DEVELOPING A PARTICIPATORY ACTION RESEARCH APPROACH

ACCESS, ACCESSIBILITY AND MEASURING DISABLING ENVIRONMENTS

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FINAL REPORT TO THE ROYAL IRISH ACADEMY

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CONDUCTING RESEARCH ON DISABILITY

We … are not interested in descriptions of how awful it is to be disabled. What we are interested in is the ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our … impairments by the way this society is organized to exclude us (UPIAS 1976: 4-5).

Introduction

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

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

In this report moral and ethical issues are examined in relation to geographical studies of disability.   This is achieved through a theoretical examination and through empirical research. The theoretical examination is the main focus of the remained of this chapter. It provides the context for the three empirical studies that follow. In the first half of the chapter the moral responsibility of (non-disabled) academics to undertake critical emancipatory and empowering research concerning disability issues is examined. In the second half of the chapter the epistemological and ethical bases of conducting such research are explored. Central to, and linking, the two halves of the discussion are the questions: 'can academics representatively address the exclusion and marginalization of disabled people within society?'; 'can an academic adopt and enact an emancipatory and empowering position in relation to both societal oppression *and* the research process?'. These questions have come to the fore in my own research as I have increasingly questioned my positionality and motivation as a non-disabled researcher studying issues of disability. In particular, I have two main concerns: 1. to find an approach that is emancipatory and empowering, and which is representative of the disabled people taking people taking part in my research; 2. the legitimacy of acting and writing on behalf of a group I am not a member of. These reservations clearly have currency beyond geographical studies of disability to include other excluded and oppressed groups within Western society and research on other cultures (see Deur and Rundstrom, and Gormley and Bondi, Herman and Mattingly, in press).

Moral Responsibility

> Justice in modern industrial societies requires a societal commitment to meeting the basic
> needs of *all* persons (Young 1990: 91, my emphasis)

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

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

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

In the first position are academics who view their role as voyeurs, objectively and neutrally studying society. They argue that it is not the role of academics to try and influence decision and policy-making. Instead it is for others, in democratically elected or institutional positions to interpret research findings and influence future policies. In general, this position in geography is occupied by academics who envisage and practice geography within a 'scientific' framework. An example would be Reg Golledge, himself disabled, whose work whilst seeking to improve the material conditions of disabled people in an implicit manner does not extend to political emancipation (see Golledge 1993). Academics occupying the second position recognize their own subjectivity and positionality in relation to a researched group, but likewise feel it is not their place to be suggesting and seeking societal change. A third group recognises the need for change but seek alternative futures through implicit means such as raising consciousness. Here, discourse is itself seen as an action, and writing and lecturing as mediums in which to engage fellow members of society and alter world views. As such, traditional research methods are still adopted and no explicit action is taken. Academics occupying a fourth position recognize the power imbalances in their own research and seek research strategies that will empower their research subjects either to be able to seek justice themselves or to be able to seek justice through the research (see Herman and Mattingly, in press). The fifth group comprise of academics who recognize the need for change and who explicitly seek change through their own research and their political and social actions.

Those occupying the fourth and fifth positions argue that by not *actively* seeking change through empowerment or emancipation, that will improve the human condition, the academic is guilty of averting their gaze from oppression and human suffering. Not actively engaging with the group which is oppressed or their respective politics would be the academic equivalent of what Dickson (1982, cited in Mohan 1995), in relation to student education, termed 'systematized selfishness' - the study of a subject without giving anything in return. He suggested that unapplied knowledge is knowledge shorn of its meaning. Oliver (1992) contended that this has been the common model of disability research. He described this model as 'the rape model of research' as whilst the researchers benefit from respondent's knowledges or experiences, the research subjects remain in exactly the same social situation. As a

consequence, Routledge (1996) has questioned the current marginal, social responsibility of academics, given their training, access to information, and freedom of expression. He suggested that by not joining their work with political practice or imparting their knowledge to empower oppressed people academics are complicit in oppressive practices. Mohan (1996) has similarly lamented that the current focus upon identity, culture and difference is failing the research subjects and there is a need for critical geography to become more critical.

In other words, geographers should be engaged in an emancipatory project aimed at improving the lives of disabled people (and other groups) in both practical and political ways (see Chouinard 1994, 1997). This involves bridging the chasm that still exists between radical, academic theorists and 'on-the-ground' activists (Pfeil 1994) and engaging with what Touraine (1981) termed 'committed research', Katz (1992) a 'politics of engagement', and hooks (1994) described as an 'ethics of struggle' both within the academy and beyond. Here, there is a recognition that people are not merely subjects to research 'but lives to be understood in the interests of working for a redistribution of wealth and justice' (Deur and Rundstrom, in press). As Chouinard (1994: 5) argues:

> 'This means putting ourselves 'on the line' as academics who will not go along with the latest 'fashion' simply because it sells, and who is take 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 opposition you have to 'connect' with the trenches.'

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

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

> reflections upon moral questions that arise in research, publication, and other professional activities [and] systematic intellectual reflection on morality in general — morality being, as commonly understood, the realm of significant normative concerns, often described by notions such as good/bad, right/wrong, justified/unjustified, and so forth — or specific moral concerns in particular.

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

Emancipatory and Empowering Research Strategies
Central to finding a path that is emancipatory, empowering and representative are epistemological debates concerning how knowledge is derived or arrived at; and the assumptions about how we can know the world (what can we know? how can we know it?). Such debates are currently taking place in the disability literature, particularly in respect to how we gain knowledge. As noted, debates within the disability literature

have increasingly questioned the relationship between (non-disabled) researcher and (disabled) researched. Protagonists on one side of the debate (predominantly academics who are disabled) have argued that is only disabled people who can know what it is like to be disabled. They question the legitimacy of (non-disabled) experts to draw conclusions about disabled peoples' lives and experiences. They argue that research concerning disability research is invariably researcher-orientated, based around the desires and agendas of the (non-disabled) researcher and able-bodied funding agencies rather than subject(s) of the research (disabled people). Indeed, Oliver (1992) argued that current expert models of research are alienating, and disempower and disenfranchise research participants by placing their knowledge into the hands of the researcher to interpret and make recommendations on their behalf; that researchers are compounding the oppression of disabled respondents through exploitation for academic gain.

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

Drawing on work within feminism in particular, these disabled academics argue that power-relations within the research process need to be destabilized and the research agenda wrestled free from academic researchers still using traditional research methodologies. Indeed, Finkelstein (1985 - cited in Barners and Mercer 1997) has called for 'no participation without representation'. Such a reformulation they argue will close the emerging credibility gap between researchers and researched, provide a

'truer' picture of the experiences of disability, and strengthen policy making formulation by moving away research practice currently defined within a social engineering model (Oliver 1992; Sample 1996). Stone and Priestley (1996: 706) suggested that the core principles of a new research agenda should be:

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

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

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

Consequently, disabled academics argue that there needs to be a change in the way that we research and come to understand the world; a shift to emancipatory and empowering approaches.

Not unsurprisingly not all researchers agree on the path to emancipatory and empowering studies and three alternative approaches have been forwarded. The first seeks to retain the expert model of research but to enforce a strict code of ethical practices that are designed to try and make the research process fair and non-exploitative. These are usually designed and enforced by professional bodies whose members are meant to comply to the ethical codes adopted. For example, The Council for Exceptional Children (CEC)[1] has developed the CEC Code of Ethics for Educators of Persons with Exceptionalities which state that special educators should:

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

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

'where [researchers] are committed to working with the differences between [them]selves and those with whom [they] interact, without seeking either to erase difference - that is to presume similarities or identifications that do not exist - or to treat difference as representing something essential and exotic' (Gormley and Bondi, in press).

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

The second approach seeks to alter the expert model of research so that it becomes more representative. Here, feedback (empathetic) loops are inserted into the research process so that whole process is monitored by the research subjects who provide

constructive criticism at all stages (see Barnes 1992; Oliver 1992; Sample 1996). As such, the academic retains control of the research process and the questions being asked but the participants get the opportunity to correct misinterpretations and influence the direction of the research. By using such feedback loops the researcher aims to make her/his research more representative of the subjects views and experiences. This is the approach advocated by Deur and Rundstrom (in press) in relation to cross-cultural studies.

The third approach, and the one this project sought to examine, seeks a radical departure from the expert model of research, forwarding a partnership approach. This approach seeks to more fully integrate research subjects into the research process so that they take on the role of co-researchers (see Lloyd *et al.* 1996; Kitchin 1997; also see Chouinard 1997 for a similar approach). Here, the research process is 'collectivized amongst its participants' (Priestley 1997: 89) with disabled people taking an active role in the whole research process from ideas to hypotheses to data generation to analysis and interpretation to writing the final report. In this approach, the role of the academic is not as expert but as enabler or facilitator. As such, the academic takes an emancipatory position which seeks to inform and impart her/his knowledge and skills to the disabled people who are co-researchers in the project, and provide an outlet to inform the policy makers. The academic's role is primarily to provide specific technical advice to co-researchers to help them make informed choices. Secondly, it is to provide a relatively privileged position through which the co-researchers can speak. Cocks and Cockram (1995: 31) detail that emancipatory and empowering (participatory) research is premised upon five factors:

1. An acknowledgement that oppression within society creates oppressed groups and this leads to a need to engage in some transformation of the larger society to counter it.
2. Knowledge generation, control and application is central to the effort to emancipate and liberate people who are oppressed.
3. People have the capacity to work towards solutions to their own problems.
4. There is a vital link between knowledge generation, education, collective action and the empowerment of oppressed people.

5. Researchers should act in accordance with an explicit values position and should become actively involved in the process of liberation.

Many researchers would reject inclusive, partnership-based research because scientific principles (e.g., separation of researcher/researched) are clearly being compromised. However, collaboration does not mean a radical departure from the procedures of conventional positivistic or interpretative science, just that such science is carried out with and by the participants. In other words, there is a re-negotiation of the relationship between the researcher and researched rather than a radical overhaul of the scientific procedures underlying the research: the study still aims to be professionally administered. However, in contrast to the standard expert model of research where research subjects have little opportunity to check facts, offer alternative explanations or verify researcher interpretations, inclusive approaches facilitates such interaction. As a result, inclusive approaches far from diminishing the academic rigour of research, enforces a rigorous approach that is cross-checked at all stages of the research process through the participant co-researchers. Consequently, Elden and Chisholm (1993) argued that inclusive approaches provide more valid data and useful interpretations and Greenwood *et al*. (1993) contended that this increase in validity is due to a democratization of knowledge production giving the participants a stake in the quality of the results.

Current indications highlight that disabled people do want to be involved in disability discourse. The growth, politicization and radicalization of disabled people's movements over the past two decades demonstrates a desire by disabled people to take charge of their own lives; to wrestle free control from professional services and charity organizations. Disabled people and organizations run by disabled people have been commissioning their own research and actively undertaking their own projects (see Ward 1997). Disabled people are becoming more involved in academic research as valued consultants, research students and research assistants (see Vernon 1997; Zarb 1997). Emancipatory and empowering research is another step towards independence, self-advocacy and self-determination. Involvement also provides a rational and democratic basis for disability discourse shifting discussions and policy from tolerance, charity and common humanity to diversity, difference and rights (Beresford and Croft 1995). This provides a more effective basis for the campaign for

civil rights and the fight for self-organization, independent living and anti-discrimination legislation (Beresford and Wallcraft 1997).

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

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

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

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

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

2

THE PROJECT

To explore the ideas concerning how disabled people are treated by research, their opinions concerning how research should be undertaken and the viability of adopting emancipatory and empowering research strategies an empirical investigation was undertaken. This investigation consisted of two phases. In Phase 1 in-depth interviews were undertaken to assess disabled peoples experiences and opinions concerning research. In Phase 2 two participatory action research projects were implemented, one in Dublin and one in Belfast. In this chapter, the research design of these phases are reported with the results detailed in Chapters 3-6.

Phase 1

Thirty-five disabled people with a variety of physical, sensory and mental impairments were interviewed. The majority (26) of them were working in the disability field for a variety of organisations. The remainder were either attending a training course or day centre at the Irish Wheelchair Association, Clontarf. 17 of the interviewees either lived in the Belfast Urban Area or within 15 miles of Belfast city centre and the other 18 either in Dublin or County Kildare. Interviewees in Belfast were sampled using a snowballing method, with initial contacts supplied by Disability Action. Interviewees in Dublin were arranged by the Irish Wheelchair Association, and in County Kildare using a snowball sample. All the data were collected between March and Nov 1998 by the named author. Interviews lasted from 25 minutes to over 3 hours.   24 of the respondents were interviewed separately, either in their home or place of work, 2 were interviewed as a pair and the remaining 9 in two focus groups of 6 and 3 (these were the training centre and day centre attendees). Interviews were taped except in one case where notes were made by both interviewer and interviewee.

Respondents were interviewed using an interview guide approach. Here, topics and the issues to be covered are specified in advance in an outline form but the interviewer can vary the wording of the questions and the sequence in which the questions are tackled

(Kitchin and Tate, in press). As a result, the interviewer has much greater freedom to explore specific avenues of enquiry and logical gaps within the data can be anticipated and closed. The interview also takes on a more conversational feel while ensuring that all the topics of interest are explored. In the present case, the issues to be covered in the course of the conversation centred on six themes: whether respondents had taken part in research and their experiences; their general opinions concerning research; whether they thought research had served/was serving disabled people well; how research on disability should be conducted; who should conduct research on disability; and finally what they would like to be researched.

All the interview data were transcribed, typed into plain ASCII files and imported and analysed using NUD-IST 4.0 (Non-numerical Unstructured Data Indexing Searching and Theorising). NUD-IST allows qualitative data to be easily managed, cross-referenced, and analysed using simple Boolean operations to identify patterns. Using NUD-IST the data were analyzed using the prescription detailed in Dey (1993) and Kitchin and Tate (in press). This prescription is structured and rigorous consisting of three primary stages: description; classification; connection; that are operationalized through a sequence of standardized tasks. First, each discrete passage was annotated, detailing potential category allocation. Next, the data were sorted into categories of related material. Where relevant, data were assigned to more than one category. To aid the process of connection, the data categories were then split (divided into new discrete categories) or spliced (merged to form new more generalized categories) to create new sorted categories of related data. Where appropriate, links between sorted categories of data were then examined using the Boolean operations within NUD-IST. Finally, the interpretations drawn from the data within each sorted category were corroborated in relation to evidence within other sorted categories.

To allow the data to 'speak for itself' the text in the following chapters is generously adorned with passages from the conversations between the interviewer and the respondents. All respondent names have been coded to preserve anonymity; codes starting with F refer to female respondents, M male respondents.

Phase 2: PAR Projects

In the final stages of the interviews conducted in Phase 1, interviewees were asked whether they would like to take part in partnership based research. As is reported in Chapter 3, despite a collective agreement that partnerships were the most desirable form of disability research, only three respondents were interested in undertaking such research. As a consequence the envisaged PAR approach, whereby a committee of disabled people would decide upon the topic for research and then undertake that research, failed to be realised. Instead partnerships were formed with individuals, one in Belfast the other in County Kildare. These individual decided upon the topic for research and co-designed and undertook research generation. In practice, the academic researcher undertook the bulk of analysis and interpretation of the results in consultation with the partner. In practice both partnerships worked well and a strong working relationship developed. The project therefore succeeded in its aims of performing an emancipatory and empowering approach, with partners researching topics that were important to them, gaining knowledge and skills, although the project did not achieve these on the scale anticipated. The action part of the projects were fairly limited, although it is hoped that two reports arising from the projects will have an impact - one to be published by the Family Planning Association and the other, hopefully, by Combat Poverty (funding applied for).

Phase 2: Family Planning in Northern Ireland

For reasons detailed in Chapter 5, the first partner decided to assess the levels of access for disabled people to family planning, sex education and sexual health in Northern Ireland. To achieve this we conducted a short questionnaire survey of all family planning clinics in the Province. Because the clinics are providing a service to the public, they are by law meant to ensure full disabled access under the provisions of the Disability Discrimination Act (1995). By failing to achieve this standard not only are clinics failing their statutory requirements but they are reproducing cultural ideologies in relation to disability and sexuality.

The survey consisted of two sections. In the first section, the clinic staff were asked to assess the overall accessibility of the clinic and conduct an access audit of their building. Questions related to parking, entrances, internally design, toilets, signage, specialised equipment (e.g. minicom for deaf people), and treatment rooms. In the

second section, the clinic staff were asked about information access and specific services. Questions included asking whether the clinic provided information that was accessible to disabled people (e.g. Braille, audio-tape, signing), how soon that material could be provided; whether the material was specifically produced for disabled people; whether services were provided to people with learning disabilities; whether any staff member was dedicated to disabled clients; whether clinic staff had received disability awareness/equality training and if so how many staff and taught by whom. The questionnaire was distributed by post in August 1998 and included a self-addressed envelope. The questionnaire was anonymous to encourage responses without fear of undue publicity. The aim was to assess the state of play not to make scapegoats of particular clinics. 34 of the 54 questionnaires distributed were returned, a response rate of 63%.

Phase 3: Education in County Kildare

The second partner, for reasons detailed in Chapter 6, decided to assess current practice and the viability of educationally 'mainstreaming' of all disabled children living in the county. To achieve these aims we adopted a threefold strategy. First, we reviewed the development of educational practice for disabled children in Ireland. Second, we conducted a survey of all first and second level schools in the county. A questionnaire survey was mailed to all first level (age 5-11) and second level (age 11-18) schools in County Kildare (self-addressed envelopes were included). The survey comprised of six short sections: (1) school details, (2) a census of numbers of pupils, including those with different disabilities, (3) school policy, (4) access and provision, (5) plans for the future, (6) further comments. Sections 3 through 6 concerned the schools policy towards, and provision for, disabled children. Section 4 comprised the largest part of the survey with questions relating to disabled access in its broadest sense: physical, educational, social. Questions relating to physical access asked whether the school considered itself to be physically accessible to disabled children and included an access audit in which the school detailed its provision. Questions relating to educational access concerned whether the school considered itself to be educationally accessible and included an audit of education mediums/resources accessible to disabled children (e.g. specialist equipment, adapted software) and remedial teaching. Questions concerning social access included questions concerning out-of-hours activities and disability awareness training for staff

and pupils. Data were analysed using simple descriptive statistics, except in the case of Section 6.

A total of 60 (63%) first-level schools and 14 (50%) second-level schools returned completed survey forms. These schools varied in catchment area (rural/urban), size (first-level, 17 to 635 pupils; second-level, 131 to 810 pupils), and form (mixed, single-sex, private, Irish-medium). A total of 13,448 pupils (6369 boys, 7,079 girls) attended the first-level schools and 7,210 pupils (4315 boys, 2895 girls) attended the second-level schools.

Third, to complement the survey data, a random selection of 10 school principals, who indicated that they would be willing to discuss further issues raised in the survey, were interviewed. Interviews were conducted over the telephone and were recorded and transcribed in full. An interview guide strategy was adopted. Issues covered in the course of the conversation centred in particular on sections 3 (admission policy) and 5 (future) from the survey. Transcripts were sent to those interviewed for checking. Along with the comments expressed on the survey form, the interview data sought to shed light on, and provide a context for interpreting, the survey data.

3

DISABLED PEOPLE'S OPINIONS OF RESEARCH

In this chapter, the representativeness of some of the arguments posed in chapter 1 by academics such as Barnes, Finkelstein, and Oliver are investigated through the reporting of the in-depth interviews with 35 disabled people. In particular, the discussion centres on the extent to which disabled people are dissatisfied with academic research, and their opinions on how and by whom disability research should be conducted, are gauged.

General Opinions Concerning Disability Research

The majority of the respondents were of the opinion that research concerning disability issues is important and is needed. As respondents F5 and M8 stated:

> F5: I think it is a necessary evil. Is how I would describe it. I do think there is a need for it and I do think that it has to be done.

> M8: Research is absolutely vital because the more research that is done the better the argumentation that can be made. ... The fallacy out there is that all disabled people are against research. I probably wouldn't be alive today if it wasn't for medical research and many thousands of others I know would probably be in a similar situation.

This is not to say that research is accepted unproblematically. Respondent M8, for example, continued with a warning that the research undertaken needs to be carefully selected, presented in a way that is unambiguous, have clear connections between theory and the lives of disabled people, and needs to be acted upon:

> M8: … there is so much being written and so much being researched, again, again, and again about disability. The whole thing is ludicrous you could fill this hotel with reports and research studies and research papers that have been done in the past ten years - but what's the progress for people actually on the ground? It's very, very small. And that's one of the most annoying things that all these studies, all of this research - where does it actually lead in the long term? And what use is it put to? Some of it can be used by governments to defend what they want to defend. A lot of it is written in such a way that it is very academic. I have problem with some of the academic work

as I don't think it relates really to the what life is like for people on the ground. So, yeah, it can be interesting but reading some of the academic studies you wonder how the hell ... or who or why they are coming from?

