Being researchers with the label of learning difficulty: An analysis of talk in a project carried out by a Self-Advocacy Research Group

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Being researchers with the label of learning difficulty

An analysis of talk in a project carried out by a Self-Advocacy Research Group

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PhD Thesis

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May 2002
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Abstract

This thesis examines the talk-in-interaction in an inclusive research project carried out by four people with the label of learning difficulty. They set out to see whether other people in similar positions shared their feelings about labelling, which they perceived as part of the social oppression of being a service user, a less-than-full member of society, restricted by dominant and naturalised discourses about Learning Difficulty. Through a close analysis of the talk, this work characterises and describes the research activity which they undertook. The analytic method draws on elements of conversation analysis and critical discourse analysis, and examines identity work as a matter of local interactional business.

Inclusive research as exemplified by this project is shown to be a new and distinct type of activity, drawing on academic models, but also creating its own parameters, through its essential link with the self-advocacy movement. The discourses of resistance and self-reliance are a necessary backdrop to this type of research activity, which springs from strong personal and collective feelings about injustice. Distinctive features include the open nature of meaning-making, blurring of the distinction between researcher and researched, and the working up of a shared identity. Further, the supported nature of the work is critically examined. Reflexive analysis reveals some discursive strategies to support self-advocacy talk and research, and explores the dilemmas of power and ownership.

It is concluded that members did in fact address the social problem from which they started, by the very act of doing research. In reclaiming interactional rights, they challenged notions about their own rights to knowledge, and their presumed incompetence as people with learning difficulties. The talk not only reflected the instability of meanings within the world of Learning Difficulty, but members also contributed to these debates, by taking on the right to define themselves.
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Accompanying material: an anonymised copy of the tape-recorded extracts analysed in this thesis.
Acknowledgements

This thesis would not have been possible without the efforts and achievements of all the self-advocate researchers with whom I have worked. My main debt of gratitude must therefore go to the four original members of the Self-Advocacy Research Group, and to those who took part in the later phases of the work. In order not to single out any individuals, all participants remain anonymous in this thesis, but the Research Group members themselves are happy for me to name them here, so that I can acknowledge their achievements.

- Brian Vasey
- Florence Anne Turner
- Chris Peacock
- Neil Palmer
- Tiffany England
- Gary Bourlet
- Deborah Bayliss

They supported my work as much as I have supported them, and my hope is that they will be able to gain from it. We would particularly like to remember here
- Clifford May
who was a member of the group for a short while, and who sadly died in 1999.

Over the years of working together, I have been privileged to learn from self-advocates, to exchange ideas and to share in the excitement of developing the new and challenging form of social activity that is described in these pages. Many other self-advocates and their supporters also took part in the talk that is analysed here, and to them I am also very grateful for allowing me to tape-record and mull over their words.

I would like to express my gratitude to my two superb supervisors, Pam Shakespeare and Ruth Townsley, who have encouraged and guided me around all the obstacles, and kept me on track over the last five years. Their respective expertise in discourse analysis and in disability matters came together to give me a particularly good base to develop my own thinking. Additionally, my thanks to those who have been brave enough to read chapters: Ken Simons, Beth Tarleton (and Nick for the bleeps), Richard Barwell and of course Jane Eccles for proof-reading. Everyone at the Norah Fry Research Centre has given me great support, and without them I would never have completed this work.

Last of all, I would like to thank Rob, my husband, for bread-making and printing and my children, Ben and Naomi, for moving to London so that I could complete my writing on time.
Terminology

In this thesis I do not want to take the category of ‘learning difficulty’ for granted; this was a term that was rejected by members of the Research Group with whom I have worked. However, it is still generally considered to be the least offensive term, if a general category name has got to be used. When it is necessary to use the words ‘learning difficulty’ about a person or group of people, I use either inverted commas, or I make it clear in the text that the words are a label that do not entirely define the person. Capitals are used to denote the field of Learning Difficulty.

