on experiential fieldwork, in: Ley, D. and Samuels, M.S. (eds) *Humanistic Geography: Prospects and Problems*, London: Croom Helm, 173–193.

Szasz, T. (1961) *The Myth of Mental Illness*, New York: Harper and Row.

Williams, S.J. and Bendelow, G. (1998) Introduction, in: Bendelow, G. and Williams, S.J. (eds) *Emotions in Social Life*, London: Routledge, i–xxx.

Wilton, R.D. (1996) Diminished worlds? The geography of everyday life with HIV/AIDS, *Health and Place*, 2, 69–83.

Wilton, R. (1998) The constitution of difference: space and psyche in landscapes of exclusion, *Geoforum*, 29, 173–185.

Wouters, C. (1992). On status competition and emotion management: the study of emotion as a new field, *Theory, Culture and Society*, 9, 229–252.