Similarly, respondents M2 and M12 questioned the logic in continuing to do any more research given that much of it is repetitive and remains unacted on:

M2: Everybody knows the problems - why are people conducting research, research, research? We should actually be out doing something about it. ... 90% of research projects end up in the bin anyway.

M12: Ireland needs action not more research.

Indeed, one of the central themes concerning general opinions of research, expressed by the majority of respondents, was the fact that they perceived most research to be ineffective and not acted upon. As respondent F1 noted:

F1: … I would be cynical about what actually happens with research. The majority of times it just sits on a desk. May be it is referred to by academics or somebody actually doing a bit of study …

Indeed, respondents M10 and F2 both felt that research which not acted upon was essentially worthless; that research concerning disability should not be for knowledge's sake, especially given the need to improve the quality of life for many disabled people:

M10: There's no point doing research if no one is going to do anything about it.
INT: So what sorts of action are you talking about?
M10: Well what you find is implemented to improve the situation for disabled people.
INT: So, you basically want whatever has been done ...
M10: … to have an effect on my life and other peoples.

F2: yes there has to be an outcome to it. There is no point doing research for the sake of research.

Such arguments have also been made in academic writing. For example, Mohan (1995) contends that not actively engaging with the oppressed group being researched

in practical ways or their respective politics is 'systematised selfishness' - the study of a subject without giving anything in return. He suggests that unapplied knowledge is knowledge shorn of its meaning. Oliver (1992) contends that this is the common model of disability research.

Some of the respondents found discussing the relative merits of research difficult because they had had little exposure to reports of research findings, and experienced difficulty in engaging with and interpreting that to which they had been exposed. For example, respondent F6 reported:

> F6: ... I think in general as disabled people we don't always know what research is going on and sometimes it is totally academic - it is way, way away from the practical. Sometimes the bits you read in the journals are really obscure things that are done as a theoretical exercise rather than as something that is going to have any impact on our lives. And possibly, sometimes the evidence is used against us to confine us or keep us in institutions or whatever, but in general people won't know what research is being done. If it is done in social science departments and academic institutions we won't know about it.

Respondent M11 explained that the reason many disabled people do not know of the research being conducted is because:

> M11: there's loads of research going on within the system but it stays within the system or leaks out when trying to get funds for this that and the other like. But actually bringing out to the mainstream audience is where it needs to be.

As M5 pointed out, compounding the problem of informing the wider, disabled community, and organisations who can make very real differences to disabled people's lives, such government, health bodies, voluntary agencies, service providers, is the fact that the majority of reports are written in a certain style and demand a certain level of literacy and time to invest in digesting the material. Even textbooks aimed at summarising a wide variety of ideas and research findings into a manageable form generally expect their audience to have an undergraduate standard of education. Inaccessible academic texts are exclusionary and deny the disabled community the opportunity to act on the findings in a positive way [i]:

> M5: I think it can be useful but it depends upon how it is going to be used, how it is going to be put into practice. I think an awful lot of research tends to be ... we talked about Colin Barnes and Mike Oliver earlier - some of those books are very sociology orientated. And they are very hard to read and I think that is one of the things with academic research is that it is very jargonised.

M7 suggested that one method that will inform both disabled people and the wider community of research conducted, and the actions needed to address the central issues arising from the findings, is to beyond traditional academic outlets such as journals to other media:

> M7: By advertising your research when it is finished. By advertising it, by making it public. By going to media with it - press, radio, television, come what may. But by making yourselves known.

Indeed, respondents articulated that one of the most annoying aspects of research they had participated in was not knowing the results or recommendations stemming from the study:

> F3: The only thing I would have liked to know was the outcome of it. That would have been very, very helpful. I didn't actually know whether it was for her own benefit or for a project - I knew she was funded but I didn't know ...
> INT: So you got no feedback?
> F3: No, not at all.

> F8: I think the research, and all the surveys that are actually carried out, they never get back to the person. And the person can't actually say - 'yes I helped'. Or they don't see what actually happens in society as a result of the work that they have done with any of the research.

Their knowledge and experiences had been 'mined' by the researcher(s), who was then never heard of again. This left some respondents frustrated and wary of taking part in future studies[ii].

Respondent F3, drawing on her experiences of commissioning a feasibility study, also questioned the value for money of some research projects in relation to the benefits gained from their undertaking:

> F3: I suppose in a way that it was extremely useful but I felt our feasibility study was extremely expensive. It was an extremely expensive project of which most of the information was supplied from here. We sort of gave the information and they wrote it up.

In addition, respondents were asked about whether they felt that disability research was serving/had served disabled people well. Whilst some respondents were unsure because they had little knowledge of current or past research and how it was acted on, the others were divided between those who thought research had/was serving disabled people well, and those that thought it was had not/was not. For example, respondents F8 and F1 were reasonably positive, and argued that research although not ideal was helping to breakdown ableist social relations:

> F8: It's keeping going forward. Obviously there are [...] things that are helping people and even research into things like accommodation has meant that there is more accommodation available for disabled people now. And also people are now more aware of certain needs such as access. ... making people more aware ... and ignorance, stopping ignorance has helped.

> F1: I suppose it does to a certain extent, it can highlight things and people like me can actually use it. Take the PPRU report. We quoted from it continuously, 201,000 adults with disabilities in Northern Ireland, 118 are men - are women - 83 are men, 16,000 are children. ... it serves me well going out and quoting things and saying 'research has shown, blah, blah, blah'.

In contrast, a number of respondents felt that on the whole research had not served/was not serving disabled people well. For example, respondent M4 noted that research has been used to justify the institutionalisation of people with mental illness.

> M4: In the past that has happened - that is fact. That ... I know from own experience - that thirty years ago I would have been put into an asylum because I hear voices or whatever. And the research showed that that was the way it was treated.

Similarly, respondent M1 noted that some forms of research relating to disabled people still explicitly enforce ableist attitudes and practises by exploring and advocating ideas relating to eugenics:

M1: I've read a lot of research and some of it is very good and impresses me. Especially research that comes from the social model of disability. However, research that comes from the medical model of disability quite frankly frightens disabled people because of eugenics, and people monitoring, and all the implications that they might have. So ... so you can understand disabled people being slightly sceptical of disability research.

Indeed, given that academic research has (and still) perpetuated, reproduced and legitimated the marginalization of disabled people, justifying segregation, eugenics, and the denial of civil rights, it is little wonder that disabled people are suspicious of research by non-disabled researchers including those who claim to be allies (Rioux and Bach 1994). This suspicion is based, as described by respondents F5 and M3, upon the fact that academic researchers do not approach a project from a neutral, objective position but are situated within constructed and historically-rooted, discourses of knowledge and power. As such, researchers come to a project with a 'set of baggage' and a pre-determined agenda:

F5: On the whole I would probably say no. And I think - this is just my own opinion - I think it is because of societies attitudes towards disability. Hopefully researchers try to be as neutral as they can be but they still have their baggage with them. And if they haven't had much contact with disabled people, then you know ...

M3: Most research will achieve something but some of it is just done so badly and so incompletely. In Hitler's Germany a group of scientists would just be bunged into a room and given a weird hypothesis and they wouldn't be allowed out until they had proven it. Which rather stretched the imagination sometimes. And I do feel that a lot of academic research sets off with not a dissimilar attitudes. It is decided in advance that certain traits are present in the community and it seeks to prove it.

At a more fundamental level, some disabled people are worried that research currently being undertaken is not representative of their views and is conducted in such a

manner that unless changed will continue to misrepresent them. It is to these issues and the relationship between researcher and researched we now turn.

Researchers and Researching Disability

Despite having varying levels of exposure to disability research, all the respondents had strong opinions about how disability research should be conducted and by whom. It was widely appreciated, as with charity organisations and service providers, that disability research is dominated by non-disabled researchers. To the vast majority of respondents this created issues related to representativeness. First, and foremost, some respondents forwarded the argument that non-disabled researchers can potentially misrepresent and misinterpret disabled people's experiences and knowledges because they themselves have never experienced what it is like to be disabled. Traditional expert model approaches, when used by a non-disabled researcher, means that disabled subjects' knowledge is placed into the hands of the researcher to interpret and make recommendations on their behalf. Such a situation means that there is greater potential to discount, deny or even fail to acknowledge the lived experiences of disabled people who are under the analytical gaze (Imrie, 1996). For example, respondents M10 and M8 stated:

M10: You don't know how a disabled persons life works. You can only imagine how it works. But you actually don't know.

M8: I would love to see the day when disabled people are doing research about disability. Because it is much easier - no-one can ever say to me if I was doing a research project, 'look you've never gone through this, you've never been in that situation', because I use a wheelchair. It's quite easy to see that I can't get on the bus, I can't get into 60% of the shops, I can't get into most of the universities. So it's very difficult to say to me, 'well you don't know what it's like'. But it's quite easy for me - say your asking me about public transport or you know - you've never been in that situation. You've never sat at a bus stop and sat there ... you've been given a free bus pass but you can't blooming well use it. You've never been in a situation, like a blind person who has got on the wrong bus because there is no audible to tell them where it is going. Simple little things like that, that you can't empathise with, but someone like myself as a disabled person can. I think eventually it will come around to the fact that disabled people are doing research but to get people to that situation is going to need a lot of time and effort.

At a second level, some respondents suggested that disabled people will only tell partial stories to a non-disabled researcher for fear of embarrassment or reporting things which may lead to a reassessment of benefits/services or that the researcher will not believe them. Moreover, they will, in the main, make situations seem better than they really are. As respondents F10 and M8 report:

> F10: What I mean is people won't tell you [able-bodied researcher] the embarrassing stories.

> M8: because people will be more open with me. ... when we asked whether they [disabled constituents] had ever bought this to the forefront in the past, or have you ever spoken to anyone, it was 'no, because no-one would ever listen to us, and at least you will have some idea about what your going through and we wanted to share that with you.' And that's why I'm saying that, that we will get a lot more than the normal researcher.

At a third level, respondent M9 argues that it is important that disabled people undertake and present research because it makes more of impact due to the fact that it is 'straight from the horse's mouth'. As such, research being presented by a non-disabled person potentially undermines the impact or significance of the research or point being made.

> M9: No disrespect to you, but when a disabled person voices it it comes out a lot better. Because they can get their point across and actually show what they need. Actually show it in a physical form, rather than an able-bodied person trying to explain it. Which is difficult to do.

The discussion of representation and who should be conducting research on disability issues led in to a discussion of how research should be undertaken. Two sets of approaches, broadly categorised as exclusive and inclusive approaches were identified. Exclusive approaches are those where research is conducted solely by a (or team of) non-disabled or disabled researcher(s). Inclusive approaches are those where research is conducted by a team of disabled people (non-academic) and disabled/non-disabled (academic) researchers.

Exclusive approach

Only three respondents expressed views concerning the adoption of exclusive approaches. Both also backed the adoption of partnership approaches when discussed at the end of the interview. As such, whilst instructive the following two quotes should in no way be seen as representative. Respondents M7 and F11 initially suggested that research should be undertaken by a 'neutral', non-disabled outsider fearing that researchers with a specific disability may concentrate their efforts, and channel recommendations, towards themselves:

> M7: I suppose if a disabled person was doing it themselves, then I suppose it would be with ... obviously the disability they have, it would lean towards their favour. I suppose an independent body would be the best. Someone like yourself who hasn't got a disability. Some one who can try and get to the root, to try and get to the understanding of the problems in regards to the disabled community.

> F11: ... basically I think the best approach would be if the government say appointed someone .. if they wanted research for a particular report or whatever that should really appoint somebody independently. I don't think really ... this is a personally opinion but organisations like Cheshire Homes or IWA [Irish Wheelchair Association] don't do it effectively because they push their own agenda. And I have seen them do it and I don't like the findings. I don't know whether that is a terrible thing to say but ...

Respondent F9, in contrast, continued the theme of representation, arguing that it is only disabled researchers people that can truly understand and represent disabled people.

> F3: People with disabilities. ... I think it is - I feel very, very strongly not only about research but also in giving disability awareness. This is a very in-thing at the present. It would be like you, with all respect, standing up in front of a lot of women and giving them awareness on what it feels like to be a woman. You can give the theory and you can give what you have been taught but you cannot get inside the skin and know exactly what it feels like. ... I think it should be given by disabled people because they have the insight. They know what it feels like and the empathy is probably something that can't be taught.

Respondent M1, whilst not advocating the adoption of an exclusive approach, noted that academics do have a role and influence within society; that disabled people have

a vibrant academic arena centred around disabled academics is important in seeking the emancipation of disabled people:

> M1: And very often, whether we like it or not, academics take the lead and we need to have as a movement, as a disabled peoples movement, our academics.

Inclusive approaches

The vast majority of disabled people interviewed were of the opinion (for reasons stated above) that disability research should involve disabled people beyond the subject source. Moreover, the majority of the respondents argued that disability research should involve non-disabled researchers and that the way forward was through consultation and partnerships (see below). The role of non-disabled researchers was seen as important for a variety of reasons. For some interviewees, the disabled status of the researcher was simply seen as a non-issue as long as the researcher was approaching the research from a 'disabled-friendly' position:

> F5: Some people would argue that for credibility's sake its better coming from a disabled person. I wouldn't necessarily agree with that but I think that whoever is doing the research has to do it with disability as their focus and not coming from a non-disabled perspective.

> F7: I don't see it as a uniquely disabled initiative or as a uniquely able-bodied initiative - I really think there has to be a true partnership that has to emerge.

Respondent M1 similarly argued for the need for researchers committed to disabled emancipation but continues that any exclusion of non-disabled researchers reproduces forms of discrimination, and thus perpetuates the duality of abled/disabled and the maintenance of dualistic power relations, albeit with disabled people in power, that much emancipatoty and empowering research seeks to challenge:

> M1: Quite simply people who are committed to the social model of disability. And people who are committed to productive research that is based upon helping people fulfil the expectations that they have. ... people who are committed to the principles of disability equality would be my preferred researchers. ... if we as a movement put that stipulation on people [need to be disabled to do research on disability] we would be

discriminating against them the way they are discriminating against us now. ... I don't think that we can progress unless we are inclusive. And for me to adopt the attitude of 'oh, he hasn't got a disability, why should I be talking to him?' is wrong.

The disability movement whilst growing does need allies that will help to fight ableist discrimination. To the interviewees in this study, alienating this group is counter-productive and does not aid the disability movement's cause.

F12: I think it has to be in conjunction with a disabled person and abled-bodied because there are disabled people out there who I wouldn't want representing me. A lot of people. And I resent the fact that everybody else with a disability thinks they understand me because they don't. We are all individual. I think it doesn't really matter as long as they aren't out just for themselves, that's it's going to be worked on, and that they do get feedback from the person with a disabilty and they do work hand-in-hand with someone who has a disability. I don't think it matters as long as it's done in a positive way.

Other respondents were concerned that the removal or discrediting of non-disabled researchers from disability studies would leave the fledgling field in the hands of a small number of disabled academics, who are already seen as having their own agenda. Keeping non-disabled people involved allows the field to develop whilst the base of disabled academics grows, and also provides another perspective. As M6 and M11 stated:

M6: I am quite concerned that there is the development of a disability elite who are centred around certain universities in England. ... who are trying to control everything that is going on but bending it to serve their own purposes. … I am a freelance journalist for papers like Disability Now and I find that the reaction of the real disabled people, i.e. people living in dire straits is actually markedly different from these people in the rarefied atmosphere of these universities. I think the elite have caught themselves up in this ideology and it is spiralling out of control. The real disabled people tend to look at it and .. think that they are all in denial. And you know, it's probably not true but you know, its an impression that is hard to shift.

M11: No, I don't buy that argument at all because you can be an arsehole with a disability. And I know people in the movement who would say 'we are the experts.' To a certain extent that is true, but that doesn't mean that you don't have blind spots, you

know. And I mean coming at things from a totally different perspective, it all depends on how you approach it. I think that if your coming at it from an expert view, or expert position, no matter who you are, whether you're a disabled person or not, I still consider that to be a bit dodgy. Er … and what pisses me off about some people in the movement is that they consider themselves to be the sole expert in the area and ... they go on and on as if their word is gospel and only they can do stuff ... or even talk to a person with a disability - 'Well I have a disability and I'm the only person who does understand it,' but that only ghettosises it further.

Another argument for the involvement of non-disabled people, but one not discussed by interviewees, is that forwarded by Wilton (in press). He argues that ableist relations by nature consist of non-disabled (oppressors) and disabled people (oppressed). Therefore non-disabled people should be a vital focus of disability studies. However, he suggests that, given the problems of seeking to represent a group to which they do not belong, non-disabled researchers should focus on studying non-disabled oppressors rather than the recipients of oppression. By marrying disabled and non-disabled perspectives we would then gain a greater understanding of ableism.

Other arguments for research involving disabled and non-disabled people are discussed in relation to the inclusive approaches recommended by the interviewees.

Disabled people as consultants

Some respondents suggested that studies by non-disabled researchers could be enhanced and made more representative by employing disabled people as consultants:

> F4: May be they could have some sort of advisory group they could go back to once they know what it is they want to research and the areas they want to research and why they want to research. ... They should have an advisory group of disabled people that they can show a layout of their research and they will give you a more of an insight into problems areas that need to be looked at and the things that have been missed and that sort of thing.

> M8: The problem I have about research up to this has been in the main conducted by academics or by medics and it never goes through at a proof reading stage - getting a group of people of the consumers together and to bring it forward in a language that they can understand and which they can utilise. The dignity of the individual has to be first and foremost - at the core of it. And that doesn't happen enough. And that's why I

think a feedback or a group of disabled people prior to the final publication looking at the thing and discussing the thing with the researcher.

In practice this approach would consist of feedback (empathetic) loops being inserted into the research process so that whole process is monitored by the research subjects who provide constructive criticism at all stages (see Barnes 1992; Oliver 1992; Chouinard 1997). As such, the academic would retain control of the research process and the questions being asked but the participants get the opportunity to correct misinterpretations and influence the direction of the research.

Disabled people as partners

In the main, however, interviewees favoured a partnership approach where instead of merely advising the researchers, disabled partners have a degree of control over the research process which is not tokenistic. As respondents F3 and M4 stated:

F3: At the end of the day you have to live in the world so I suppose teams. For example, I would be ... my assistant would have to compliment me. There are things I can't do, so may be research could be done that way. That, together, partnerships between people who have disabilities with people who don't. But equal partners. That people with disabilities are not going to be there as a token. They have to know and they have to feel their true worth.

M4: I've always wanted a like, sort of, a 50/50 democracy because I have respect for the person who is not disabled and his point of view is as valid as mine but he might have insight that I have. …I want to be together both the researcher and the researched on an equal level instead of the way it is really - the way society has it at the minute

Such partnership approaches seek a democracy between (non-disabled) researcher(s) and disabled co-researchers that is based upon recognising that both parties have expertise but from differing frames of reference (Kitchin, in press):

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

A partnership approach thus seeks to allow the research to become more representative and reflexive by addressing the issue of unequal power arrangements within the research process and recognising the 'expertise' of disabled people in their own circumstances. As discussed in Chapter 1, inclusion acknowledges and signifies a respect that the contributions of disabled co-researchers are valuable and worthwhile and leads to the development of a mutual sharing of knowledge and skills (Lloyd *et al.* 1996). Indeed, it is only with their active involvement that disability discussions will reflect their needs, concerns and interests. Inclusion provides a platform from where disabled people can speak for themselves, to seek the services and support they want, to explicitly influence social policy, and fight for disabled rights. As such, the shared benefits to researchers, policy makers and disabled co-researchers potentially outweigh costs in terms of time and organisation.

Being a disabled researcher does not preclude the use of inclusive approaches. Indeed, what is really being advocated here is the movement of some of the subjects of research to a inclusive position. As such, academics who are themselves disabled do not occupy privileged positions where they can speak on behalf of their fellow disabled people. Rather, they too must develop a partnership with non-academic participants to allow the research to become more representative of wider views and thoughts. Admittedly, this partnership may be more 'comfortable' as the disabled academic will have the benefit of insider and outsider knowledge. However, as the recent debate between geographers who research disability issues (see Golledge 1993, 1996, Butler 1995, Gleeson 1996 and Imrie 1996), and the views of interviewees in this study (see M6 and M11's statements above concerning 'elitist cliques' and not being represented by disabled academics), demonstrates, not all disabled academics adopt a critical, emancipatory position, or all disabled people agree with disabled academics.