I have tried to embolden all technical terms on their first usage, with some explanation. This includes both discourse and disability terms. However, complete consistency here is a theoretical and practical impossibility. What is technical to one person may well be ordinary to another.

All names of people and places are anonymised. The term (Self-Advocacy) Research Group is used as a shorthand for the full name of the group whose work is explored throughout the thesis.
Preface

My aim in this thesis is to characterise a social activity which I term inclusive research (see 1.7.2), using discourse analytic methods. That social activity is embodied in a particular project undertaken by a small group of people who have the label of learning difficulty. The data for this thesis are not the findings of that research project, but consist of transcripts of naturally occurring talk within it. Since the work of that small group of people and my own are so closely intertwined, the following thumbnail sketch is given to set the scene, and to clarify points of reference, both about the stages of their activities (presented in italics and based on their own published accounts: Palmer and Turner 1998; Palmer et al. 1999) and about my own evolving stance, and position within, their work.

First stage: forming the group

In January 1997, four people in Norton started their own research group. They were all people who had the label of learning difficulty. In this thesis they are referred to as ‘Mark, Angela, Harry and Ian’. During 1995/96, three of the members had been part of a European interest group in college, which became part of the development of a networking movement which drew together representatives from around the UK. It was this local interest group that formed the basis of the new Research Group in Norton. The first stage was the identification of a problem, which the Research Group members described as ‘labelling’. This was their starting point, and as I explore with them in Chapter 1, it results in some very real social problems for the people who are labelled.

My own stance towards the Research Group members was, initially, that of supporter. Three of the members had been known to me as students in the local college, where I had been the facilitator of their European Interest Group. At the time the Research Group started, we had started to hold sessions in the local People First offices, and two local supporters also had some involvement. I was not a People First supporter, but had just started work as a researcher, and I cannot deny the influence that my career path must have had with members. However, this particular project was not part of
any contracted research I was engaged in, and this was how group members subsequently chose to frame their ownership of the group:

All the work is done by us. This gives us power, as researchers and as self-advocates in a way. But we also have to take responsibility. For instance, we are in charge of trying to get money for our group, and managing the money ourselves. It is a bit nerve-wracking, how to budget it, and we do get a bit of support with this. But it is our responsibility.

(Palmer and Turner 1998: 12)

Second stage : planning the Finding Out project

In the second stage of the work the Research Group members set out to tackle the problem that concerned them. In September 1997, the group was successful in obtaining funding in its own right from the small grants scheme of the UK National Lottery Charities Board, which paid for transport costs and a small fee to group members for each session. They then planned exactly how they would accomplish their research. Research Group members are often asked why they wanted to embark on this project and this is their response:

We do research because we enjoy doing it, otherwise we wouldn't be doing it. Also, it's our job. It's interesting to get people's opinions, like people who go to day centres, and at college. We find out what their ideas are, how they cope when they get angry and how they go about things. Through research we meet lots of people, and we achieve things.

(Palmer and Turner 1998: 12)

Third stage: doing the field work for Finding Out

The Research Group's project consisted of visits to other self-advocacy groups (November 1997 – February 1998) to ask them a series of questions. These visits created the data for their own project. The purpose of their research, as one of the members described it in the first meeting, was:

To find out – 'are other people hitting their heads against a brick wall like we are?'

(Research Group minutes. January 17th 1997)

This phase of the work is written up by members in Palmer and Turner (1998), and by myself Williams (1999), and will be referred to here as the Finding Out project. The work they did at that time, and subsequently wrote up and published, has an importance of its own which exists independently of this PhD.
During this third stage I continued to work voluntarily as the Research Group’s supporter. I was not at that point doing discourse analysis in any sense of the term. We were engaged in discourse, and I was available to group members both for support and reflection. Audio and video tapes of these visits were originally made for Research Group members’ own purposes, so that they would have a record on which to base their own thinking and writing.