As discussed in Chapter 1, many researchers might reject such inclusive, partnership-based research out-of-hand because scientific principles (e.g. separation of researcher/researched) are clearly being compromised. However, collaboration does not mean a radical departure from the procedures of conventional positivistic or interpretative science, just that such science is carried out with and by the participants.

In other words, there is a re-negotiation of the relationship between the researcher and researched rather than a radical overhaul of the scientific procedures underlying the research: the study still aims to be professionally administered.

One particular partnership approach, participatory action research (PAR), was detailed at the end of every interview and respondents invited to comment. PAR consists of a research process that is 'collectivized amongst its participants' (Priestley 1997: 89) with (non-academic) disabled people taking an active role in the whole research process from ideas, to hypotheses, to data generation, to analysis and interpretation, to writing the final report. In this approach, the role of the academic is not as expert but as enabler or facilitator. As such, the academic takes an emancipatory position which seeks to inform and impart her/his knowledge and skills to the disabled people who are co-researchers in the project, and provide an outlet to inform the policy makers. The academic's role is primarily to provide specific technical advice to co-researchers to help them make informed choices. The approach is action-led in that it explicitly aims to use the research to change social relations.

In every case, respondents expressed enthusiasm for the proposed PAR approach. There were, however, a couple of queries concerning how the project would work practically and who the disabled co-researchers would be:

> F6: As long as the people involved at ******* feel that it is them that is taking the lead. That it is something that they want to do rather than they are pushed into.

> M8: It's brilliant as long as you get the right people involved. Because, you see again ... certain self-interest groups within the disability field … would have a number of disabled people active within an organisation. And it [would be] a way for them to build their own empire.

The paradox within the current research project was that when offered the opportunity to conduct research on whatever aspect of disability and society they wished almost without fail the interviewees (including strong advocates of inclusion), bar three, declined. They wanted inclusive research to be conducted but were unprepared to undertake such research:

M10: I think that you have to get disabled people to carry it out and get as involved as possible, and be involved in all aspects of it.

INT: How would you feel about doing something like that?

M10: I don't really know I'd get involved now. I'm quite happy to give these ideas, now, but getting involved is a different story.

INT: You wouldn't want to do it yourself?

F12: No, God no! I want to be out of here at five o'clock and have a life. That sounds awful, but I'm like a lot of other people in that way. I'm selfish, I have to say. I've got my life together now and, it took me a long time, you know, I fought every inch of the way and I don't want to ... do it anymore. There will be people who love that, who relish it, but I don't. But it is still a good way, but it wouldn't be everyone's cup of tea, you know what I mean.

In general, time was cited as the main reason for not wanting to take part, although there were in some cases clearly issues of confidence linked to conducting a project funded by an academic funding agency and administered by a university lecturer. As such, if partnerships projects are to be successful, then locating potential partners is an issue that will have to be addressed. Given time constraints, especially on large projects which need concerted effort over a long period of time, a strategy of partnership-based consultancy (still have decision making powers but all labour undertaken by research assistants) may be a viable alternative.

Training for Researchers

Whether adopting a consultancy or partnership approach some interviewees thought that non-disabled researchers should have to undergo a process of disability awareness training that would ensure that were approaching the research using an appropriate frame of reference:

F5: Well I would like researchers to have training in that particular field. If they are going to go into disability research they should have some sort of training in that particular area. How or in what format it would have to be decided after a process of consultation. ... It could well be that they would have to work with disabled people in different environments for a time or whatever, or have structured training sessions. ... I think they have to know where disabled people are coming from.

> F10: My strongest opinion is that whoever is doing it should be put into a wheelchair for a day, I'll lend them my wheelchair and let them see what it is actually like. Or if your doing it for the blind then put glasses on you and be led around for a day and see what it is like to be .. not to know where you are going. To be blindfolded. ... it's the only way you would get an insight.

The politics of the second suggestion are not straightforward. There is a danger that by giving non-disabled researchers a 'snap-shot' experience of disability for a day it provides a site from which they can claim to 'know' what it is like to be disabled. This is clearly not the case given that the experiences of disability are complex and go beyond the removal of bodily functioning or senses. A better strategy might therefore be to use the inclusive approach to allow disabled people to fully articulate their experiences.

Methods to Generate Data

The final aspect to be considered briefly here is how data relating to disability issues should be generated. Interviewees were invited to discuss some of the shortcomings of data generation methods employed in studies they had previously participated in or just to comment generally on how they think data should be generated.

In general, respondents were wary of questionnaires and statistics. Questionnaires they felt were often poorly presented, poorly conceived, limited their responses, and thus led to a limited understanding of the subject which they seek to reveal. As respondents F6 stated:

> F6: Well there are times when you are cornered into doing it. There are times when I have felt that I am answering questions that I don't really want to answer because I feel it does not really apply to me. Sometimes I feel restricted by the questions. That, the questions your asked, or rather the response your forced to give doesn't always give you the opportunity to say what you want to say. … someone asking you pre-set questions where you need to - even if the answer is meant to be yes or no you really need to qualify it sometimes. It doesn't always give you the opportunity to do that.

Similarly, respondent M11 contended that quantitative data and statistics are limited and potentially deceptive. He suggested the use of qualitative data as an alternative.

M11: I can never get to remember the term but qualitative stuff is much better than the quantitative stuff. I've done stuff with both of them .. with numbers where you produce frequency tables and t-tests and all that sort of stuff and I've done the more narrative stuff where it's more chunks of text and transcribe from tapes and ... er, the later is much more meaningful. ... you can manipulate numbers. I would have done a fair bit of statistics in my time and for one, nobody can understand them, ... you can bullshit people away and they really haven't got a clue what your talking about it. ... a lot of documents that supported that ['strategy for equality' report] ... are large chunks of text of what people said and the feeling comes through and the injustices come through and you wouldn't get that out of '56,500 people interviewed 46 were dissatisfied with their situation...'. You know you aren't going to get that.

In general, there was strong support for qualitative methods of research, particularly interviews because they allow respondents to express and contextualise their true feelings rather than having them pigeon-holed into boxes with no or little opportunity for contextual explanation. As respondent M7 stated:

M7: Well I think the way that you doing it at the minute is quite good. Your going and your meeting people. People who you don't know and your prepared to meet them and talk to them and you are prepared to listen to them.

Respondent F12 suggested that in-depth discussion-based focus groups might be advantageous as they provide supporting structures for a group who might be intimated by the researcher:

F12: I think it's better to talk to people and I think it's more positive because you can say more than a list of questions. … You get more feedback face-to-face with a person. And not in a huge group may be. If it was two or three of us in a group may be. … There are times when we can feel intimidated. And especially I feel, many disabled people, they get intimidated by able-bodied people and by institutions that do all this research, because they feel like that they are being ... I'm not sure what it is really ..

Respondent F5 also noted that within the interview framework there has to be flexibility to allow the respondent the freedom to express themselves as they wished:

F5: Whatever suits that particular interview. Because if you try to access information from an individual in a format that does not suit them you would not get the best out of

them and it's highly unlikely that you would get a true picture of what's going on, because they are feeling uncomfortable about it or whatever - they just won't be forthcoming.

Discussion

It is clear from the analysis of the interview transcripts, and the actions of disabled people in society (e.g. growth, politicization and radicalization of disabled people's movements over the past two decades) that disabled people want 1) disabled people to be more involved in disability discourse (including the research process) 2) academics to be engaged in emancipatory and empowering research projects aimed at improving the lives of disabled people in both practical and political ways. As academics (disabled and non-disabled), the engagement with the emancipation of disabled people can take one of two forms. Both forms consist of engaging with disabled people in a common struggle against ableism. The first form is merely the adoption of an inclusive research approach. The second form takes the inclusive approach one stage further so that it becomes action- and politically-led. As such, the second form seeks the formation of strong links between academic theorists, disabled people and 'on-the-ground' activists. Here, it is recognised that for academia and research to become truly emancipatory and empowering it has to actively seek change rather than hoping that the 'right people' read the work and act upon it. As the interviewees in this study strongly argued, research needs to be acted upon and not just be gathering dust on a library shelf. This means ensuring that the results reach their audience and academics engaging with what Touraine (1981) has termed 'committed research', Katz (1992) a 'politics of engagement', and hooks (1994) described as an 'ethics of struggle' both within the academy and beyond. As Chouinard (1994: 5) argues:

'This means putting ourselves 'on the line' as academics who will not go along with the latest 'fashion' simply because it sells, and who is take 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 opposition you have to 'connect' with the trenches.'

Such links are not as yet well developed and where they are developed are often partial and not research-based.

Given the views of the disabled respondents in this study (e.g. the enthusiastic endorsement of the participatory action research (PAR) strategy) it seems that the route of partnership-based, action-led research needs to be investigated as a viable strategy of conducting research. The second part of the study did seek to explore the experiences of conducting action-led, partnership-research and the findings from these studies are documented elsewhere. It is suffice to say that whilst challenging to undertake and not without its difficulties, that a 'third-space' (Routledge 1996) between researcher and researched, academic and activist, can be occupied. Given, however, the paradox that the vast majority of disabled people approached turned down the opportunity to conduct a small research project for a variety of reasons (time being the main concern), and the general problems of literacy and lack of third-level education amongst the disabled population, a route of consultation may be the most appropriate to follow.   Clearly not all researchers will agree (e.g. Shakespeare 1996). As respondent M6 stated:

> M6: Are you talking about the sort of argument about disability circles that you are only allowed to academic research that they have agreed before hand what you should do? My point is that you should do it. Academic research ... research is the researchers agenda, you know. I don't think you should necessarily pay attention to anybody else.

Whilst having sympathy for the researchers right to choose, one also has to consider the position of the researched. Therefore, whilst not denying that there has been, and will no doubt continue to be, high-quality, rigorous, scholarly, and critical studies of and for disabled people the route of critical studies *with* disabled people needs to be fully explored. This is because as argued, emancipatory and empowering research (whichever strategy is chosen - consultancy or partnership) potentially represents another step towards independence, self-advocacy and self-determination. Involvement provides a rational and democratic basis for disability discourse shifting discussions and policy from tolerance, charity and common humanity to diversity, difference and rights (Beresford and Croft 1995). This provides a more effective basis

for the campaign for civil rights and the fight for self-organization, independent living and anti-discrimination legislation (Beresford and Wallcraft 1997).

Conclusion

> F3: We have to teach everyone to change attitudes - which we do - we also have to let ourselves be used to change attitudes.

In this chapter, the results from 35 interviews with disabled people concerning their general opinions of disability research, how disability research should be conducted and by whom has been reported. There is much support for the arguments advanced by academics such as Barnes, Finkelstein and Oliver, that disability research is alienating and disempowering.   Such feelings are generated because disabled respondents feel that their knowledges and experiences are being 'mined' with little feedback, knowledge of the conclusions reached, and suspect that little action is being taken on the basis of findings.   Moreover, many interviewees felt that research conducted by non-disabled people may be unrepresentative and may not be serving the interests of those participating.   However, the majority of respondents recognised that research can play a vital role in the emancipation of disabled people but contend that research as currently practised needs to be changed.   The ideal model forwarded by the respondents was one of inclusivity; an equal-based, democratic, partnership between disabled people and disabled/non-disabled academics.   The model did not preclude non-disabled researchers but positively welcomed them. Such a model would be action- and politically-led, seeking to explicitly change social relations. This model, because it seeks to balance the concerns and power of researcher and researched, interviewees felt would address their concerns of focus, lack of action, the inaccessibility of disability studies literature, and levels of representativeness.   As such, the viability of using inclusive models of research to examine disability in society needs further investigation.

4

SETTING AN AGENDA FOR RESEARCH

Eleven broad agendas for research were identified by the disabled people interviewed. This variety illustrates the range of disability issues that need to be addressed through empirical research in Western societies. Indeed, the agendas below cover all aspects of life: social, cultural, economic, political, legal, medical. Whilst there are quotes and supporting evidence from a good number of the respondents not all are represented. This is because in many cases, rather than detail what they would like to be researched, respondents would identify a specific issue that they felt needed to be addressed. So for example, a respondent would start to detail what needed to be changed in an environment ('we need more ramps') or how that should be addressed ('they should put ramps in these locations') rather than to describe a research agenda that would focus on the ways in which environmental design disables people and how to design 'barrier-free' locations. This was particularly the case in relation to access and public transport where respondents would give detailed descriptions of particular issues rather than detailing how research might address these issues beyond their identification (i.e. that is notions of research were largely confined to access audits, rather than the reasons why access continues to be poor, or the effects of poor access on all aspects of life, etc.). This in the main was because the disabled people interviewed were interested in improving their lives in quantitative and qualitative means and an access audit would provide concrete evidence to local planners, architects and governing officials. The sorts of questions that might interest an academic in relation to access and public transport, relating for example to power-relations and theories of social exclusion, whilst moving forward debates and ideas around disability, does not necessarily seem to provide anymore concrete evidence needed to make an immediate difference 'on-the-ground'. The following discussion is largely confined to statements concerning broad research agendas rather than the identification of specific, localised issues (although these are included if used in the argumentation for further research, see Kitchin et al. forthcoming). The agendas are ordered alphabetically.

It should also be noted that whilst all respondents had suggestions for research topics that many were sceptical of the worth of research. Some for example, felt that many of the issues and their solutions were already well known. The real issue lay with gaining action based upon the findings of research already undertaken. For example, respondents M8 and M2 argued:

M8: … there is so much being written and so much being researched, again, again, and again about disability. The whole thing is ludicrous. You could fill this hotel with reports and research studies and research papers that have been done in the past ten years - but what's the progress for people actually on the ground? It's very, very small.

M2: Everybody knows the problems - why are people conducting research, research, research? We should actually be out doing something about it. ... 90% of research projects end up in the bin anyway.

This was a sentiment shared by the majority of respondents. As respondent F2 stated:

F2: … there has to be an outcome to it. There is no point doing research for the sake of research.

Moreover, respondent F11 questioned the usefulness/value of research as currently practised, sensing that at present research is not persuasive enough given that it largely gets ignored by state agencies:

F11: I don't know whether its been done by the right people or its been useful because the government gets so many x, y, z reports but I don't think the research undertaken on behalf of people with disabilities is persuasive ... being pushed enough.

Access/Planning

It was clear from the interviews that access despite regulatory changes (e.g. Part M Building Act, Disability Discrimination Act (NI)) that access is still a central issue in many disabled peoples lives and should be a core component of any future research agenda.

F9: oh ... access would be the nearest to my heart as it's the gateway to society and if the access isn't there then they can't participate in social life ... or other things like the economy, if they aren't involved, if they can't circulate, if they can't have the transport, and things like that.

This is not to deny that there have been improvements:

M9: It's getting better, it's getting better. I've been using the chair or nine years now - nine years since I had the accident - and I can see the difference in nine years but when you've been away to other countries like Canada and America you can see the difference.

but that these improvements are qualitatively poor and that architects/planners still seemingly remain ignorant of the benefits and politics of universal design and seem reluctant to implement current guidelines:

F4: I know that for the likes of new buildings that there are guidelines - specifications and standards that have to be done. The specifications are still low - they are still not hitting the point. Architects need to be made more aware of the problems that people are facing.

Some respondents felt that research needed to be directed at current provision standards, whether they fulfil their aims, and the attitudes of architects/planners/government officials towards them in terms of acceptance and enforcement:

F6: ... existing standards. Are they acceptable? Could they be improved? Design of buildings, those sort of things. But it is also about how those designs are implemented. That includes attitudes of people and those in authority and, you know, for building regulations, how strictly those are enforced and why that happens.

Indeed, one of the aspects that infuriated many respondents was the abuse and misuse of the facilities that had been implemented, the lack of regulation and enforcement of statutes, and the maintenance of facilities. In particular, some respondents were concerned about the symbolic messages communicated to disabled people by lax

provision, regulation and maintenance and felt that research that addressed this issue would be valuable. As respondents F3 and F7 stated:

F3: But you know what annoys me? You hear of bars in particular that, new buildings that are planned, in the planning situation they have to disabled loos and access, but when people come in and use it - there should be some power that comes in to make sure that the provision is kept in the way that they ...

F7: they were in Dublin quite recently and you know the crossings? You push the button and you are meant to have the little bleepers to tell you. I think 4 out 5 weren't working out of the ones they surveyed. So things like the need to keep on top of that. Research needs to done why are they not being kept up to standard. What are the underlying trends there? What are the messages that's all giving out if they are not looking after those things, not taking care of them?

Respondent M11 felt that in relation to access that disability is to narrowly conceived. He felt that so far research had failed to recognise the heterogeneous nature of disability and the diversity of roles played by disabled people in society. He wanted to see access research widen its remit to recognise all aspects of daily life and to become more systematic in its practice:

M11: Access, basically, is appalling. And again people are looking at very narrow aspects of it. They don't see the people with disabilities as parents or whatever. You go to any playground - like I have a friend that is a wheelchair user after an accident and she has a 5 year old child. Playgrounds all have this stuff on the ground to stop the child hurting themselves if they fall but that means that she can't get through it. … they think about access to shopping centres and all that sort of stuff but it needs to be systemic, it needs to take in people with disabilities are parents … they want to be able to go to playgrounds with their children, they want to go to leisureplexs ... not just to get into buildings or into NRB offices or something like that. Because they have a life outside of that. … so really just to look at access but not just buildings but also access to leisure and recreation, access to sport facilities and so on. But all people have looked at is access to buildings and access to training centres - very stereotypical stuff.

Attitudes/Language

Another key area, mentioned by many of the respondents was attitudes - identifying, deconstructing, and explaining the attitudes of non-disabled people towards disabled

people and finding ways to improve attitudes, increase disability awareness and promote disability equality. Again, respondents tended identify the need for research that led to potential concrete findings that could be used by disabled people in practical ways (e.g. the development of awareness/equality packs). As M5 and F1 stated:

M5: The most important thing is to change peoples attitudes.

F1: Attitude, perceptions, the myths ... that people, that non-disabled people have of people with disabilities. I would like a really good - at the end of it - I would like a really good disability equality package for what I'm talking about to actually empower and let other people - because you can put as much legislation in place - you can talk to people until the cows come home but unless you change mind sets, - really, really change them, to open up and see the person not the wheelchair. So I would research into attitudes and how that could be changed.

Strongly related to attitudes, one respondent desired research into the concept of normality and another into the use of language in relation to how disabled lives are situated, regulated and reproduced within society:

M1: I think that, personally, that the greatest piece of research that can be commissioned, and I pray to God that I see it, is this normality business. Conduct research and tell me what is normal because ... again normal is in the medical model so we need to get rid of all of this. … You know, all this 'if you fall below this level your not in the charmed circle', you know what I'm trying to say. I would like some researcher to go out and research a load of people and get a consensus of what a charmed circle is and then I and other disabled people can challenge that notion of normality.

F11: Well I think the use of language. You know. How society uses different language. I find that whole area very interesting.

Respondent M1 continued by suggesting that another related area of study to normality should focus upon value, and how society judges and places values on its members and uses those values to justify actions such as exclusion, marginalisation and segregation:

> M1: how we choose to see and how we choose to value people in society is very important here. We don't value humility, we don't value simplicity, we don't value godliness. … We do not want to be getting into assimilation here. That is one thing that disabled people have to really fight against - to be treated equal does not mean to be treated the same. It's given your parity of esteem and the taking into account your needs. … Very often if you can't make the grade, you're out there in the big bad world and you can't make it because of the intransigence of a school principal or a works manager you're not really being treated properly and your human rights are being abused.

Respondent M3, however, warned that the focus of study should not be confined to the external attitudes of non-disabled people but should also investigate the internalised attitudes of disabled people towards other members of the disabled community. Here it is recognised that disabled people themselves can help reproduce exclusionary social relations through their internalisation:

> M3: There are different attitudes amongst disabled people. There are borders. The big one being between people who are perceived as having a physical disability and people who are perceived as having a mental handicap, as it is often still referred to. And a lot of people with a physical disability would not want to be associated with people who are perceived as having a mental handicap. There are all different types of disability. … disabled people themselves are always drawing lines and not wishing to be associated.

Education

Highly related to attitudes/awareness was a desire for research that would focus on the education system. Many of the respondents felt that attitudinal issues are seeded in and develop primarily due to systems of segregation. Segregation defines disabled people as different and legitimates and perpetuates differential attitudes. Schooling is where formalised segregation first occurs and so it was felt that the education system and its effects is a key site that needs further research. As respondents F7 and M5 stated:

> F7: It is a societal thing - that's why I would like to get them at a young age, at the educational level and bring them together because you don't make as many differentials. If you go to school with someone in a wheelchair they are a person,

somebody. The fear issues that emerge when you talk to non-disabled people is amazing.