Fourth stage: Research Group’s analysis and writing up

We had been approached to contribute a chapter for a book to be published (Swain and French 1999), and so our initial focus was to do some quick analysis, and for group members to write up their findings, which they did in the main by dictating onto tape (Palmer et al. 1999). Following that, the group was successful in obtaining another small grant from the National Lottery to make an accessible version of their findings (Bristol Self-Advocacy Research Group 1999). In order to do this work, group members reviewed the video tapes from the visits, picked out the important parts for them, and produced a booklet called ‘Finding Out’. They wrote back to all participating groups to obtain permission, and shared the drafts with them.

Fifth stage: moving into the PhD

Through my participation in the Finding Out project, I became increasingly excited by the potential it had for challenging and changing received discourses, and it was at that point that I started also to read some of the work which became influential in shaping my own analytic methodology (Fairclough 1992; Antaki and Widdicombe 1998; ten Have 1999). I approached Research Group members, to seek their consent for me to use their data for my PhD, which was planned both as a study of talk but also as a participatory venture. More information on consent is given in Appendix D. Thus commenced the fifth stage of the study, in which I aimed to turn the analytic spotlight onto the process of what we had done together, which of course included reflexive analysis of my own role. The work involved in
exploring methodologies, finding a research focus, and transcription took at least another year.

Sixth stage: working together on the PhD

My role as supporter to the Research Group has continued to the present date (2002). However, as discourse analyst I adopted a very different stance, that could have distanced me considerably from Research Group members. How can a difficult, seemingly abstruse, discipline have anything to do with a group of people with the label of learning difficulty? Despite this, we were all anxious to keep the participatory loop alive, as this was the Research Group's own project, and we wanted to maximise the chance for the thesis to be of some value to members, and for them to contribute their insights. I was also encouraged by Fairclough's (1992) challenge, that a corpus of data is not constituted once and for all, but can be added to by expert opinions, panels and co-researchers, and is: 'open to ongoing enhancement in response to questions which arise in analysis' (Fairclough 1992: 228).

In the summer of 1999, I facilitated three sessions with two members of the original group and two who had joined since the data was first collected. We were then successful in obtaining a small bursary from the Open University, so that members could be paid a small fee for their participation in a series of six discussion sessions during the ensuing year. In these sessions I checked out various insights and tentative findings with members. I also returned to the original participating groups, to explain the discourse work, and obtain informed consent (see Appendix D). The continuing involvement of the group has been extremely helpful in structuring and grounding my work, and some members are still active in the project. Two members have recently (March 2001) hosted and presented a seminar for the original research groups we visited, about self-advocacy and research (see Appendix F); also, as a group they have since moved on to other research projects.

Over the years, those who remain in the group have naturally acquired some interest in the topic of talk. However, I do not mean by that to claim that they have become discourse analysts. Indeed, the act of taking back data to participants is always fraught with the dangers of falling into a rehearsal of the original concerns or issues discussed
in the data. In our case, there were certain practical devices that we used to move to a different plane, including a discussion about talk itself (see Appendix G). The business of social interaction through talk is simultaneously both a concrete and a very abstract phenomenon. It is something in which we are constantly engaged, and which continually re-constitutes our experiences, our identities and our fates. These facts were not lost on the Research Group, since their original concern was with the effect of labelling on their own lives (see Chapter 1). One can however have a general interest in these issues, without wanting to take part in a minute analysis of how talk works.

The present thesis is but one more stage in this process, and will be matched by an accessible version, thus enabling the group members and other colleagues to continue their own enquiries. I would now describe what we have achieved in the following way (the reader is referred to Chapter 10 for a fuller exploration of these issues). Group members have a dual achievement. They carried out their original work, in the vanguard of inclusive research by people with ‘learning difficulties’, and carried on to publish and present that work to others. Moreover, they have maintained a general interest in how their work should be characterised and described, through their involvement in this thesis. As for myself, I aim both to contribute to the debates about inclusive research, and to the world of discourse analysis. It is to be hoped that we will continue to construct knowledge in a spirit of partnership.

Table 1: Tape recordings referred to in this thesis

<table>
<thead>
<tr>
<th>Stage</th>
<th>Activity</th>
<th>Code name</th>
<th>Use made by Research Group</th>
<th>Use in this thesis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Second - fourth stages</td>
<td>Sessions</td>
<td>S 1 – S 10</td>
<td>Not used.</td>
<td>Overviewed, and sections transcribed¹ for analysis.</td>
</tr>
<tr>
<td>Third stage</td>
<td>Visits</td>
<td>V 1 – V 6</td>
<td>Used for own writing.</td>
<td>Transcribed for analysis.</td>
</tr>
<tr>
<td>Third stage</td>
<td>Visits</td>
<td>Videos 1 – 6</td>
<td>Used for Finding Out book.</td>
<td>Back up to audio, and small sections transcribed in detail.</td>
</tr>
<tr>
<td>Sixth stage</td>
<td>Discussion</td>
<td>D 1 – D 9</td>
<td>Used to prepare presentations.</td>
<td>Transcribed for content.</td>
</tr>
</tbody>
</table>

¹ For details of transcription methods, the reader is referred to Appendices A and B, and discussion in Chapter 2.4.
Chapter 1
What does it mean to have a ‘learning difficulty’ at the turn of the millennium?

1.1 Starting point

The words ‘learning difficulty’ were given to us by other people – by those people who diagnosed us. We know we’ve got this problem, seeing, speaking, understanding – but it doesn’t mean we have to have this label on our forehead. I feel like screaming, because people laugh.

(Minutes of Self-Advocacy Research Group meeting: January 15th 1997)

This thesis is about talk and interaction. It follows the work of people who defined themselves as self-advocates (see 1.6) and who put together the above statement. They were all people who had been labelled as having a learning difficulty, a label which, as will be seen, they rejected. They pursued their interest in this through a research project called Finding Out, which has been outlined in the preface. The purpose of this thesis is to explore how members with the label of learning difficulty achieved through talk the business of being researchers. I am interested in talk precisely because it is an important way to ‘enact social actions’ (Pomerantz and Fehr 1997: 65), and this particular social achievement was one that constituted important challenges to discourses about Learning Difficulty. Theoretical and methodological perspectives on talk will be explored in Chapter 2, while Chapters 3 – 9 are analytic chapters, presenting data. I will return to the aims of this study at the end of the current chapter, as those aims emerged from shifts in my own interests and thinking.

In the meantime, this first chapter provides an introduction to the issues faced by Research Group members, and asks: ‘What is the nature of the social problem that they face?’ In order to frame that problem, and to start to position the current work within that frame, section 1.2 will raise some epistemological issues about the basis of our claims to know things about the lives of people with ‘learning difficulties’. These questions relate to the history of this research project, and so to some extent are autobiographical, but they also relate in a more theoretical sense to the ethical issues central to the whole endeavour.
This first chapter will go on to look at the social problem from the point of view of Research Group members, in their own terms. Set beside their formulation of the issues is an exploration of the literature relating to those areas of Learning Difficulty which concerned them: labelling (1.3), being a service user (1.4), and competence (1.5). The following two sections (1.6 and 1.7) will then look at how they, and others in similar positions, have started to develop solutions to their own problems, by developing self-advocacy and doing research. The chapter concludes (1.8) with a formulation of the research questions to be addressed in this thesis.

Those who come to this thesis from a disability perspective will find much in this chapter familiar territory, although a novel perspective is added by seeing the issues through the eyes of those whom they concern. It is thus a reflection of, and an attempt to further, the participatory aims of the thesis as a whole. For those interested in talk as social action, this chapter functions as an introduction to an area of social life, and the problems and issues that are the motive for undertaking the analysis presented in this thesis.