M5: There is the whole area of inclusion, such as looking at segregated education. That's where the problems stem from. If disabled people were in mainstream education from the age of 4 other children would not be afraid of disability. You actually see - I've seen myself - some mother and the child will stop and look at me and go 'look at that man' and the child has been pulled away, and that child is going to have a fear of disability instead of turning around and saying 'that man has got a bad leg and he can't walk properly.' And that is all the child wants to know. And people aren't aware of these issues and they are afraid of it. How we actually deal with that I'm not quite sure. … Probably trying to change government departments thinking is the main one. The Department of Education are probably the hardest one to get to listen.

At another level, it was felt that the education system as currently organised and run, both in the Republic and the North, was not only helping to reproduce ableist relations but was failing to serve the best interests of disabled children. That is, many respondents felt that segregated schooling is not adequately preparing disabled children for life post-18 or providing the necessary education for third-level education or well-paid employment:

M8: Of the 370,000 estimated disabled people in this country I would safely say that 50-60% of them have literacy problems because of the special school systems and the other systems they have been through.

This perceived failure of the education system to adequately cater for disabled children provided the motivation for the Republic-based participatory action research project. This project consisted of an access audit (physical/educational/social) of all primary and secondary schools in County Kildare, with follow-up interviews with several school principals and education officials (see Kitchin and Mulcahy, forthcoming).

Employment/Careers Advice

Another key area for researchers to address is access to quality employment. As detailed in previous research (Kitchin *et al*. 1998) employment in Ireland for disabled people remains a key issue. Access is very poor constraining disabled people to

welfarist lifestyles that entrap them below the poverty line. The respondents in this study identified a number of employment issues that they felt needed to be understood so that issues of inequality could be tackled effectively. For example, respondent F4 wanted research into careers advice and why some disabled people were not availing of some of the opportunities presented to them:

> F4: When I was leaving school I would like to have had far better ... someone advising you. … telling me what sorts of opportunities were available. You can get lots of opportunities for people who are non-disabled people but it does not necessarily mean that these are suitable for disabled people. … We want to know why more disabled people are not taking up opportunities - is it lack of confidence or because they have never had the chance before or is because they are not qualified enough or what?

Respondent F3 wanted research conducted on the availability of opportunities to move within the employment market and the role of interviewers as gatekeepers to paid employment:

> F3: I think I would use it - as I said - in the work place … I think there is a barrier in the workplace in terms of trying to get that first job and trying to move on. Even trying to get the qualifications to start with to get a job can be quite difficult. … And also the barriers of someone sitting on an interview panel and actually judging what think a disabled person can do and can't do. I think I would probably try and do research into something like that - into the views of the interviewers.

Similarly, respondent F7 wanted research that would focus on understanding state and employers attitudes towards disabled trainees/employees and the values attached to disabled workers and their work with the aim of improving awareness and promoting equality:

> F7: How to improve, and absorb, and to develop the idea of people with disabilities in the workforce and viable ... not just some pat on the head job. An awful lot of the mentality we are dealing with is - its sincere - but its .. its patronising. I would like to change that. Where I can say, 'you annoying me', or where others 'well done there, you did a god job' without being patronising, you know?

Respondent M11 felt that research should be conducted into the use and value of segregated training schemes. He feels that whilst they have many faults they also

have some benefits and that before dismantling the system and alternative system to aid the process of mainstreaming needs to identified and implemented:

> M11: Er, employment is another one that sticks out. There is all this money, and ESF reports as well, that all this money is being spent on training and basically it has fuck all effect … there are conveyor belts of training schemes. But people see things as black and white, especially so called activists will say things like 'the training centres do absolutely nothing.' Well I say that a lot of what the training schemes do whether it be NRB or FAS or whatever is wrong but I … you need to have a bridging system into a mainstream system. People should have a choice as to whether they want to stay in a segregated system. … co-operative style social initiatives … that might be something that would be worth researching.

Housing/Independent Living

Two respondents, F5 and M3, identified housing as a key concern. The home is the location where we spend the majority of our time and the base from where we venture out into the world. Suitable, comfortable, adaptable housing that suits the needs of the residents was a concern for both respondents:

> F5: That is another area I would like research done into … a home should be built for a life time living and not just while your abled-bodied. My opinion would be … that homes should be adaptable so you don't have to move, say if you were in a car accident and ended up having to move. If your a disabled person why should you have to move? If you like that area, if your family live in that area, why should you have to move? Why aren't homes built in such a way that they are adaptable for someone's lifetime?

> M3: Housing. Housing for disabled people is often not as good as it could be. What I'm in at the moment is a pensioners bungalow - when I came to live here that was fine. Then I had my leg removed and its not so good now and I'm waiting to move. But there isn't enough housing built for disabled people, so for a lot of disabled people to live where they want to live they have to accept ordinary housing and have it converted. It can take up to a year to convert it. That may mean living in a place where they may need help to have a bath, where they may need help to get in out of the premises. That is not really good enough. There really should be a much smaller time slot for this to happen.

Related to housing was the issue of independent living. One respondent, F13, was keen for research to be conducted into how to facilitate independent living programs and how these programs are affected by issues such as state and individual attitudes:

> F13: Oh my goodness! [long pause] Off the top of my head without thinking about it at any length. It's a bit like winning the lottery. What I think ... I'd like .. the research I would be looking for would be around how to facilitate people for independent living, as in being able to have control and choice in how they live. Not to be measured by how you look or whether can wash or dress yourself, or go to the toilet. That sort of disrespectful thing. That would be my topic. And one of my reasons for that sort of research is that it might make an awful lot of people wake up to how little services there are.

Legal

As discussed in the access section a number of respondents, identified legal issues as in need of research. Respondents felt that new legislation needed to be examined in relation to its form, remit, effectiveness and how it was conceived. In particular, respondents F5 and M1 wanted the relatively new disability discrimination act to be thoroughly researched. In addition, M1 wanted research into the effectiveness of a body set up to represent and fight for disabled people.

> F5: I would like to see research done in to the DDA. … In all of it. I would research into why they put it across in the way they did - why after all those other bills did they suddenly opt for this particular one? Why put it across in the form it is in? Why use the definition of disability that they use?

> M1: I think we need a major piece of research on the disability discrimination act and how effective the NI Disability Council is because that's a separate council from the National Disability Council.

Medical

Whilst the majority of disabled people interviewed suggested research topics that focused on the social, cultural and economic aspects of disability, predominantly from a social model perspective, a few respondents wanted continued medical research as their primary choice. As M8 acknowledges, whilst the medical model is seen to reproduce social exclusion within society through the way it conceptualises disability

and disabled people, there can be little doubt that medical research and practice has benefited many disabled people:

> M8: I probably wouldn't be alive today if it wasn't for medical research and many thousands of others I know would probably be in a similar situation.

In M7's case, he wanted research to provide him with an understanding of his condition.

> M7: I would have to basically go and look at what caused my blindness and why. … Just wanting to know - getting to the back of it because there is no cure for it, my type of blindness. Just asking questions why … In the early 1950s there were lots of premature births throughout the UK and we were put in incubators for anything up to 2 months. And basically the muscles of the eye are basically burnt with the oxygen … that's what caused the blindness. I would just like to know how that happened and why it has happened, because nobody has ever told me.

Clearly medical research is not unproblematic, especially in relation to issues such as bioethics and eugenics, but it should be acknowledged that many disabled people want it continued for reasons such as enlightenment, rehabilitation, and cure.

Research/Projects

One respondent wanted research to focus on research itself - the motivations, aspirations and background of the researchers. This she felt would help identify how researchers were positioned in relation to their studies of disability and help highlight the ways in which research contributes to disabled peoples lives:

> CF: I would also like some research done into how the researchers - if they are doing research on disability issues, what sort of background are they coming from? Are they aware of the impact of certain questions or terminology or phrases or whatever they might use? Why do they feel - or why did they become experts in disability? I think there perhaps should be research into that particular area.

Respondent M3 felt that research should be directed at assessing the implementation and usefulness of community-based projects set up to serve disabled people. Many of these projects he felt were replicating work, providing jobs for a group of people with

no real tangible benefits to disabled people. Here, research could assess the extent to which these projects serve disabled people and investigate alternative ways to spend the money more effectively:

> M3: I would want to research why so much money appears to be flushed down the sewer ... in setting up projects for disabled people. There are lots of money available at the moment from European sources, from the Millennium Fund, Making Belfast Work, all that sort of stuff, and a lot of it is handed out to what are perceived to be good causes - disability is usually considered to be a good cause. The ... a lot of disabled organisations replicate work - quite frankly a lot of disabled organisations replicate work very badly. There are a lot of disabled organisations who have the usual project worker and a sort of development officer which is perceived as being commonly necessary. And typically large sums of money, may be for a development officer and project officer together you are talking, may be, 30-40K a year. And quite frankly it's a lot of money. And quite frankly a lot of them do nothing. They just sit on their bums and spent their time going round having meetings with other charities. Nothing is achieved, nothing is done, and disabled people do not benefit from it.

Rural

One respondent, M1, identified living with an impairment in a rural area as an area of research that needs to be investigated. It is probably true to say that the vast majority of research to date has focused upon disabled people living in urban areas. As he identifies, however, there are a number of novel issues concerning living in a rural area, in addition to a number of similar issues, that differ qualitatively:

> M1: rural areas are very, very misunderstood and under-researched. … It easier, Rob, if its in the town to be more accessible than a rural area. The bus could be accessible but if you can't get out of your house because there is no accessible kerb for half a mile up the road its no good.

Transport

Another key issue, discussed by a number of respondents, was transport: both public and private. In general, most of the respondents that discussed transport detailed localised issues rather than broad themes or agendas (see Kitchin et al. forthcoming). As such, the following quotes are a sample of a range of material, much of which was

localised. Many of the respondents felt that public transport in all its guises, buses, trains, taxis, planes needed to be researched in relation to provision, service, regulation, ,

F5: Well public transport, particularly since they have now upped the price of petrol and someone like myself who relies heavily on my car to get around. And Tony Blair is all very keen on getting us all ono this public transport system that is going to materialise out of nowhere and be accessible for everybody. I think there needs to be more research done into that. The transport, I mean under the DDA, the transport provision is not great. The goods and services provision don't really cover transport under the DDA so what are they going to do about that? The kneeling buses - they aren't great. They need to be investing in design mechanisms that will make the public transport accessible if they are intending to hike up all these petrol prices and get people off the roads. If I don't have my car I can't get around. It's as simple as that.

F12: Access is the main one and public transport as well. I can't see after all these years why there aren't more accessible buses, you know, because they have been changed so many times over the years. They are changing all the time as they buy new buses and why they can't bring them. Surely to God it is costing more in other ways by not getting accessible buses. You know. More public access to transport.

F6: One of my bugbears at the moment is air travel. All the airlines have really good guidelines on paper but it does not work in practice. It becomes a real battle to get from one place to another. Obviously things have been improving but maybe looking at why that happens is a part of access as well.

In relation to private transport, a number issues were detailed in relation to the provision, design and use of motibility cars and parking.

Discussion

It is clear from the analysis of the interviews that there are a number of coherent topics that disabled people would like to be researched. Whilst support for more research tended to cluster around a few key themes such as access, attitudes, education and employment it would be wrong to suggest that these areas supersede the others in importance. Respondents were asked to identify the one area they would like research conducted on. Whilst some identified a number of themes many

constrained themselves to just one topic as requested. It was clear that for these respondents there were many issues they felt needed to be addressed, and some had difficulty identifying the topic they felt most important. As such, the fact that only two prioritised housing as a concern does not mean that the other respondents do not think that research in this area would be valuable. Indeed, it would be anticipated that most would welcome research into housing. It should also be clear that this list is partial and not exhaustive; it only represents the views of thirty-five people and it would be expected that a number of other themes/sub-themes would be identified if the same was broadened. For example, it might surprise some readers that nobody chose to conduct/commission research on welfare and benefits.

The common themes linking these topics are that they all concern improving the quality of lives for disabled people; they all concern social issues relating to societal relations and organisation (with the exception of two respondents who prioritised medical research); and that disabled people strongly favour research that is action-led, leading to changes in the real world (research that moves beyond the library shelf). In general, it is probably fair to say that much disability research within the social sciences fulfils the first two themes (quality of life, social focus), however, few and far between are action-led. In this respect at least, disability research is failing its constituents. As the research reported in Kitchin (forthcoming) also details it is also failing in the sense that many disabled question the value of research, suggesting that it has not served the interests of disabled well, and does not necessarily represent the true views and experiences of disabled people. The majority of respondents in this study wanted to see more inclusive research strategies adopted which include inputs into the agendas of research.

The logical conclusion from this discussion is that if disability research is serious in its intentions to be emancipatory and empowering then research agendas should, to a large degree, follow the wishes of the constituents. Disabled people know what issues they would like to be addressed and how they should be addressed. Clearly for many researchers, particularly those who are schooled in traditional praxis of scientific method, the collapsing of the division between researcher and researched, in terms of setting agendas, would be problematic. It is generally accepted that a researcher should have autonomy over their research. By opening up the research process so that

it is overtly directed by interests outside those of the researcher could potentially cause conflicts of interest. Here the researcher will become answerable and responsible to the researched as well as funding agencies and so on. Furthermore, allowing research to be guided by its constituents could potentially prioritise empirical research, particularly that which is action orientated, over theorising. As noted, many of the respondents tended to focus their research agenda around specific, localised issues rather than a broader framework that would have utility in many cases. Consultancy-based research is more suited to deal with localised issues, whereas academic research often seeks to gain a broader understanding with more universal implications. As has been amply demonstrated in relation to disability studies and the development of the social model of disability, the ideas and theory that provide the conceptual frameworks in which researchers interpret the world are extremely important. While they might not seemingly provide concrete actions in the short term they are key in changing mind sets over the long term. As such, theorising, which can often seem intangible to non-academics, particularly when universalised, is an important venture but not necessarily one that would be prioritised by constituents.

Even for those dedicated to the emancipation of disabled people allowing the researched to set the agenda for research might seem unsettling for some of reasons detailed (see Shakespeare 1996). Indeed, following an agenda solely dictated by its constituents is a dangerous and unhealthy strategy. But then so is following a strategy solely dictated by researchers who are separated from the experiences and knowledges of those they research by impairment, class, wealth, etc. Such a strategy could lead (and is leading according to interviewees) to research that is not representative of disabled people and is of marginal use. It is important, therefore, that however the researcher decides to position themselves, the opinions and feelings of the researched should not be discounted or ignored, and where possible/reasonable research is driven by the desires of the constituents it seeks to represent, rather than the desires of non-disabled researchers and funding agencies. Knowing which issues are particularly salient for disabled people is then important for both empirical research and theorising.

Conclusion

This chapter has highlighted some of the issues that we as disability researchers should be turning our attention to. It has also highlighted the fact that researchers need to consider what use is made of their work. Much empirical research could be more action-led and applied in character than is currently practised, and could engage with respondents in ways that extend beyond a simple researcher/researched relationship. Action could range from simply making results available in forms that are useable to disabled activists to joining with activists to provide evidence for, and voice to, lobbying.

5

PROJECT 1:

ACCESS TO FAMILY PLANNING SERVICES IN NORTHERN IRELAND

Written with Paul Anderson.

Setting the Scene

> [D]isabled people are people, and people *are* sexual. Much of our sense of person-hood comes from our ability to play a sexual role. … [D]isabled [people] share with the rest of us the misfortune of living in a society that has traditionally avoided and censured sex, but this hits … disabled [people] harder than others. Moreover, virtually nobody is too disabled to derive some satisfaction and personal reinforcement from sex - with a partner if possible, alone if necessary. (Comfort 1975, quoted in Monga and Lefebvre 1995: 305; our emphases)

> … the disability rights movement has never addressed sexuality as a key political issue, though many of us find sexuality to be the area of our great oppression. We may well be more concerned with being loved and finding sexual fulfilment than getting on a bus. (Waxman and Finger 1991: 1)

There can be little doubt that disabled people[1] need access to services that provide advice and health care relating to sexual issues. Despite common stereotyping to the contrary, and attempts to treat disabled people as though sexuality and self-image do not exist (Monga and Lefevbre 1995), disabled people are sexual beings. Like non-disabled people they experience feelings of desire and love, seek sexual gratification, and hope to sustain long-term sexual relationships and start/care for families. Like

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[1] We broadly define disabled people, as discussed in this paper, as those people who have physical/sensory impairments, chronic pain, developmental/learning impairments or mental illness.

non-disabled people they can also be the victims of sexual abuse. In fact, it is widely reported that disabled people are more likely to be sexually abused (for overviews see Fagin *et al*., 1993; Watson-Armstrong et al. 1994; Nosek 1995). And yet, it is only recently that researchers and practioners have started to consider access to sex education, sexual health and family planning. Most of this work has been from a medical perspective, concentrating on the levels of support needed from health care professionals and the form that this support should take. In this chapter, we examine from a social perspective the ways in which society reproduces the myths that disabled people lack sexual desire, are unable to partake in sexual activity, and are unable to engage in long-term mutually satisfying sexual relationships (DeLoach 1994), and how these myths are manifested in access to family planning clinics both in relation to how they are designed and built, and in the levels of services they offer to disabled people.

Cultural Ideologies, Disability and Sexuality

Disabled people generally occupy marginal positions in society. In recent years a number of scholars have started to deconstruct the ways in which the marginal position of socially excluded groups, including disabled people, is sustained and reproduced. Central in this project has been the examination of the ways in which groups are positioned in relation to each other and how these positions are maintained through power relations. So for example, Imrie (1996) and Kitchin (1998) have applied Young's (1990) five forms of oppression to expose the ways in which disabled people are oppressed by non-disabled people.

In the first instance, disabled people are rendered 'powerless': disabled people are kept in the same social position through political means and being denied access to important decision making positions within society. Secondly, disabled people are marginalised within society and social life: disabled people are kept in the same social position through social means. Disabled people are 'pushed' into poor housing, denied access to private and public transport, and are ostracised from 'mainstream' social activities such as visiting a bar or movie theatre through poor provision and weak statutory laws. Thirdly, disabled people are exploited within the labour market: disabled people are kept in the same social position through material means. Disabled people are often excluded from labour market through discriminatory practices and poor levels of mobility. Where

they do gain access it usually in margin positions undertaking low-paid, low-skilled work often on a part-time basis. Such a situation works to deny disabled people prosperity and wealth, and their associated power. Fourthly, disabled people are suppressed through violent means: disabled people are controlled through physical violence and imprisonment. For example, the system of asylums and imprisonment have been one particular method used to confine and oppress disabled people.

Driving these four forms of oppression is the fifth, cultural ideologies. Cultural ideologies work to legitimate the above practices by suggesting that current social relations (how society is structured) are common-sense and natural (rather than constructed and negotiable); that the lifestyles and practices of the dominant group (in this case non-disabled people) are promoted as the norm and those of disabled people portrayed as deviant, thus legitimating how non-disabled people view and treat disabled people. In other words, cultural ideologies work to ensure that the cultural norms of the dominant group remain intact and that disabled people and non-disabled people accept the ideological message and its concrete manifestation in the form of attitudes and behaviours. This is not to deny that there is a complex interplay between domination and resistance.

One particular method in which ideologies are popularised is through the use of cultural representations. In these representations, certain groups are portrayed negatively. Cultural representations take on a number of forms but often portray those that do not belong to the dominant group as being impure, defiled, contaminated or dirty. Jackson (1989) details that common strategies employed within cultural representations include: (1) animalisation, whereby a group is portrayed as taking on the characteristics of different animals. Here, a group is dehumanised and people encouraged to treat them as if they were animals. (2) naturalisation, whereby a group is portrayed as being closer to nature and therefore less civilised and more suited to certain jobs and conditions. For example, women have often been portrayed as closer to nature and therefore more suited to childcare, domestic labour, and non-skilled employment. (3) medicalisation, whereby a group is portrayed as being the source of disease and ill-health and therefore should be castigated and cut-off from society for the protection of everyone else. A good example, is the initial reaction to the growth

of AIDS in the 1980s and its labelling as a gay disease. This led to a widespread homophobic reactions.

These representations, although they might seem harmless, are powerful psychological tools that shape how we view other groups. For example, Nazi Germany used a combination of animalisation, naturalisation and medicalisation to argue that the Jews and Gypsies, along with both physically and mentally impaired people, were dirty, animals, contaminated, physically different and imperfect thus threatening the purity and stability of the Aryan race, to motivate widespread persecution of these groups. Their power can be seen in the ways in which subordinate groups are labelled with derogatory terms (sometimes used by the dominant group to chastise or make fun of their peers) and such is the power of language that their continued use means that the popular images of these groups are perpetuated within the dominant group.