1.2 Ethical questions

1.2.1 Social oppression

Underlying this research is the position that the lives of people with 'learning difficulties' are shaped by society in ways that constitute oppression. By contrast with previous formulations of disability, which constructed disabled people as individual victims of their impairments, this work follows Oliver's (1990: 1) 'social oppression theory', in which disability is seen to be produced by society. There are some important themes here. This notion of oppression does not necessarily imply active hostility, but can encompass both witting and unwitting, overt and covert actions. The locus for responding to impairment shifts from ameliorating the negative consequences for individuals to changing the way society as a whole is organised, and the way in which it relates to disabled people. Finally, and importantly for this thesis,
Chapter 1: What does it mean to have a 'learning difficulty'? it is also about identity; social oppression theory provides a framework for disabled people to think about themselves in relation to their community.

The academic literature about Learning Difficulty (Williams 1989; Walmsley 1994; Swain, Gillman and Heyman 1999) also suggests that the situation of people with 'learning difficulties' can be best understood from the point of view of social oppression. However, such professional discourses (Foucault 1980) constitute a privileged knowledge about a group of people, from which they themselves are almost universally excluded. In common with Nunkoosing (2000), this thesis aims to contribute towards reformulating that privileged position, and to allow the knowledge-making of Research Group members to be heard.

This is not value neutral research. In common with others in the tradition of critical discourse analysis (Fairclough 1995; Van Dijk 2001), I start from the position that I am on the side of a particular group of people, in this case, people who have been labelled as having a learning difficulty, and in particular those who want to change and challenge the status quo. This project follows disabled researchers themselves (Barnes and Mercer 1997; Oliver 1992, 1997), in proposing that:

Disability research should not be seen as a set of technical, objective procedures carried out by experts but part of the struggle by disabled people to challenge the oppression they currently experience in their daily lives. (Oliver 1992: 102)

My concern is not to prove, by some objective standard, whether or not research done by self-advocates works. Disabled people have a right to do their own research, and this thesis aims to give wider currency to research done by people with the label of learning difficulties, and to explore some of the issues it raises.

1.2.2 Dilemmas about power

There are two ethical dilemmas that pervade this thesis. The first is my own role within the Research Group’s project. As explained in the preface, I supported the work that created the data for the present thesis, and thus I was deeply implicated in the whole process. The issues of power and ownership are central, and it is by
exploring these that I hope to come to a closer analytical understanding of how members did research. The contributions made by myself, and by other supporters, can be explored and problematised, as they constitute part of the data (see Chapters 7 and 8); this thesis is reflexive in its analysis.

The second ethical issue is more complex and leads to some paradoxes. As I have stated above, I propose to foreground the knowledge-making of Research Group members. Why, then, am I writing this thesis and not them? I realise that I am open to the accusation that I have simply taken away their views, and imposed on them my own theoretical framework, thus replicating or producing yet another form of privileged knowledge (Aspis 1997).

What are the alternatives? Some authors have expressed doubts about the feasibility of people with the label of learning difficulties taking part in their own theorising (Chappell 2000; Walmsley 1997). Both these authors speculate that the very nature of the impairment may make this theorising difficult, if not impossible. The present research has not solved these problems, but confronts such dilemmas throughout the analysis, since the central research aim is to expose and describe the process of research which is led by people with ‘learning difficulties’, in partnership with a non-disabled research supporter. This thesis explores in depth the central dilemma of being a researcher with the label of learning difficulty, and the main part of the thesis is about their activities, while Chapter 9 gives a fuller exposition of the work done by myself.

1.2.3 Team approach

Some features of our ‘team approach’ (as this project is characterised in Walmsley 2001: 198) should be mentioned here. Firstly, members of the Research Group have already analysed their data, and had their findings made public, in their own names (Palmer et al. 1999; Palmer and Turner 1998). The basis on which we embarked on the PhD work together was that they would now be turning the tables, and supporting me, as I had previously done for them. The fundamental principle of this thesis, then, is that of dialogue, creating knowledge together. This is more than just a concession to ethical niceties, as Kress (1996) observes:
Chapter 1: What does it mean to have a 'learning difficulty'?

Equity cannot be left as a matter of making concessions; it has to be seen as a matter of equality of cultural trade, where each social group is seen as having contributions of equal value to make to all other social groups in the larger social unit.

(Kress 1996: 18)

Secondly, it has to be recognised that creating an academic thesis can lead to yet another jargon-ridden discourse of exclusion. Therefore I am producing an accessible version of the thesis, which offers Research Group members and their colleagues the chance to gain access to some of the academic writing which has been published about their own lives.

Thirdly, the way in which I have worked through the analytical process, including this opening chapter, is to return to group members, and discuss the findings with them. This is a method recommended not only on ethical grounds, but also on the grounds of producing robust and valid findings (Fairclough 1992). The ethical questions raised here very briefly will be addressed throughout the thesis.

This chapter concerns itself with the question: ‘What is the nature of the social problem faced by members of the Research Group?’ I will address this question by considering their discussion of their own lives. In the sections that follow, the views of Research Group members will be presented first, allowing them to frame their own issues. All unattributed quotations are from a tape-recorded group discussion held in November 1999, during the sixth stage (see Preface), after the fieldwork. Four different individuals took part in this discussion, with four different lives, aspirations and viewpoints. Their theorising is supplemented by views of other people with ‘learning difficulties’, from the small but growing literature published by them. Following each of these sections, these same issues are explored in the academic and professional literature, through the eyes of Research Group members, in order to bring it to their attention and enable them subsequently to engage with it.
1.3 Labelling

1.3.1 Views of members: rejection of labelling

It might be expected that the identification of any social problem must start with the identification of people who have some common characteristic, and so can be considered together as a group. In this case, however, the very constitution of that group is in question, and one dominant aspect of the social problem is the gulf between how members perceive themselves and how society groups them together as people with 'learning difficulties'.

This study started with the issue of labelling. This was the term they used to present their problem, as the opening quotation of the thesis illustrated. They perceived that others viewed them as a group, contingent on their label. However, as one member put it, this name does not express the way she feels about herself:

Member: I don't feel I am suffering with a 'learning difficulty', I'm actually like yourself, normal as other people.

Although rejection of labelling was universal amongst Research Group members, their arguments about labelling represented quite a few different logical positions. For instance, one member commented that: ‘you've got different degrees of learning difficulty, that's the thing’. Although someone may reject the idea of being within a particular labelled group, he or she may still accept that such a label is rightly assigned to others. Another member acknowledged that such a thing as ‘learning difficulty’ does exist, but claimed that he had overcome it. Other members argued that everyone has a ‘learning difficulty’ of some sort, and that their own position was no different from that of others in society, since: ‘everyone who is alive has a learning difficulty’.

Interestingly, their theorising about labelling did not affect their ability to refer to themselves as self-advocates, thus identifying as members of the social movement constituted by people with ‘learning difficulties’. The relationship between identity and self-advocacy is returned to below (1.6), explored in Chapter 4, and discussed in 10.3.3, and 10.4.2. Therefore the rejection of the label ‘learning difficulty’ is not quite
so simple as it first appears, since any identity category gains relevance and will be foregrounded only in certain contexts. Early on in their work, members realised that they each held different positions about labelling, and this is what fuelled the research project in the first place. Their first research question concerned labelling, (see Appendix E), and is explored fully in Chapter 9.

Whatever the individual differences in emphasis, it is fair to say that all the Research Group members, and all the people they talked to, felt that labelling was problematic. It reduced their right to individuality as people first, and it had material consequences for their lives. In that sense, they were in line with definitions proposed within the social model of disability (French 1994: 9-14). They did not perceive their problem to be one of individual impairment (a direct result of having a 'learning difficulty'), but they described it in terms of the reactions of others in society. As Aspis points out:

How we understand the personal experiences of our lives depends on how we view our disadvantage in society and what action is needed in order to fight back and seek justice.  
(Aspis 2000: 68)

1.3.2 Medical labelling

The academic literature on labelling is vast, and this section will just sample some of the main themes. The power to categorise people with the label of learning difficulties has, through much of the twentieth century, been invested in the medical profession (Harris 1995; Rioux and Bach 1994). As Rodgers (1996: 25) writes: 'people with learning difficulties have become the objects of both the discourse and practice of the profession of medicine.'