As Barton (1996: 8) states 'labels such as 'invalid', 'cripple', 'spastic', 'handicapped' and 'retarded' all imply both a functional loss and a lack of worth' and perpetuate and legitimate offensive responses by non-disabled people including horror, fear, anxiety, hostility, distrust, pity, over-protection and patronising behaviour. Disabled people are often portrayed as abnormal, child-like, 'damaged goods', 'freaks of nature', unattractive, dependent, in need of protection, a danger unto themselves, an object of pity, unproductive, anti-social, and tainted by disease/ill-health. These representations have been fed in the main by ideas of deviancy from the norm and supposed inferiority and danger. These images are perpetuated in the media where few positive images of disabled people exist. As Lamb and Layzell (1994: 21, cited in Shakespeare et al, 1996) stated:

> There is an unspoken taboo about relationships and disabled people. Disabled people's sexual and emotional needs are rarely included in any discussion or representation in everyday life, whether this is in the papers and magazines we read, or the movies we watch. This reinforces the public's attitudes and expectations towards disabled people as seeing them as 'sick and sexless' rather than participating in full sexual and family relationships.

Most media images are pleas for charity contributions, feeding on pity and sympathy, and adding to ideas that disabled people cannot cope and need constant aid. As organisations run by disabled people have been recently arguing, disabled people want full rights to housing, education, work, and sexual relationships not charity.

Highly related to cultural representations, myths take on the form of malicious gossip which feeds into stereotypical representations.

> Myths once initiated are powerful tools which are often self-reinforcing: once initiated, the many "mainstream" fears and prejudices regarding certain "outsider" groups often feed into concrete social practices through which distinctions between these "mainstream" and "outsider" peoples are reproduced and even rendered more acute (Philo 1989: 259).

Myths in relation to disability and sexuality include disabled people being asexual, that is lacking a biological sex drive, being unable to partake in sexual activity, and that disabled people (particularly those with a developmental/intellectual disability) lack the requisite social judgement to behave sexually in a socially responsible manner (DeLoach 1994). For example, a number of myths have been used to reinforce and reproduce heterosexual and patriarchal ideologies in relation to disability and gender roles. Women's identity in western society is often defined around themes such as reproduction, home-making, and body-image (Schlesinger 1996; Tilley 1996). Disability disrupts these themes. O'Toole and Bregante (1992: 166) list a number of common myths relating to disabled women and sexuality: disabled women are asexual; disabled women who are not married do not have sex (and those who are married did so before they became disabled); disabled women cannot be mothers; if a mother becomes disabled, her children are not getting a 'real' mother; in relationships, the non-disabled person runs the relationship; disabled women should be grateful for a sexual relationship; disabled women are too fragile for vigorous sexual activity; all disabled women are heterosexual. Women with disabilities thus have a poor body-image and are unable to ever fulfil their role as women. In addition, they are economically unproductive and thus worthless and a burden to society (DeLoach 1994; Nosek 1995). A consequence of these myths is that, as Tilley (1996) reports, disabled women are less likely to have received sex

education, and basic sexual health such as Pap smears, internal and breast cancer examinations. Moreover, many intellectually disabled women have been forcibly sterilised. In relation to men, identity is often defined around sexual prowess, fitness and work. Again disability disrupts these themes and undermines disabled men's sense of masculinity. Several researchers have noted that many disabled people suffer from low self-esteem and feelings of inferiority due to their disability and body image (e.g. Tan and Bostik 1995; Schlesinger 1996).

These myths help to sustain, and provide legitimacy for, current socio-sexual relations - reinforcing them for non-disabled people and internalising them within disabled people. As such, DeLoach (1994) argues that these ideologies lead to self-perpetuating and reproducing cycle: (1) non-disabled people's attitudes towards disabled people are primarily negative; (2) feelings associated with these attitudes range from hostility and aversion to sympathy and pity; (3) behaviours associated with these attitudes lead to the isolation or marginalisation of disabled people; (4) the attitudes and behaviour of disabled people are strongly and negatively influenced by non-disabled attitudes and behaviours. This has led Waxman and Finger (cited in Monga and Lefebvre 1995: 309) to conclude that in western society '(1) it is almost illegal to be severely disabled and married [indeed, in some countries it has been/is illegal for disabled people to be married (Fegan *et al*. 1993; Tilley 1996)], (2) disabled people are denied sexual and reproductive freedom and the liberty to establish families in forms that they choose, (3) there is no other group in [Western society] that faces the sorts of sexual and reproductive restrictions that disabled people do, (4) disabled people are frequently prevented from marrying, bearing or rearing children, learning about sexuality, having sexual relations, and obtaining sexual literature'. The currency of these myths feed in part to the breakdown of marriages and relationships when one partner becomes disabled or suffers chronic pain. For example, Pitzele (1995) reports that 75% of women who became disabled were later divorced and Badeau (1995) reports that healthy partners can place a strain on relationships through a tendency to mother, infantilise and overprotect or through behaviour changes due to fear of hurting their partner or catching a condition.

The effects of this maintenance of hegemony is even more pronounced for disabled people who are gay, lesbian or bisexual, and for those over the age of fifty, as ableist-

based sexual oppression intersect with aspects of homophobia and ageism. O'Toole and Bregante (1992) and McAllen and Ditillo (1994) report that lesbians with disabilities experience particular circumstances. Not only do they have a sexual identity, but it is one which is considered by many to be deviant. The effect of this is often externally-situated social isolation (from non-disabled people) coupled with internalised isolation (homophobic disabled people). This has led to a situation in which disabled lesbians are largely invisible. There is virtually no information available for disabled lesbians and sexual health care can be affected by negatively positioned health care workers (for example, O'Toole and Bregante 1992, detail cases where disabled, lesbian patients were abused by nurses). Moreover, O'Toole and Bregante (1992) report that partners are denied the same rights that would expect in a straight relationship, and are often positioned as somebody 'taking advantage' or being 'a corrupting influence' by family and health care workers.

In relation to age, Pitzele (1995) details that there is a common misconception that sexuality and interest dissipates rapidly over the age of fifty and that it disappears entirely amongst those who acquire a chronic illness or disability. Gsuhn (1995) reports that the sexuality of institutionalised older people is often ignored or misinterpreted, and is nearly always seen as inappropriate or deviant. Badeau (1995) suggests that older disabled people are effectively neutralised sexually through the desire to fit into social norms and the fear of being reprimanded and stigmatised.

A consequence of the reproduction of ableist ideologies is that disabled people live in an overprotective environment that inhibits ordinary and social exploration (DeLoach 1994; Tan and Bostik 1995). Parents of disabled children often mollycoddle their children, denying them the time, space and opportunity to develop and explore their sexuality, fearful that their children will be unable to establish and maintain a relationship leading to hurt and resentment (Nelson 1995). Efforts are directed at discouraging sexual expression for fear of opening Pandora's box (DeLoach 1994) and sources of learning about sexuality such as playing with peers, joining clubs, falling in love, experimenting, peeping and reading pornography are denied (Rousso 1982).

Similarly, the sexuality of institutionalised disabled people is repressed and overt sexual expressions punished in many institutional settings, primarily due to staff conceptions of 'appropriate' sexuality (Wolfe 1997). This is particularly so for people with developmental/intellectual disabilities. Indeed, McCabe et al., (1994) report that the majority of this group themselves believed that someone else decides about the level of their sexual experience and their levels of sexual knowledge and consent were poor and naive, potentially leaving them open to abuse - particularly if deinstitutionalised into the community (Szollos and McCabe 1995). Fegan *et al*. (1993) suggest that people with developmental/intellectual disabilities are vulnerable because they are less likely to resist, less likely to report, and if they do report less likely to be believed. They are, therefore, a group in particular need of sex education. This suppression of disabled peoples' sexuality in part is due the conception that it may encourage unacceptable behaviour, although there is little evidence (myth) that rates of sexual offence are higher for intellectually disabled people (McCabe et al 1994). People with intellectual disability are either viewed by staff as asexual or oversexed and lacking control, with men seen as potentially sexually aggressive and women promiscuous (Clements et al. 1995; Szollos and McCabe 1995). Szollos and McCabe (1995) detail a number of studies conducted in North America that revealed that staff enforced rules concerning physical contact and sexual behaviour through segregation and supervision and that many felt that sex education and conversations about sex should not be permitted. Here, staff subscribe to a view that sex education for disabled people should consist of control or elimination of sexual interest and expression through sterilisation, restricted privacy and controlling behaviour (Fegan *et al*. 1993).   A consequence of this overprotection and 'mothering' is that disabled people, regardless of impairment, are socialised into a disabled, asexual role, with poor body-image and low self-esteem (Rousso 1982), and thus internally reproduce current dominant cultural ideologies.

Cultural representations and myths are reinforced through the popular media and other mass-audience media such as the church. In the case of Ireland, both North and South, the State's attitudes and policies towards, and the churches preaching on, disability has left many disabled people in marginal positions. Indeed, Hughes (1998) details that religious constructions of disability portray disabled people as deviant and 'unnatural beings', and a literal reading of the Bible portrays disabled people as

abominations (see for example, Leviticus 21: 16-20). The value of disabled life and the contribution to society by disabled people has been questioned by the church. We know of at least one example where a cleric refused to marry a disabled couple on the grounds that they could not consummate the marriage through penetrative sex.

It is inevitable then that cultural ideologies work at all levels of society, including health and social services. This leads to a situation where the level and types of services health care professionals provide matches the low expectations of disabled people. That is, there is an expectation within the health services, as with society in general, that disabled people are asexual: uninterested in, and unable to perform, sex or in the case of children and people with developmental disabilities that they need to be denied the opportunity to explore their sexuality. For example, Wolfe (1997) surveyed 98 special education teachers and administrators in Virginia about attitudes towards disabled people (specifically those with moderate or severe disabilities) and sexuality. The majority felt that sexual relations were inappropriate for disabled people. Moreover, the majority of respondents felt that disabled people should not have children and should be sterilised. Similar attitudes exist in other service providers (for example, see special issue of Journal of Applied Rehabilitation Counseling). Many of the disabled people we have talked to over the past year have confirmed that these attitudes are common. For example, one female, life-long wheelchair user described her frustration that people automatically assumed that she was a spinster and not sexually active - her husband was her brother and her children her nephews, and the ways in which society and health care providers viewed her as irresponsible.

Situating Cultural Ideologies Within Disability Discourse

Theorists within disability studies suggest that ableist ideologies are enshrined in a medical model of disability. This model conceptualises disabled peoples position within, and experiences of, society as a function of their impairment. In other words, the problems facing disabled people are viewed purely a result of biology. The focus of attention then should be the impairment and how to compensate for it, overcome it, or live with it. Here, disabled people are conceptualised as the unfortunate victims of nature or fate.

Since the mid 1970s a number of academics and activists have sought to challenge the medical model of disability. They have forwarded an alternative model which posits that disabled people are predominantly disabled by societal attitudes and the ways in which these attitudes are expressed. As such, the vast majority of daily difficulties faced by disabled people are caused by society failing to accept disabled people for who they are failing to provide adequate facilities. For Shakespeare *et al*. (1996: 16) the;

> 'social model is a valuable corrective to the prevailing approach to disability and sexuality, because it encourages us to examine the social processes which make it hard for disabled people to express their sexuality, and the particular difficulties caused by the attitudes of parents and professionals, the inaccessible environment, and the lack of appropriate services.'

The social model, then, in relation to sexuality focuses on understanding the how disabled people are conceptualised and catered for as sexual beings; to examine the reproduction of cultural ideologies and their real world manifestations and effects. It is this perspective that we have adopted in researching and writing this chapter.

Bob Bureau (1997; cited in Rauscher and McClintock 1997) argues that the these two models of disability, medical and social, have led to four different conceptualisations of how society currently views and approaches disability in *practical* terms (see Table 1). The first two conceptualisations, medical and rehabilitation, draw from the medical model of disability and advocate practical approaches of treatment. The second two conceptualisations, independent living and interdependency, draw from the social model of disability and advocate practical approaches of acceptance and independence. As we have illustrated, the medical model tends to dominate the ways in which disabled people are treated within health care and social services, including sexual health and family planning services and sex education units. We would suggest that an important development would be for health care professionals to adopt a social perspective and to think critically about their services and the messages these services convey.

Socio-Spatial Constructions of Disability and Sexuality

'On the subject of families, I stopped going to the family planning clinic because I felt so *out of place*. The waiting room was always full of 'young girls', and I felt conspicuous with my sticks (I couldn't go in my wheelchair because the ramp was too steep!). I usually feel strong as a disabled person, but hospitals and health centres have an adverse effect.' (Caroline in Shakespeare *et al*.1996: 15, our emphases).

In the rest of this chapter we adopt a social model perspective to examine how cultural ideologies are reproduced and reflected in how family planning clinics are designed and built, and in the levels and types of services they offer to disabled people. We do this through an examination of the ways in which the built landscape is socio-spatially constructed. Here it is recognised that buildings and services are designed and produced by people. They are therefore social constructions, imbued with the values of the designers.

Geographers and others have for a number of years been examining the ways in which space is organised to reproduce dominant ideologies and exclude certain social groupings; to map out landscapes of exclusion (see Gleeson 1999; Imrie 1996; Kitchin 1998). Part of this project has involved identifying the ways in which disabled people are excluded and marginalised in society through the ways in which that society is spatially designed and organised, and the messages inscribed within certain spaces:

'The human landscape can be read as a landscape of exclusion. ... The simple questions we should be asking are: who are places for, whom do they exclude, and how are these prohibitions maintained in practice.' (Sibley 1995: ix).

The landscape is replete with examples of spaces that explicitly segregate disabled people into differing spatial spheres: asylums, segregated schools, employment training centres and day-care units; and implicitly marginalise disabled people in public and private space: inaccessible toilets, restricted seating in theatres and cinemas, places that use steps but have no ramp, cash machines that are placed too high for wheelchair users,

places linked by inaccessible public transport. Many urban spaces are inaccessible or difficult to negotiate for many disabled people because they have not been designed with them in mind (see Imrie 1996; Kitchin 1998). The message conveyed by segregated and marginal spaces is clear - that disabled people are 'out of place':

'Good inclusive design will send positive messages to disabled people, messages which tell them: 'you are important'; 'we want you here'; and 'welcome'. …if the way that disabled people are expected to get into a building is round the back, past the bins and through the kitchens, what does that message communicate? How will it make a disabled person feel?' (Napolitano 1995: 33)

The consequences of these spaces are numerous. At a fundamental level they reproduce the current social relations of disabled people. In other ways they feed directly into issues of sexuality that affect disabled people. For example, Muccigrosso (1991) reports that living in segregated and overprotective environments denies disabled people access to formative relationships and sex education and has a number of by-products (1) lack of knowledge, (2) overcompliance and socialized vulnerability, (3) an unrealistic view that everyone if a friend, (4) limited social opportunities, (5) low self-esteem, and (6) limited or no assertiveness.

In the project reported here we sought to discover the extent to which disabled people are 'out of place' in family planning clinics through an assessment of their levels of access: physical, social and informational. That is, to determine through an analysis of the socio-spatial environment the extent to which the disabled people are viewed and treated as having a sexuality and in need of sexual health care services. The work extends and entwines a number of discourses within the geographic literature concerning geographies of sexuality, geographies of disability, and geographies of health care provision/siting. In our example case of Northern Ireland, we were interested in the ways in which sexuality and disability are socio-spatially written, and how dominant ideologies manifest themselves in the provision of sexual health-care and family planning clinics. The only related work we have found are a few quotes by respondents in Shakespeare et al's (1996) study that highlight difficulty with access to family planning clinics in the UK, an observation by Tilley (1996) that disabled women tend not to have Pap smears largely due to inaccessible doctor surgeries, and

an informal survey of battered women's shelters in Houston which found that 64% were inaccessible to wheelchair users (and presumably other physical and sensory impairments) (Nosek 1995). Here, it is likely that disabled women were not even considered in the purchase and use of the shelter due to an implicit assumption that disabled women would not be in relationships, let alone abusive ones.

Results

The data were analysed by simply converting the total values to percentages and interpreting the significance of levels of provision against an ideal (i.e. full physical, service and informational access). We first discuss the findings in relation to physical access, and then detail findings in relation to information and service access.

Physical Access

'Family planning services are usually inaccessible to most disabled men and women.' (Shakespeare et al. 1996: 28).

In contrast to Shakespeare et al's observation, 29 out of the 34 clinics (85.29%) who responded considered their premises to be accessible to disabled people. As the data in Table 2 illustrates, however, there is clearly a mismatch between what staff completing the questionnaire determine to be accessible and what proponents of universal design consider to be accessible.

Comparatively, wheelchair users fair quite well. There are, in the majority of cases, accessible parking spaces (although whether these are designated spaces is not known), a ramped/flat entrance, accessible treatment rooms and accessible toilet. The extent to which these are really accessible is not known, but we know from experience that what a non-disabled assessor thinks is accessible and what in reality is accessible can differ significantly. For example, if at the top of a ramped entrance a wheelchair user needs to open a double door that opens outwards then they are unlikely to be able to enter without help. Similarly, toilets that are accessible for lightweight wheelchairs are often still too small for battery-operated wheelchairs, and corridor access to the toilet can often be restricted. Whilst the majority of clinics appear to be relatively accessible to wheelchair users, between 20-25% of family

planning clinics are not accessible. A rough estimate suggests that over 10,000 adults aged between 16-64 in Northern Ireland are wheelchair users (approx. 5% of disabled people, based on PPRU (1993) figures).   This means that approximately 2-2,500 wheelchair users have to travel extended distances to visit accessible clinics. Moreover, few of those clinics needing a lift to get to other floors have one, and few have low counters. In both cases this limits access, conveys the message that disabled people are not fully-valued clients, and just as importantly would make working in the clinic difficult for a wheelchair user (only 4 clinics employed a disabled person).

Whilst wheelchair users might fair relatively well, those people with sensory impairments do not. For example, just under half the clinics had tactile floorways or large print signs suitable for visually impaired people, and only 4 (11.76%) clinics had minicom systems for use with deaf clients.   In only 2 cases were minicom systems located in treatment rooms. This effectively meant that only two clinics were accessible to deaf people, as the highly personalised nature of family planning and sexual health would preclude discussion in reception areas.

Table 2: Access audit of family planning clinics in Northern Ireland (percent)

	Yes	No	Don't know - N/A - non-response
Accessible parking spaces	91.20	8.82	-
A ramp and stairs at front entrance	79.41	14.70	5.88
Accessible treatment rooms	76.47	20.59	2.94
An accessible toilet	73.53	26.47	-
Tactile floorways	47.05	38.23	14.70
Large print signs	44.12	52.94	2.94
Low counters	26.47	55.88	17.64
Accessible lifts/stair lifts (if appropriate)	23.53	38.23	38.23
An automatic door	11.76	8.82	79.41
A Minicom system	11.76	79.41	8.82
Accessible treatment rooms (with	5.88	55.88	38.23

Minicom)			

Information Access

'Accessing information is a major barrier to many disabled people. The information is either not available or is in a format which is inaccessible to the particular needs of the individual: for example, tape or Braille is not readily available, and simple English formats for people with learning difficulties are still a largely new concept.' (Shakespeare *et al*. 1996: 18).

The above quote by Shakespeare et al. was amply demonstrated in our study. Only 9 (26.47%) of the clinics could provide sex education, family planning and/or sexual health information (e.g. leaflets, booklets, etc.) for those with sensory and developmental/intellectual disability. None of these could supply this information immediately. In relation, to people with visual impairments 4 of the clinics could provide information in Braille and 3 on audio tape but in all cases it could not be supplied in under 24 hours. Signing for deaf people could be provided by 8 clinics, 3 within 24 hours and 5 over 24 hours. 4 of the clinics could provide simplified versions of sexual health/sex education information, but only 1 within 24 hours. Only 8 clinics provided services to people with developmental/intellectual disability and only 1 clinic indicated that it provided family planning and sexual health information that was specifically targeted towards disabled people. In two cases, clinics indicated that staff members were dedicated to working with disability clients, although staff at 10 clinics had received disability awareness/equality training. In the majority of cases (8), however, training had been to less than 25% of staff (given that 91% of clinic employed less than 5 staff, this meant that only 1 person had received training). This paints a picture of a service that is ill-prepared to provide family planning services to disabled people.

Discussion

These results indicate to us that disabled people are not expected to be using the services (consultation, treatment, information) that family planning clinics provide. The levels of physical access appear to be partial and inadequate, and clearly fail to

meet the general guidelines of the Disability Discrimination Act (1995) that all public buildings should be accessible to disabled people. Whilst there appears to be relatively high levels of wheelchair access, the provision for people with sensory disabilities is woeful. Access to information is severely limited and in the vast majority of cases involves ordering material. Services to disabled people are partial and few members of clinics in Northern Ireland have received disability awareness/equality training. As we have illustrated there are a number of issues concerning disability and sexuality that clinic workers should be aware of when consulting with clients. Disabled people are sexual beings, with the same desires and sexual feelings as everyone, this needs to be recognised in service provision. We suspect that many clinics would plead that their access in all senses is poor because there is no demand. We would argue that may be demand is poor because disabled people either know provision is weak or feel they cannot avail of services thus boycotting clinics. Moreover, we would argue that this is a social justice and equality issue and, regardless of demand, all clinics should to be inclusive enterprises.

To us the lack of family planning facilities, services and information reflects dominant cultural ideologies that expect disabled people to be asexual. Family planning is not an inclusive enterprise and this is reflected in the socio-spatial construction of clinics as landscapes of exclusion. This is not to say that the exclusion of disabled people has been an explicit, deliberate strategy but rather that disabled people have not even been considered in the planning and design of family planning clinics; the effectiveness of cultural ideologies has normalised their exclusion to the extent that they are not even considered a potential user group This clearly has to be rectified. This rectification however should reflect a desire to recognise and tackle socio-spatial exclusion and should not be a cosmetic exercise aimed at fulfilling DDA requirements. To us this means that family planning clinics should develop an inclusive strategy of assessing their access and services through a consultation process with disabled people. Part of this process would necessitate all clinic workers to undergo sexuality and disability awareness training. Such a strategy should be accompanied by a promotional campaign aimed at undermining cultural representations and announcing improved access.

One theme, we have yet to discuss is the levels of access available to gay and lesbian disabled people. It is a subject that we did not cover in the questionnaire. It is fair to say that Northern Ireland is a generally homophobic place. For example, in a city of 350,000 people Belfast has only one openly gay bar. Although we have no evidence to prove this, these attitudes are likely to be prevalent in health care and social services. This has real implications to the lives of gay, disabled people and their access to sex education and sexual health care services. The needs of gay disabled people need to be catered for in the Province's family planning clinics. This means awareness training for staff and promoting clinics as inclusive spaces.

Another theme that needs to be addressed is the process of getting to the clinics. Making the clinics themselves accessible is of little use if you cannot travel to them. Disabled people as a group are poor. For example, Berthoud *et al*. (1993) estimates that 50% of disabled people and their families live below the poverty line due to exclusion from work. A consequence of this poverty is that many disabled people cannot afford to run a car and are reliant on friends, family, public transport and taxis. At present, public transport in Northern Ireland is largely inaccessible, although this is starting to slowly change with the phased introduction of kneeling buses. Taxis are expensive when living on a limited budget. Thought therefore needs to be given to ways to overcome transport difficulties. A solution, for example, might be for the Local Authority to provide transport until the public transport system becomes more inclusive.

Conclusion

Family planning clinics as currently designed and run are not adequately catering for the needs of disabled clients. Clinics are largely inaccessible in terms of physical access and informational and service provision. They are therefore landscapes of exclusion, reproducing the notion that disabled people do not need to avail of their services. As we have argued throughout the chapter, disabled people are sexual beings. Moreover, disabled people do have sexual health issues that extend beyond the general population. The family planning clinics in Northern Ireland need to recognise this and undergo a program of improving their levels of access, and the information and services they provide. This should be accompanied by disability awareness training and an examination, using a social perspective, of the ways in

which the clinics reproduce cultural ideologies in relation to disabled people and sexuality.

6

PROJECT 2: ACCESS TO EDUCATION IN COUNTY KILDARE

Written with Frank Mulcahy.

Introduction

Access to education for disabled children is an emotive issue. Educational policy advisors, the government, teachers, parents and children themselves often hold strong and, in many cases, principled opinions on how disabled children should be educated. Viewpoints are often conflicting with some favouring the separation of non-disabled and disabled children into a segregated system of mainstream and 'special' schools, and others advocating an inclusive education system where disabled and non-disabled children share the same school environment.

The former position, that of separation has been the traditional model in most Western countries, including Ireland. Ruhl (1983) and Tomlinson (1982) note that segregated education can be traced back to the late 18th century when institutions were established near Paris, France (deaf, 1760; blind 1784; retarded, 1798) and in Scotland (deaf and dumb 1760) and England (blind, 1791). In other countries, segregated education grew out of the institutionalisation of disabled people throughout the 19th century. Many schools were started by voluntary organisations, often with well-founded, if misguided, humanitarian aims (Cole 1989), before later coming under state control (e.g., Elementary Schools Act of 1893 in England and Wales laid duty on local authorities to provide segregated schooling, Tomlinson 1982), and many were residential and not locally-based. Segregated education made sense to those who controlled the education system economically - specialised resources were more economically viable if concentrated; academically - segregating these students meant that those in ordinary schools were not held back through placing too many demands on teachers and resources; students would get specialised provision in small class sizes with material pitched at an appropriate level rather than being driven by an age-related curriculum (Jenkinson, 1997; Thomas *et al*., 1998); socially - the eugenics movement was just starting at the time of most special

education schools and many believed that keeping 'defective' and ordinary children apart a sensible strategy (Thomas *et al*., 1998); and morally - it 'protected' disabled children, who were viewed as unable to cope with the wider world, within a humanitarian environment (Vlachou 1997).   As Vlachou (1997) notes, the paternalistic stance of educational reformers in the 19th and early 20th century meant that the views of disabled people were little considered.   Special school provision grew dramatically post 1960s in most Western countries as educational systems assumed responsibility for students who had previous been in the remit of health services.

This segregated approach, labelled the withdrawal approach by Ainscow (1991a), has been supplemented in more recent times with the introduction of a remedial approach. This approach recognises that educational ability is variable along a continuum and there are many children towards the lower end who require additional, 'specialised' teaching (the often cited 1978 Warnock Report reports that 20% of children have special educational needs on top of that ordinarily obtained in mainstream schools). This additional teaching takes a number of forms (see Booth 1983) but more commonly takes place outside of the usual classroom, thus segregating its recipients from their classmates.

Both the withdrawal and remedial approach are still popular today[iii].   However, over the course of the past two decades or so, segregated schooling has come under increasing criticism.   Critics contend that the strategy of segregated education is flawed in many respects. Segregated schooling it is argued is negatively perceived and reinforces attitudes and expectations of pupils, teachers and parents; the designation of specialists encourages teachers to pass on to others responsibility for children they regard as special; resources are channelled into separate provision reinforcing divisions; educational experiences within segregated schools is characterised by narrowness of opportunity and low levels of achievement; segregating schooling does not prepare disabled children well for life beyond school, in particular in relation to participation in mainstream community life (Hegarty 1993; Ainscow 1991a; Jenkinson 1997).   Moreover, because the numbers of disabled children are small (typically 3-5% of children) provision is usually centrally located, meaning that children have to attend school outside of their community, often having

to travel relatively long distances to attend, and in the case of some schools children are boarders (for example, deaf schools in Ireland where children board from the age of 5, McDonnell, 1983). This isolates disabled children from their peers and sets them apart. In the case of boarding, which has been increasingly phased out, it isolates children in institutional settings and limits their circle to other children with the same impairment. As documented by Rizvi and Christensen (1996) life in many residential institutions was harsh, disciplined and regimented. In rural areas many physically disabled children have to attend special schools for those with intellectual and developmental disabilities. This places them in an environment that holds them back educationally.

As should be clear, the arguments for inclusive education are concerned with both the education received and social justice. In particular, the issue of social justice has come to the fore in recent years in tandem with the growing political voice of disabled people. Indeed, Booth (1983) contended that choosing an inclusive approach to education is a moral choice - it represents a choice of different kinds of society (inclusive or exclusionary). The morality of this choice is revealed when we consider the issue of rights. If all citizens have the same rights then they should have access to the same life chances. Segregated education, disabled people and many educationalists are arguing, goes against egalitarian principles and is exclusionary, denying civil rights by removing disabled children from their peers and their community (see Christensen and Rizvi 1996)[iv]. It is with these sentiments of equity and justice that Gaden (1993) and ⊡ Murch✷ (1993) have been arguing for inclusionary schooling in Ireland.

Ainscow (1991b) detailed that many involved in special education have slowly come to realise that whilst often well intentioned to be a form of positive discrimination, providing a 'specialised' environment that concentrates solely on disabled children's education, 'special' schools often limit opportunities and helps perpetuate the discrimination of disabled children. In part, it perpetuates discrimination because it individualises educational provision, portraying the child as the problem, rather than the problem being the systems inability to be inclusive. Here, the stark differences between the medical model of disability and the social model of disability are

revealed. In simple terms, the social model states that disabled people are disabled not because of their impairment but by the way in society fails to accept and cater for their impairment. In other words, disabled children are disabled by the educational system because it does not provide an inclusive environment. The consequences of this 'medicalised' schooling system is the maintenance of long-term social and economic marginalisation. Disabled people generally have the highest rate of exclusion from the labour market, and where access is achieved it is usually in poorly paid jobs with few fringe benefits (e.g. company pension). As Kitchin *et al.* (1998) report disabled peoples access to the labour market in Ireland is extremely limited, particularly in rural areas. Moreover, the children caught between the 20% in need of some special educational provision and the 2-5% who attend 'special' schools are often poorly catered for, and are often abandoned within the system (Sayer 1994).

In contrast, inclusive education offers a number of educational and social advantages including: students allowed to perform at the level of their abilities (bright children are not held back in segregated schools); disabled and non-disabled children learn with their peers, thus helping those with developmental disabilities learn social skills and other disabled children grow in self-esteem, and help dismantle stereotypical views of disability held by non-disabled children and reinforced through segregation (Ruhl 1983).

It is important to note that advocates of inclusive education do recognise the need for exclusive teaching for specific cases. However, it is contended that these exclusive classes should be based within certain mainstream schools, and where possible activities integrated (i.e. all activities outside of specific lessons).

The arguments against segregated schooling and in favour of inclusive education are strongly advocated and articulated by disabled people themselves. For example, in interviews with 35 disabled people, in the first phase of research of which this study was apart, when asked to identify areas of concern that needed to be researched several respondents argued for research on access to education (see Kitchin, forthcoming for a full discussion). To them 'special' schools had not served disabled people well. Firstly, it was perceived that special schools were more about keeping disabled children out of the way of ordinary children than about educating them to

their full capabilities; of filling their time until they reached the age of 18 when they become the responsibility of the welfare system and training centres:

> F3: when I look at colleagues of mine - you know, the same age as me, who went - all it seemed to be at that time was if you could read and write and you could work out the change from a pound you were educated.

This is reflected in the literacy levels of disabled people in Ireland, which one well-known disabled activist believed to be very high:

> M8: Of the 370,000 estimated disabled people in this country I would safely say that 50-60% of them have literacy problems because of the special school systems and the other systems they have been through.

As noted, consequence of poor educational attainment is a future reduction in life chances through reduced opportunities in the labour market. It is believed by many disabled people that current 'special' education reproduces this exclusion by not allowing disabled people to reach their full potential, as the following interview quote from another study demonstrates:

> Anon: The system perpetuates this self-fulfilling prophecy - people with disabilities are given an inadequate education because they are believed to be 'inadequate' and this education fails to provide them with the skills necessary for adult life. Effectively this legitimises the original belief. This unequal educational opportunity leads, of course, to unequal employment opportunities. It has been consistently demonstrated that people with disabilities have experienced higher levels of unemployment that the rest of the adult population. Following on from this, most disabled people find themselves dependent on the social welfare system for their livelihood. In Ireland, this income does not cover the financial costs of living with a disability. Essentially, poverty is about exclusion from society, thus this lack of money further contributes to the poverty of the disabled individual (Turbridy 1995).

Moreover, many disabled people believe that negative attitudes and behaviours within society towards disabled people are reproduced through segregation. Segregation denotes difference. By separating disabled and non-disabled children at an early age it is signalling to non-disabled children that disabled children are different, that they are not part of their group. Without contact with disabled children, where they can

get to know them as people, there is a danger that cultural representations/stereotypes concerning disability get reproduced and remain in place into adulthood.   These arguments are illustrated in the following quotes:

F7: It is a societal thing - that's why I would like to get them at a young age, at the educational level and bring them together - because you won't make as many differentials. If you go to school with someone in a wheelchair they are a person - somebody.

F12: I think a lot of attitudes towards disabled has to start with schools. I really think that these special places for disabled people regardless of disability should be placed in ordinary schools. I don't mean in the same classroom all the time, ... I would like to see from the ground-level from when they are born that they see people with disabilities ... in kindergarden, from, you know, the discrimination starts there. .. And there are some people that won't even encourage them because they say 'they are not going to come to anything what's the point.' I would start definitely at school level and start from a very early age getting people to mix with people with disabilities and not to be afraid of them.

M5: That's where the problems stem from. If disabled people were in mainstream education from the age of 4 other children would not be afraid of disability. You actually see - I've seen myself - some mother and the child will stop and look at me and go 'look at that man' and the child has been pulled away, and that child is going to have a fear of disability instead of turning around and saying 'that man has got a bad leg and he can't walk properly'.

Yet it is only through children like my daughter being educated with and living among her able-bodied peers that we can start to change people's attitudes to the severely handicapped. Maybe then in twenty years time a mother like myself will have an easier road to travel. Maybe she will be able to leave her child momentarily in a public place without returning to find her with a lap full of money. Maybe she will not be interrogated about her daughter in front of her daughter. Maybe she will not feel like a travelling circus much of the time. Maybe she will not have to stand outside disabled toilets watching her daughter squirm in agony as they wait for able-bodied people inside to finish. Maybe she will be able to enjoy her daughter without the constant stress of battling for basic rights and services and the heart-destroying fear of looking into her daughter's future. (Turbridy 1995).

These issues are not confined to the first and second-level education:

> I am writing because I feel Ireland should be a more "Wheelchair Friendly" place. As a
> disabled person I am trying to live my life as independent as I can. I have applied for
> further education, training courses and employment but the answer to my letters is always
> the same: "buildings not accessible for wheelchair people" (Turbridy 1995).

These frustrations are equally shared by parents of disabled children, who find it difficult
to comprehend an education system that has until recently legally enforced taking a child
from a family setting to place in a residential school.

> My daughter and her school have been disgracefully let down by the State whose various
> officials engage in a shameful game of "buck-passing' which ensures that no State body
> ever accepts any responsibility for the child, her well-being and her education ... one   of
> the most frustrating aspects of this whole business is that if I accepted defeat in my efforts
> to have my daughter educated with her peers she would follow so many other children
> from the West of Ireland to St Mary's School in the Orthopaedic Hospital in Baldoyle ...
> There seems to be unlimited money to send my child away from home but none to enable
> her to stay at home with her family and friends (Turbridy 1995).

> In the area of education the handicapped child is discriminated against all the way. We
> have a fifteen year old child living forty miles west of Galway. There were no facilities in
> the local national school and the teacher was not trained to deal with a cerebral palsy
> child. There are no secondary schools for the physically handicapped so we send her to a
> special school in Dublin. This involves rising at 6 am on Monday morning and travelling 40
> miles to Galway and linking up with other children to be taken by minibus to Dublin. There
> are a number of stops and detours on the way and the journey often takes 6 hours. The
> reverse journey is made on a Friday. There is no helper on the bus and nobody to give the
> severely handicapped a drink. If a dog was treated in this way, you could prosecute for
> cruelty to animals (Turbridy 1995).

> It appears to us that the parents of a disabled child face a lifetime of fighting each and
> every agency and department for their rights and that of their child (Turbridy 1995).

The combination of these factors means that disabled people who did go through
mainstream schooling consider themselves to be fortunate, because they grew up in
their local community, made life-long friendships with non-disabled children, and
attained an education which provided more opportunities (e.g. access to third-level)
than they would have gained from the 'special' education system:

F3: I was extremely **lucky** when I was a child simply because you were put to a special school, you were sent to a special school. There was no provision in ordinary schools. My mother actually kept me from school until I went to an ordinary school - now

F8: I've been **very lucky** in that I went to a normal stream school and got my exams, but I know a lot of people who didn't get their exams and so the move on to a job is quite difficult.

In light of this discussion and the recently passed Education Act (1998), in this chapter we examine access to mainstream education for disabled children in County Kildare, Ireland. Our aim is to provide a bench mark of current practice and to assess the viability of 'mainstreaming' of all disabled children living in the county. In order to achieve these aims we adopted a threefold strategy. First, we reviewed the development of educational practice for disabled children in Ireland. Second, we conducted a survey of all first and second level schools in the county. Third, we interviewed ten school principals. The results from each of these three phases of research is reported in the following sections[v].

Disability and Education Policy in Ireland

O'Fiarchra (1983) reports that special schools for sensory and physical disability have existed in Ireland since the last century but were small in number. Schools for intellectual and developmental disabilities were started by religious orders in the 1930s but did not come under the remit of the department of Education until 1953 (*Report on the Education and Training of Severely and profoundly Mentally Handicapped Children in Ireland*, 1983). In the late 1950s special day schools were introduced in Cork and Dublin, a number of hospital schools and specific disability schools organised by voluntary groups established (e.g. National Association for Cerebral Palsy), a Special Education Inspectorate established in the Department of Education and a diploma for Teachers of the Deaf (1957) introduced. In the 1960s a Diploma in Special Education (1961) was introduced at St Patrick's College, Drumcondra, and home tuition for severely physically disabled children introduced in 1969 (*Report of a committee on the Education of Physically Handicapped Children*, 1982). Since the 1950s the number of schools and the children they cater for have

grown quickly. For example, O'Fiarchra reports that numbers of children attending special schools rose from just over a 1,000 to 10,500 by 1979 (this number is now falling and is at 7,536 in 1997). The distribution of these schools by impairment category, however, means that access is limited or on a residential basis. For example, O'Fiarchra reports that as of 1983 there were two schools catering for visual impairment, both in Dublin; five schools for deaf children (based in Cork, Limerick and Dublin) of which Dublin was also a residential school; and three residential schools for physically impaired (Cork, Limerick and Dublin), with 12 other special schools; 65 schools for mental impairment; and 653 remedial teachers serving 32,650 pupils (ratio 1: 50). The development of these schools was premised on the assumption that certain groups of children had identifiable educational needs which could not be met by conventional schools (*Report of a committee on the Education of Physically Handicapped Children*, 1982). Prior to these developments most people with disabilities were institutionalised in psychiatric hospitals, country homes and hospitals for physical disability.

The above developments, according to McGee (1990) and Lynch (1995) were achieved on an ad hoc basis. Education policy tended to concentrate on educating 'ordinary' children within a state-funded school system that was administered by the church and shaped by little legislation. Post-independence government policy towards education mainly focused on keeping the system running, given the poverty of the state, and many schools were poorly resourced (McGee 1990). Special education was not a primary concern and any education provision that occurred was initiated outside the system by parents, friends and professionals (McGee 1990). The change in emphasis in policy away from ad hoc developments and residential care and schooling seems to have started with the 1965, *Report of the Commission of Inquiry on Mental Handicap*. This commission accepted that, as a general principle, community care was more beneficial to people with intellectual and developmental disabilities, that schooling should be provided between the ages of 6 and 15, and that these children should not be placed in psychiatric hospitals. However, policy continued to promote a segregated system of special care, arguing that while it was recognised in principle that disabled children should be integrated and valued in the same way as other children, there were a number of practical and pragmatic reasons for maintaining segregated schooling such as educational ability, medical needs,

service provision (e.g. specialised transport) and the fact that significant financial investment had taken place in providing special schools (see *Report of a Committee on the Education of Physically Handicapped Children*, 1982).   Difficulties of segregated education such as social isolation and preparation for later life was to be mediated through parents, teachers, counsellors and psychologists. Recommendations then favoured integration for those children the school system as currently run could cope with, rather than wholesale restructuring of the education system. The capacity for integration, in reality however, was very weak. For example, by 1982 only three post-primary schools nationwide had special facilities that would allow physically disabled and non-disabled children to attend the same classes (two in Dublin, one in Cork, catering for 46 physically disabled pupils). The situation in primary schools was better with 146 special classes in primary schools, though they only catered for 107 physically disabled children, 14 of which used wheelchairs. Moreover, in 1982, 903 physically disabled children were attending schools for intellectual and developmental disabilities, many of whom did not have mental impairments (see *Report of a Committee on the Education of Physically Handicapped Children*, 1982). Not only were these children segregated but they were in environments unlikely to serve their educational needs well. Remedial teaching was introduced in 1971 and has grown slowly (*Guidelines for Remedial Education*, 1988). Furthermore, in 1986, 2,000 severely and profoundly mentally impaired children were excluded from education altogether, although this figure had been reduced to a 1,000 by 1995 (Lynch 1995).

Gash and Feerick (1995) detail that the path towards integration really started with the meeting of EC Council of ministers of Education in May 1990. Here it was recommended that 'mainstreaming' should occur as quickly as possible for all 'appropriate cases' as assessed by individual evaluation. The *Report of the Review Group on Mental Handicap Services*, in July of the same year, recommended that children with intellectual or developmental disabilities, should not be referred to residential services if the only reason to do so was to facilitate attendance for special education, and that closer links should be forged between special and ordinary schools. *The Report of Special Education Review Committee* (1993), however, again reiterated the position that whilst integration was desirable it should only be implemented where feasible without significant restructuring and investment. It was

recommended that where possible pupils spend time in both special and ordinary schools to foster integration and more special classes be introduced in selected (rather than all) schools, but the centralisation of services would continue for reasons of economic rationalisation, meaning that pupils would continue to have to travel outside of their communities. The view was stereotypically within the medical model but on the positive side, it was recommended that any future new schools should be accessible to allow attendance, that significantly more remedial teachers be employed and pupil-teacher ratios reduced, and that ordinary schools who enrol disabled children should be given adequate resources to support their education (the last being a significant step forward). The 1995, white paper on education, *Charting our Education Future*, reiterated the position of the *Report of Special Education Review Committee* for the need for an inclusive education and a system that promotes equality, respect, personal development and awareness of others, and is flexible to allow students to move between appropriate educational settings.

Despite the reluctance to move towards a truly inclusive education system, there are clear signs that integration is slowly starting to occur. As of 1997 there were 5998 pupils with special needs in ordinary schools, 3177 male, 2821 female (almost double that of 10 years ago (2,872)). 4842 were at infant/primary level and 1556 in secondary (non above age of 14). However, these are matched by 7,536 pupils in special schools, 4678 male, 2858 female, with 3032 at infant/primary level, and 4504 in secondary schools. In total there were 119 special schools (Department of Education and Science 1997)

Possibly the clearest statement of intent for inclusive teaching was the 1998 Education Act (23rd Dec). Whilst building upon previous reports, and not advocating the abolishment of the system of *segregated* special schools, the Act does signal a clear intention to foster inclusion through legislation. Indeed the first statement starts:

'An Act to make provision in the interests of the common good for the education of every person in the State, including any person with a disability or who has other special educational needs …'

The Act provides disabled children and their parents the right to seek an education in their local community, and for schools to be resourced to accommodate local disabled children (clauses 6a, 6b, 6c, 62, 6g, 7(1)a, 7(2)a, 9a). The implications of this Act, if enforced, are wide ranging and it has the potential to radically alter the education landscape in Ireland. The real question at this point is whether there is the will to implement and if so, whether there are the resources to be able to cope with increased levels of disabled children in ordinary schools. It is to these questions we now turn.

School survey

Numbers of disabled pupils

Just under half of the first-level schools (48.3%) reported teaching a child with a disability. In total, 184 disabled children (1.37% of all children) were taught by these schools, with 128 classified as having a learning disability. Only 46 children (0.41% of all children) with sensory or physical disabilities were taught in the mainstream, first-level schools surveyed (see Table 1 for a full classification). The picture from the second-level schools is slightly different with 64.3% reporting that they taught a child with a disability. In total, 170 children (2.35%) were classified as having a disability. A seemingly significant increase from first-level education. However, this rise can be explained by the re-classification of children, once at second-level, into the category of learning disability, mainly through the identification of conditions such as dyslexia and ADD (Attention Deficit Disorder). This is illustrated by the fact that the proportion of sensory and physical disabilities remains stable (30 children, 0.40% of the total) (see Table 1).

Table 1: Disabled children in Kildare by disability category

Category	Disability	First-level	Second-level (11-16)	Second-level (16-18)
Perceptual	Visual impairment	6	1	1
	Hearing impairment	11	8	6
	Learning disability	80	104	36
Illness-related	Multiple Sclerosis			
Physical	Cerebral Palsy	7	1	1
Developmental	Down Syndrome	5		1
Psychiatric	Bi-polar			

	Chronic depression			
	Manic-Depressive Syndrome			
Mobility	Quadriplegia			
	Paraplegia	1	1	1
Other		10	5	4

Classification from Rauscher and McClintock (1997)

Admission

Only one first-level school and no second-level school had refused to accept for admission a disabled child in the past five years. In the case of the one first-level school, a child with Down Syndrome, not from the school area, was advised to go to his/her local school for discussion. 25 (41.6%) of the first-level schools and 6 (42.8%) of the second-level schools said that had a school policy on the enrolment of disabled children. In only two cases (both at first-level), however, was this a written policy, and despite a request neither policy was returned with the survey. Moreover, the policy was only available to all prospective parents in 8 first-level schools and 2 second-level schools. From the interview data it was clear that the majority of schools did not have a specific policy because their practice was to try and take all applicants, only dealing with particular issues as they arose. In cases where specific issues arose such as disability, or where there was an application procedure (e.g. Irish-medium schools with limited places), then a decision on applications were made in a variety of ways - by principals, teachers, board of management, using departmental guidelines, assessing facilities and resources. This situation is likely to change under clause 15d of the Education Act 1998, as schools in future will be required to publish their policy on admission. How application decisions are determined in displayed in Table 2.

Table 2: Determinates of applications by disabled children for enrolment

Determination of decision	First-level	Second-level
Principal	21	9
Teachers	16	4
Board-of-management	21	3
Departmental guidelines	12	2

| Lack of facilities | 7 | 5 |
| Monetary considerations | 1 | |

Physical Access

55% first-level schools and 71.4% of second-level consider themselves to be accessible to disabled children. On analysis of specific provision it is clear that this is not the case. No one school could answer yes to all the access provisions detailed in Table 3. As such, no one school can provide a school environment that would cater for independent attendance by *all* children regardless of impairment. In the case of the first-level schools, in only one category did more than half the schools have that provision (parking, 61.6%). In second-level schools the picture is a little better with four categories above 50%. These were parking, accessible staffroom, accessible classrooms, and accessible toilet. In all cases it is likely that schools are equating access with wheelchair access, as provision for visually impaired and deaf children is very poor with low use of large-print signs, tactile floorways and colour contrasted walls, and no school having Minicom or induction loop systems for deaf children. This lack of provision for visually and hearing impaired children is likely to be an historical reflection of these children attending specialist schools. Focusing on wheelchair access, only 31.6% of first-level schools and 42.8% of second-level schools have a ramp at the main entrance (with a further 20% of 1st level and 35.7% having another accessible entrance). This means that 48.4% of first-level schools and 21.5% of second-level schools have no wheelchair accessible entrance. Moreover, only 37.5% of first-level schools and 50% of second-level schools with ramps met the gradient requirements of Part R of the Building Act 1985 (1:12). At steeper gradients wheelchair users will become more reliant on help to climb the ramp. Even if provision inside the school is better, entry level access is critical in safety issues such as in the case of a fire. We also know from experience that a lay-persons assessment of what is a wheelchair accessible environment often deviates substantially from an assessment made by a professional access auditor. It is likely therefore that these self-reported figures flatter the schools. It is clear, that schools in Kildare need major structural investment to be able to meet the demands of the new Education Act.

Table 3: Access provision in Kildare schools (%)

	First-level			Second-level		
	Yes	No	DK/NA	Yes	No	DK/NA
Parking spaces	61.6	30	8.3	85.7	7.1	7.1
Accessible staff room	45	45	10	64.3	14.3	21.4
Accessible classrooms	45	45	10	64.3	14.3	21.4
Low counters/desks	35	51.6	13.3	14.3	57.1	28.6
Ramp+stairs at main entrance	31.6	61.6	6.6	42.8	28.6	28.6
Accessible sports facilities	28.3	60	11.6	42.8	21.4	35.7
Accessible toilet	26.6	66.6	6.6	71.4	7.1	21.4
Other accessible entrance	20	58.3	38.3	35.7	7.1	57.1
Colour-contrasted walls	10	75	15	7.1	64.3	28.6
Large print signs	8.3	75	16.6	21.4	50	28.6
Tactile floorways	5	65	30	7.1	35.7	57.1
Accessible lift	0	66.6	33.3	7.1	28.6	64.3
Automatic door	0	75	25	0	50	50
Minicom/induction loop	0	90	10	0	71.4	28.6
Acc. rooms plus Minicom	0	65	35	0	42.8	57.1

DK = Don't know, NA = Not applicable

Educational Access

Only 40% of first-level and 50% of second-level schools considered their school to be educationally accessible to disabled children. These figures clearly indicate that both first-level and second-level schools are aware that, despite the commitment and efforts of teachers, they are not providing the best possible educational environment for disabled children. As the figures in Table 4 indicate this is largely to do with the provision of educational media, resources and teaching support. Whilst the vast majority of both first and second level schools have access to computers and a library these do not cater well for disabled children, particularly those with sensory or physical disability. For example, only one first-level school and one second-level school had adapted software for visually impaired pupils, with similarly low rates for large-print media. Remedial teaching at first seems quite healthy. However, as Table 5 details, remedial teaching is patchy (schools often sharing teachers - in some cases one teacher covers five schools - as also noted by Lynch 1995) and for a very short time a week - in 30% of first-level schools pupils receive less that one hour a week

remedial teaching.   The picture is slightly better for second-level schools where remedial teaching is typically between one and three hours. This is a reflection of the late diagnosis of learning disabilities such as dyslexia. Many of the schools reported that they would like, or had requested, extra remedial teaching.

Table 4: Access to educational support/resources (%)

	First-level			Second-level		
	Yes	No	DK/NA	Yes	No	DK/NA
Remedial teaching	91.6	8.3	0	71.4	28.6	0
Computer (PC)	83.3	3.3	16.6	92.9	0	7.1
Library	81.6	15	3.3	71.4	28.6	0
Computer disk	38.3	38.3	23.3	21.4	42.8	35.7
Adapted PC/Software (learning)	25	61.6	13.3	14.3	78.6	7.1
Tape	23.3	66.6	20	7.1	50	42.8
Large print	21.6	53.3	25	7.1	64.3	28.6
Compact disk	16.6	73.3	26.6	14.3	42.8	42.8
Adapted PC/Software (physical)	3.3	83.3	13.3	0	92.9	7.1
Specialised equipment	1.6	88.3	10	21.4	64.3	7.1
Adapted PC/Software (sight)	1.6	85	13.3	7.1	85.7	7.1
Braille	0	76.6	23.3	0	57.1	42.8

DK = Don't know, NA = No answer

Table 5: Remedial teaching (%)

	No. of remedial teachers				Average hours of remedial teaching per pupil			
	<= 1	1<x<2	>2	n.s.	<1	1<x<2	>2	n.s.
First-level	95	5			30	31.6	16.6	21.6
Second-level	57.1		14.3	28.6	14.3	28.6	21.4	35.7

<=1 indicates shared teacher.

Social Access

Whilst many schools acknowledged that physical and educational access was poor, the majority of schools (70% of first-level and 85.7% of second-level) consider themselves to be socially accessible for disabled children. By socially accessible we mean that the children are treated equally by staff and pupils, and had the same

opportunities to join in events beyond the curricula. As Table 6 highlights clubs and events do not generally cater for disabled children and awareness of issues relating to disability is likely to be based on personal experience, anecdotal evidence and media portrayals.

Table 6: Social access (%)

	First-level			Second-level		
	Yes	No	DK/NA	Yes	No	DK/NA
DA training for staff	6.6	90	3.3	21.4	0	78.6
DA training for pupils	6.6	52	6.6	14.3	7.1	78.6
Accessible clubs/events	13.3	86.6	0	28.6	14.3	57.1

DK = Don't know, NA = No answer

Future Plans

As Table 7 illustrates, few of the schools in the study had made any future plans in relation to the admission of disabled children, improving access or providing disability awareness training. These findings are probably no surprise given that most schools tend to deal with catering for a disabled child on a demand basis. Therefore issues of access and awareness are only addressed once a child has been accepted by the school.

Table 7: Future plans in relation to disability (%)

	First-level			Second-level		
	Yes	No	DK/NA	Yes	No	DK/NA
Admission of disabled children	20	70	10	35.7	57.1	7.1
Improved access	20	48.3	31.6	42.8	21.4	35.7
Disability awareness training	8.3	53.3	38.3	14.3	28.6	57.1

DK = Don't know, NA = No answer

Interviews with School Principals

It was clear from the interviews that many school principals are receptive to the idea of their school admitting and teaching disabled children. These principals felt that disabled children should be able to attend their local school and grow-up with the other children in their community, and that it would be healthy for the other children to be schooled in an inclusive environment:

> Sch10: I would say it certainly is good for the other children. I think its good for awareness, its good for life skills.

> Sch3: … the classes that those [disabled] kids are in are, you have some of the most caring kids in the school.

> Sch9: I would think it would be very good for the children here … They would learn tolerance and respect for people with disabilities.

When queried about admitting a disabled child to their school, initially principals replied that they would take all applicants regardless of disability. However, on further probing it became apparent the picture was not so clear. Whilst the school might not refuse entry, some principals revealed that they would encourage the parents of the child to consider other options. Here, we encounter the 'but' clause identified by ⊡ Murch✷ (1993): 'I accept the principle of education, but …'. As the following quotes reveal, this is largely because most schools in Kildare lack the appropriate physical access, educational media and teaching support:

> Sch3: I couldn't see them being turned away anyway, you know, it would be with full discussion with parents. … when I say with consultation with parents my normal line is, 'I have no problem in the world taking your child here but I feel you have to know our limitations, before you send him or her'.

> Sch10: … we don't refuse anybody. Certainly not on the grounds of disability. … The only reason I would not take a disabled child, well I would never refuse a disabled child, but my policy on it would be that I would sit down with the parents and say to them that we welcome their child to the school, however, I would have to point out to them that

our resources and that our we, we may not be able to cater for all the child's needs and that they should know that before the child comes.

In some cases, principals revealed that, despite their wishes, they *would* have to refuse admission to the school because access was so poor they would not be able to facilitate the child attending:

Int: Are there any reasons why your school would not accept a disabled child?
Sch6: None whatsoever.
Int: Would it therefore be feasible for disabled children to attend your school? …
Sch6: I could not take in a child in a wheelchair at present. We use pre-fabs and there is a gravel substance between the buildings. It would not be possible for them to move around and into or out of the pre-fabs.

Int: So it would be feasible for a disabled child to attend the school?
Sch7: Personally speaking, I think that for wheelchair access now it would not be a particularly good school for that.

In other cases, admission *would be* refused because the school could not provide specialist teaching needed:

Sch8: Definitely we would want a lot of back ups. We would want of course. Every teacher here would say they have a large class size. ... If say a disabled child came in with a severe learning disability or with severe physical handicap we wouldn't be able to cater for such a child at the moment.

Sch4: I suppose it would be quite impossible really, come to think of it, that way, you know. Up to now I have been thinking more of physical disability.
Int: Yea.
Sch4: I don't know how a blind child could learn in a school like this, or a deaf child.

The paradox then is that while most principals were receptive to disabled children attending their schools, the reality is that schools in some cases would only take the child with parents in full knowledge that the education they would received would not be as good as it could be or in other cases schools would refuse admission because it lacked the resources to be able to facilitate attendance. A number of concerns which produce this paradox were documented by the principals.

At one level, principals are aware that their primary remit is to provide an education for the children in their catchment area. They therefore have to ensure that all children are receiving the attention they deserve. There was a perception, based on first and second-hand experience, amongst some principals that the inclusion of disabled children might well disrupt the classroom balance because the teacher might have to provide a disproportionate amount of their time with the disabled children, as the following quotes from the principals of schools 1 and 3 illustrate:

Sch1: We have taken 2 back. That is why I have to worry about it. My instinct always told me to take anyone who came to the door, no matter what their problems are. But then I realised that the teachers always have to deal with these problems and they cause difficulties in class. Do you understand? … For years I have being going to the INTO Annual Conference and hearing teachers calling for us to take everyone in and also hearing lads putting the other side of the story. Where they have taken children who are blind, disabled or have Down Syndrome and their lives can be nightmares for the year in which you have them. So we would have to establish that the child could come to the school without disrupting other pupils otherwise it would not be feasible.

Sch3: Now I had this lovely computer in a classroom ah that the child couldn't write at all, except he could work a little bit on a computer, a class teacher that had babies, senior infants, first and second in the one room 35 in the room, including him, and just didn't have the time. She could give her 3 minutes or 4 minutes here and there. So I had the school secretary going into the classroom for 2 half hour periods in the day trying to give a bit of extra help to this child.

Moreover, as the principal of school 7 noted, without teaching support, access to appropriate resources and specialist teaching knowledge, a strategy of coping is adopted which does not serve the disabled child well:

Sch7: Well I know that one of them are meant to have glasses and everything but you just, well I have one of them in my own class at the moment and you just manage and cope, you know.
Int: Yea.
Sch7: Well, you just plod along and hope for the best.

Some of the principals argued that it was unreasonable of the Department of Education to expect schools to take disabled children, who need extra resources such as more teaching attention or specialist educational media, without providing the financial resources to provide adequate education.

> Sch2: … in the mainstream school we get absolutely no credit having that child in the school in terms of extra resources, or in terms of an extra teacher or an extra helping hand.

> Sch3: But one thing the Department will have to do, and I mean that I am not getting on my bandwagon now, is while they every child has the right to go to whatever school their parents so wish, they will have to put, we'll say, the structures in place you know to make that, to make the child who is who has a disability, not have an extra one by going to mainstream education. Well, I'll tell you now, Michael Martin at the moment. Well I thought he was a grand man and he has done a lot for education. But when he comes on television before Christmas and says that from the 1st January every child that has any kind of a disability will be catered for in school, and I have parents coming to me saying my child is dyslexic and you have done nothing and the Minister said you can. There is nothing out there. I have written to special education about 3 children I have seeking help, on 5 or 6 occasions since last September alone. Each time I send a copy of the previous letters. They have yet to acknowledge one of the letters.

In those cases where there is extra resources these are invariably seen as being inadequate and in need of improvement as they currently stand. The pressure of extra workloads without substantial, equivalent investment in would effectively bring the system to the point of collapse:

> Sch2: The resource teacher is absolutely panned out trying to deal with her brief. She is covering the whole town which is about 6 or 7 schools. … It is absolutely ludicrous, and yet, if the Minister was asked a question this town has access to a resource teacher.

One useful strategy for aiding the present system, that all the school principals were in agreement with, was the introduction of disability awareness training for teachers, as illustrated by schools 5 and 6:

Sch5: I think it would be a great idea and one worth following up on. It would help the teachers to understand a lot more and therefore be able to help the children.

Sch6: I am sure that the teachers will need no encouragement to attend such a course. I think it is very necessary and would help to develop our teachers. We all need such information at regular intervals and it would help us all to be more at ease and relaxed about disability and also show us how we can assist disabled children better. And why stop at teachers. Parents and the schoolchildren could also do with this type of training. It is very badly needed.

Some principals, however, felt that courses should be on a needs be basis:

Sch3: I would encourage it all right. But you see the way things work with teachers, as you probably know, or at any level, people will go to that if there is a need within their class;

and some that the courses should be optional unless the fees were paid for by the Department of Education.

Sch2: Yes, of course I would encourage them to go on it and it is fantastic that they should go, but I mean, as you know yourself, teachers do all these things at their own expense.

In addition, some principals felt that disability awareness training should be a compulsory component of teaching training courses:

Int: Do you think such a course is necessary as a part of teacher training from here on in.
Sch3: I would definitely say so. I would definitely say so because you have more and more and more people, you know, coming into mainstream education with difficulties or with disabilities of various kinds and they are not taught that.

Whilst a clear paradox exists between the desire of the schools to be inclusive and their capabilities to fulfil these desires, it should be noted that there have been recent improvements in terms of access. For example, schools 3 and 5 both report that they are receiving improved access in the near future, and school 5 indicates that the local school inspector is also trying to improve access:

Sch3: It is ah, now, obviously we have limitations to a degree. Every level can be got into we'll say without using steps. It can be difficult at times, it could mean the back of the school as opposed to the front of the school, you know. But we are getting an extension built on during the summer and ah, part of, part of the extension will consist of a ramp plus a disabled toilet which we don't have at the moment, you know.

Sch5: As I said on the form we have just been granted a refurbishment grant from the Dept. of Education. The Inspector for this area is very aware of the needs of disabled children and is very encouraging. We have had the architects out and they are doing their best to get rid of the steps around the school.

There is a long way to go, however, before the paradox is completely removed.

Discussion

The educational landscape of disabled children is clearly changing. The new, as yet un-implemented Education Act, in conjunction with rising numbers of disabled children attending ordinary schools, means that the educational opportunities for disabled children is slowly changing. As the results from this research demonstrate however there is clearly along way to go before a truly inclusive school system exists. At present, the vast majority of schools are inaccessible, physically, socially and educationally. This is clearly shown in the findings from the school survey. There does, however, exist a paradox, which is that schools often feel that they are more accessible than they really are. For example, many schools rated themselves as physically accessible and then completed an audit which proved that they were not! In part, this perception of good accessibility is based on conflating disabled people with wheelchair users. As the survey shows, schools are much better equipped to deal with wheelchairs than blind or deaf students, for which very few resources currently exist.

Whilst schools, on the face of things, seem willing to accept any disabled children who apply, the survey and the interviews reveal another paradox. When probed it was clear that school principals would, because of structural constraints, be forced to turn away disabled children, particularly those requiring large amounts of remedial

and specialised teaching. Moreover, schools had few plans to include disabled children in school plans, improve access, or provide disability awareness training for staff and students. In part this is due to cost, but also a perceived lack of need. The fact that teachers believed that they would pay their own costs for disability awareness training does not aid the situation. Our perception is that schools can state that they have not turned away any disabled children who have applied to attend because they have been intercepted by State agencies, such social work, ahead of their application. As such, children are being intercepted before getting to schools allowing schools to duck out of a difficult decision - the reality, as revealed by the interviews, is that schools would discourage and in some cases refuse admission. This is not to deny that there is a lot of good will amongst teachers and principals but that in practice the situation is more complex than many would wish to publicly acknowledge.

This situation is set to change when the new Education Act is implemented. Schools will no longer be able to refuse admission with approval from the Minister for Education. Under clause 15d schools will need to publish an admission policy statement in regards to children with disabilities, and in accordance with clause 21(2) publish a school plan stating the objectives of the school in relation to equality of access and participation in the school by disabled students. As revealed in the survey such practices are at present limited.

How extensively and rapidly the new act will become effective is debatable. Our research has highlighted that schools at present represent a landscape of exclusion for disabled children, and unless there is significant structural investment they will continue to do so. The reality of the situation is that, despite the ground-breaking Education Act, schools are ill-equipped to teach disabled children and are likely to be for sometime. This is partly due to school structuring/resourcing (e.g. 40% of schools have less than 3 teachers, and 70% of classes consist of 30 or more pupils, McGee 1990), but also attitudes and perceptions. This is not to deny that the Act will significantly change the educational landscape but that this change will be very slowly achieved without funding matching rhetoric. This means that disabled children will continue to be denied their right to an inclusive education in the near future and means that another generation will lose out in relation to employment opportunities

and access to third-level education.

Conclusion

Our threefold analysis of policy, current provision and interviews with school principals, suggests that both current government policy and school principals favour a shift from a segregated approach to educational practice to an inclusive approach. As both our survey and interviews reveal, however, such an approach is unrealistic without significant investment of structural, teaching resources and teacher re-training - a point echoing ⊡ Murch✶ (1993) assessment. The latter point is one that is often forgotten - awareness and an ability to teach children with a range of sensory access and educational levels is a vital component in restructuring schools into inclusive environments. Teachers themselves are not immune to stereotyping and discrimination against disabled people (Jenkinson 1997). This needs for investment is accentuated by the increasing pressures upon teachers, without new pupils who need extra attention being placed in the classroom (⊡ Murch✶ 1995). As such, it should be realised that the Education Act has far reaching and important consequences, but requires both significant changes in mind-sets (management and teachers) as well as resources (see Ainscow 1991a). As Slee (1991: 43, 44) notes 'change in education is not simply an issue of redrafting legislation', and a change as large as the introduction of inclusive schooling requires much thought if it is to be a success and not be a 'concealment of interests' - i.e. cosmetic changes where the traditional system continues with a new vocabulary. Without a full commitment inclusive education is likely to slip back to the present model of integrative education, where the emphasis is upon the child to fit into the school rather than the school to change to welcome and educate all. An inclusive school is one:

- that is community-based: an inclusive school reflects the community as a whole. Membership of the school community is open, positive and diverse. It is not selective, exclusive or rejecting;
- that is barrier-free: an inclusive school is accessible to all who become members - physically in terms of the buildings and grounds and educationally in terms of curricula, support systems and methods of communication;

- that promotes collaboration: an inclusive school works with, rather than competitively against, other schools;

- that promotes equality: an inclusive school is a democracy where all members have rights and responsibilities, with the same opportunity to benefit from and take part in the education provided by the school.

(Centre for studies on Inclusive Education, 1996, cited in Thomas *et al*., 1998)

This inclusive approach does not sit well in an educational environment which is becoming increasingly competitive.

Our study has led us to draw-up a number of specific recommendations that need to be implemented to make inclusive education a success in Ireland. These essentially follow those proposed by the Report of the Commission on the Status of People with Disabilities (paras 162-217). In particular:

- The Act needs to be implemented and *enforced*. It is likely that economic pressures will work to maintain the status quo. An agency or government department devoted to ensuring that the provisions of the Act are adhered to, in particular this agency should encourage inclusive education strategies in all suitable cases (rather than least-cost or most easily implemented).

- Community as opposed to residential or segregated schools should be encouraged. Isolated special schools should be phased out, with new units attached to existing schools where children share the same space with the exception of the classroom.

- School infrastructure needs to be made physically and educationally accessible with investment made on a needs basis to help stagger costs.

- Remedial teaching needs significant investment to ensure that children with special educational needs receive suitable help. At present, remedial teaching is poor, particularly at first-level.

- More provision should be made to the early detection of learning difficulties such as dyslexia and ADD and appropriate action taken.

- There needs to be significant improvement in the levels of information provided to parents about options, with clearly demarcated roles and lines of enquiry that stop them being passed from 'pillar to post'.

- Disability awareness training should be provided for all staff on a continuing basis and it should be a mandatory component of teacher training. Costs should be met by the Department of Education. In addition, disability awareness should be made available to all pupils, regardless of whether their class contains a disabled child.

7

CONCLUSION

Whether an academic feels (s)he has a moral responsibility to address issues of social suffering, injustice and oppression is clearly a personal issue. On the basis of the research reported here though, it is clear that oppressed groups would like academics to join them in a common struggle for emancipation and empowerment. For this joining to be successful, however, the disabled people interviewed felt that research as currently practised need to change in approach - not only does society need to be radically transformed from its ableist formulation but so does the way research is produced. This is because research as currently practised does alienate and disempower disabled people who take part. Such feelings are generated because disabled respondents feel that their knowledges and experiences are being 'mined' with little feedback, knowledge of the conclusions reached, and suspect that little action is being taken on the basis of findings. Moreover, many interviewees felt that research conducted by non-disabled people may be unrepresentative and may not be serving the interests of those participating. This is not to say that the majority of respondents did not recognise that research can play a vital role in the emancipation of disabled people.

The ideal model forwarded by the respondents was one of inclusivity; an equal-based, democratic, partnership between disabled people and disabled/non-disabled academics. The model did not preclude non-disabled researchers but rather sought a partnership. This partnership would be action- and politically-led, seeking to explicitly change social relations. This model, because it seeks to balance the concerns and power of researcher and researched, interviewees felt would address their concerns of focus, lack of action, the inaccessibility of disability studies literature, and levels of representativeness.

In the second phase of this project, two such participatory action research (PAR) projects were implemented, one in Belfast and one in Dublin. The outcomes of this piloting have been both positive and negative.

On the positive side, two projects chosen and directed by disabled partners have been successfully implemented. Both have significant academic and practical implications and will be used to lobby local authorities and government for change. Both projects allowed the disabled partners to examine an issue of relevance to themselves and other disabled people. From feedback received, interviewees were pleased to receive transcripts of their interviews and to be asked to comment on papers generated form the project. Both projects were run amically and without incident, from start to finish. It is suffice to say that whilst challenging to undertake and not without its difficulties, that a 'third-space' (Routledge 1996) between researcher and researched, academic and activist, can be successfully occupied.

On the negative side, however, the projects were taxing to initially implement for two principal of reasons. First and foremost, the vast majority of disabled people approached turned down the opportunity to take part. This is part was due to time constraints but was also influenced by issues of literacy and confidence. Second, most people approached were done so at the initial and only meeting between researcher and interviewee. As such, there was no established basis of trust that might sustain a working relationship over a year long project. There is little doubt that partnerships building upon existing links stand more chance of success. The projects once initiated were also relatively taxing to run. Because both partners worked, time constraints meant that progress was slow (much slower than if run solely as an academic project). This was accentuated in this case due to the remoteness of one project (first Dublin, then Belfast after the researcher moved university). The time considerations have meant that although this final report has been submitted, that the project will be on-going for sometime in terms of dissemination and seeking change. At present, the action part of the project has yet to be implemented.

Recommendations

1) Researchers examining issues of disability need, where appropriate, to adopt partnership approaches to research.

2) Where possible, partnerships should built on established links.

3) Partnerships are best run with disabled people acting as consultants (advisory board) and the researcher collecting, analysing and interpreting data.

4) All people taking part in the research (advisory board members, participants, interviewees) should be given the opportunity to verify data generated and to alter statements, and to comment on final drafts.

5) Research, where appropriate, should seek to be action-led, seeking to change social relations.

6) Research should be disseminated beyond academia through distributed reports, newspapers and special interest magazines.

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APPENDIX

Family Planning Association/RIA Questionnaire.

Preamble:
My name is Paul Anderson, ringing from the Family Planning Association. We are currently undertaking a short telephone, questionnaire study of all Family Planning Clinics in Northern Ireland. The study is joint project with Queen's University and is funded by the Royal Irish Academy. The questions relate to disability issues. Your answers to these questions will be treated in strictest confidence.

Question 1: Do you consider your premises to be accessible to disabled people?

        Yes ⬜   No ⬜

Does the clinic have:

	Yes	No
a) accessible parking spaces?	⬜	⬜
b) a ramp and stairs at front entrance?	⬜	⬜
If no, is there another accessible entrance?	⬜	⬜
c) an automatic door?	⬜	⬜
d) tactile floorways?	⬜	⬜
e) large print signs?	⬜	⬜
f) low counters?	⬜	⬜
g) an accessible toilet?	⬜	⬜
h) accessible lifts/stair lifts (if appropriate)?	⬜	⬜
i) a minicom system for deaf people?	⬜	⬜
j) accessible treatment rooms?	⬜	⬜
(including minicom)	⬜	⬜

Question 2: Do you provide information that is accessible to disabled people?

        Yes ⬜   No ⬜

If Yes, in what mediums and how soon can they be provided?

	Yes	No	Now	24hrs or less	>24hrs

a) braille ☐ ☐ | ☐ ☐ ☐

b) audio tape ☐ ☐ | ☐ ☐ ☐

c) signing ☐ ☐ | ☐ ☐ ☐

d) simplified version ☐ ☐ ☐ ☐ ☐
   (learning disability)

Question 3: Do you provide family planning and sexual health information that is targeted specifically at disabled people?

Yes ....☐   No ....☐

If Yes, can you please send me copies.

Agreed to post ....☐   Refused to post ....☐

Question 4: Do you provide services for people with learning disability?

Yes ....☐   No ....☐

If Yes, can you please send me details.

Agreed to post ....☐   Refused to post ....☐

Question 5: Is any member of staff dedicated to working with disability clients?

Yes ....☐   No ....☐

Question 6: Have any of your staff undertaken disability awareness/equality training?

Yes ....☐   No ....☐

If Yes, how many?

<25% ☐   25-49% ☐   50-74% ☐   75%+ ☐

Was the training:

In-house ....☐   Obtained externally ....☐

Question 7: How many people work at the clinic?

       1-5 ☐   6-10 ☐   11-15 ☐   16-20 ☐   20+ ☐

Question 8: Do any disabled people work for your organisation?

       Yes _____ ☐   No _____ ☐

If Yes, how many:

1-2 ☐   3-4 ☐   5-6 ☐   6+ ☐

Schools questionnaire

Introduction:

This questionnaire concerns disabled access to 1st and 2nd level education in County Kildare. Every school in the county is being surveyed. The study is funded by the Royal Irish Academy and is being administered by NUI Maynooth. We would be grateful if you could find time in your busy schedule to answer the brief questions below (regardless of whether you have any disabled pupils).   Your answers to these questions will be treated in strictest confidence. We have enclosed a self-addressed envelope for returning the completed questionnaire. We would be grateful if you could return the questionnaire by Friday, November 20th, 1998.

Section 1: Details

Name of School: _____

Address: _____

              _____

              _____

              _____

Name of Principal: _____

School Tel. No.:   _____

School Fax No.:   _____

School E-mail   _____
(if any):

No. of Pupils: Boys: _____   Girls: _____

No. of enrolments in September, 1998. _____

Section 2: Numbers

Does your school have any disabled children attending?

Yes .... ☐   No .... ☐

If Yes, please indicate their disabilities and numbers.

Category	Impairment	Numbers	
		Pre. Jun. Cert.	*Leav. Cert.*
Perceptual	Visual Impairment		
	Hearing Impairment		
	Learning Disabilities (inc. dyslexia/Attention Deficit Disorder)		
Illness-related	Multiple Sclerosis		
	Other		
Physical	Cerebral Palsy		
	Other		
Developmental	Down Syndrome		
	Other		
Psychiatric	Bi-polar		
	Chronic Depression		
	Manic-Depressive Syndrome		
Mobility	Quadriplegia		
	Paraplegia		
Other			

How many disabled children have been turned down for places at the school in the past five years? _____

Please give reasons for non-enrolment: _____

_____

_____

_____

If the child/children were referred to other schools/institutions can you please indicate which: _____

_____

_____

_____

Section 3: School Policy

Has the school a policy on the enrolment of disabled children?: Yes… ☐ No ☐

       If Yes, is this a written policy?:   Yes ☐   No ☐

       If Yes, is this policy available to all perspective parents?: Yes ☐ No ☐

If Yes, please can you post a copy of the policy when returning this questionnaire.

If No, how is an application for enrolment from a disabled child adjudicated on (can tick more than one):

By Principal	☐	Departmental guidelines	☐
By Teachers	☐	Lack of Facilities	☐
By Board of Management	☐	Monetary considerations	☐

Section 4: Access/Provision

Do you consider your school to be *physically* accessible to disabled children?

       Yes ☐   No ☐

       Does the school have:

       a) accessible parking spaces?   Yes ☐   No ☐
       b) a ramp and stairs at front entrance?   Yes ☐   No ☐
       If Yes, what is the gradient?   1 foot in 6 feet   ☐
                                             1 foot in 9 feet   ☐
                                             1 foot in 12 feet   ☐
                                             1 foot in 15 feet   ☐
                                             1 foot in 18 feet   ☐
                                             1 foot in 21 feet   ☐
       If No, is there another accessible entrance? Yes ☐   No ☐
       c) an automatic door?   Yes ☐   No ☐
       d) tactile floorways?   Yes ☐   No ☐
       e) colour-contrasted walls?   Yes ☐   No ☐

f) large print signs?   Yes ☐   No ☐

g) low counters/desks?   Yes ☐   No ☐

h) a (wheelchair) accessible toilet?   Yes ☐   No ☐

i) accessible lifts/stair lifts   Yes ☐   No ☐

(if appropriate)?

j)   a minicom/induction loop system for

deaf children?   Yes ☐   No ☐

k) accessible classrooms?   Yes ☐   No ☐

(including minicom/ induction loop)   Yes ☐   No ☐

l) accessible sports facilities?   Yes ☐   No ☐

m) accessible Staff Room?   Yes ☐   No ☐

Do you consider your school to be *educationally* accessible to disabled children?

Yes ☐   No ☐

Does the school have:

a) a library?   Yes ☐   No ☐

If Yes, are the resources also provided in:

Large Print: Yes ☐   No ☐

Braille: Yes ☐   No ☐

Tape: Yes ☐   No ☐

Compact Disk: Yes ☐   No ☐

Computer Disk: Yes ☐   No ☐

b) computers?   Yes ☐   No ☐

If Yes, have the computers been adopted for use by, or have software to enable

use by:

Children with sight impairments: Yes ☐   No ☐

Children with physical impairments: Yes ☐   No ☐

Children with learning disabilities: Yes ☐   No ☐

c) Specialised equipment?   Yes ☐   No ☐

If so, what?   _____

_____

_____

d) Remedial teaching?   Yes____ ☐   No_____ ☐

If Yes, how many remedial teachers are there?: _____

How many hours per week would a pupil receive remedial teaching?: _____

Is remedial teaching for:

Children with learning/developmental disabilities? Yes____ ☐   No_____ ☐

Children with emotional/behavioural difficulties? Yes____ ☐   No_____ ☐

Both?   Yes____ ☐   No_____ ☐

If No, does your school need a remedial teacher: Yes____ ☐   No_____ ☐

Why?   _____

                 _____

Do you consider the school to be *socially* accessible to disabled children?

        Yes_____ ☐   No_____ ☐

Does the school have:

a) Disability awareness training for staff?   Yes____ ☐   No_____ ☐

b) Disability awareness training for pupils?   Yes____ ☐   No_____ ☐

c) Accessible after-hours clubs/events?   Yes____ ☐   No_____ ☐

If Yes, what _____

Section 5: Plans for future?
Does your school have any future plans concerning the:

Admission of disabled children?   Yes____ ☐   No_____ ☐

If Yes, what are the plans: _____

Improving disabled access?   Yes____ ☐   No_____ ☐
If Yes, what improvements: _____

Disability awareness training?   Yes____ ☐   No_____ ☐

If Yes, who will lead the classes: _____

Section 6: Other Comments

The space below is for any comments/opinions you have concerning disabled access to 1st/2nd level schools and/or to elaborate upon answers to some of your questionnaire responses.

Would you be prepared to discuss the issues raised in this questionnaire further?

Yes ⬚   No ⬚

Signature: _____   Date: _____

List of publications

Kitchin, R.M. (In Press, due 1999) Ethics and morals in geographical studies of disability. Proctor, J. and Smith, D. (Eds) *Geography and Ethics: Journeys through a Moral Terrain*, Routledge.

Kitchin, R.M. (sub) The Researched Opinions on Research: Disabled People and Disability Research. *Disability and Society*

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Kitchin, R.M. and Law, R. (in prep) 'Bogged down': The socio-spatial construction of disabled-access toilets. *Urban Studies*

Kitchin, R.M. (in prep) Setting agendas for disability research: The views of disabled people. *Disability Studies Quarterly*

Anderson, P., Kitchin, R.M. and Mulcahy, F. (in prep) Undertaking participatory action research: experiences and suggestions. *Antipode.*

Kitchin, R.M. and Mulcahy, F. (in prep) Access to education for disabled children: The Irish experience. *Journal of Special Education.*

Kitchin, R.M., Anderson, P. and Mulcahy, F. (in prep) Disabled Access in Ireland. *Irish Geography*

List of Presentations

Kitchin, R.M. and Anderson, P. (1999) Space, disability and sexuality: Access to family planning clinics in Northern Ireland. *Conference of Irish Geographers*, Drumcondra, May.

Kitchin, R.M. (1999) The researched opinions on research: Disabled people and disability research. *Conference of the Institute of British Geographers and the Royal Geographical Society*, Leicester, Jan.

Kitchin, R.M. (1998) Social exclusion, social responsibility, and social action: the role of the geographer in geographical studies of disability. *Conference of the Institute of British Geographers and the Royal Geographical Society*, Guildford, Jan.

[i] The language of this paper is academically orientated. That is because it is aimed at informing an academic audience of the need to change their relationship with the researched. There is no denying that texts need to be written to suit different audiences. However, the same texts can be written to suit different audiences. Papers presenting the results of empirical research from this project will be published in academic/non-academic forms and be available in a variety of formats.

[ii] All respondents in this study were send the transcripts of their interviews and drafts of all papers based upon their interview material. Respondents were invited to clarify/change their statements and to comment/critique the arguments within the paper.

[iii] In some countries, such as Italy and Spain, special education provision has been discontinued with all students attending regular classes (Jenkinson 1997).

[iv] It should be noted that these arguments are not to deny that there are many people working in special education that deeply care about disabled people, just that the system that they work does not always favour the children they teach.

[v] The research reported here formed the second part of a wider project concerned with assessing how research on disability issues is conducted. All phases of the research, including choice of topic, data generation, analysis, interpretation and writing-up, were conducted in partnership, linking the academy with disabled people in an attempt to provide a research arena that was both emancipatory and empowering.