Assigning learning difficulty to the practice of medicine can be linked historically with the rise of capitalism (Walmsley 1994: 151) and the perceived need to purge society of those who were 'unfit'. There was a related rise of discourses relating to eugenics (Fletcher 2001), which considered learning difficulty to be an inherited and therefore irradicable condition. The medical profession still has an enormous influence on discourses determining the lives of people so labelled. As Rioux and Bach (1994) argue, a medical model is not just about medical practices, but is about locating the problem within individual pathology. The same person can be seen as a
pathological case when viewed through medical eyes, but as an interesting human being when viewed through the eyes of a friend. Goode (1984: 231) described different views of one human being, and concluded that identity was socially produced, and ‘emerges out of a concrete and particular social situation’. More recently, Danforth (2000) and Peter (2000) discuss the objectification caused by written records being held on a person.

The concept of ‘learning difficulty’ is naturalised within the discipline of medicine, as an indisputable fact, and practitioners are aghast when this is challenged. One can still come across texts (Reid 1997) which echo the fears of Gordon (1980: 216), who complained that: ‘purging the instruments that measure society’s standards amounts to picking away at the mortar that holds it together’.

The implications of a medical diagnosis are considered by Gillman, Heyman and Swain (2000), who liken it to a ‘thin description’, a description which misses important and individual aspects of a human being. This thinness has particular implications, as these authors recognise, for people diagnosed as having a ‘learning difficulty’. While a physical illness or condition can be explained by causal agents outside the self, Gillman et al. (2000: 405) claim that ‘disabled identities for people with learning difficulties remain largely “embodied” and within the definitional control of professionals.’

1.3.3 The labelling debate

The notion that a person’s sense of identity can be affected by labels is rooted in a very extensive literature. Gove (1980) traced some of the debates about labelling back through the earlier part of the century; in the 1930s it was already being argued that: ‘the person becomes the thing he is described as being’. Goffman (1963) linked this argument with his concerns about self-presentation, arguing that a ‘flawed identity’ results from the stigma of being assigned to a particular group. He then went on to examine the problems in interaction that this stigma brings for the individual. The notion of ‘stigma’, as we shall see, is still alive today.
Chapter 1: What does it mean to have a ‘learning difficulty’?

The American debate about labelling in the 1960s and 1970s sprang from these roots, but was mostly concerned with labelling in an educational context. Was the label something that pointed to a real entity — that is, the retarded intelligence of particular people? Alternatively, was it something that adhered to them, and blighted their life by its very existence? This debate had a social context in the worries about intelligence testing, and the cultural bias inherent in the tests, which resulted in certain ethnic groups of students being labelled as ‘retarded’ and the self-fulfilling prophecy of under-achievement. Moreover, an individual may occupy this status in some social situations but not in others, as noted by Mercer (1973: 31): ‘he may change his role by changing his social group.’ It was quite arbitrary that the construct of intelligence was used to describe and group people in the twentieth century.

Similarly, in the field of criminality, Becker (discussed in Gove 1980) had argued ardently that deviance is a construct produced by the interaction between a person who commits a criminal act and those who respond to it. It is a societal construct. Theorists such as Becker felt it was possible to test out the labelling theory, and compare it with other explanatory devices by scientific means and this created a battleground, where labelling theorists confronted clinicians (see for instance Gordon 1980).

1.3.4 Changing labels and denial

Until the 1980s, a general failing in the literature was that the views of the labelled person him/herself were seldom taken into account (Gove 1980). He or she was only ever seen as an object of enquiry, not as a human being with a voice. The following two decades, however, saw a greater concern for hearing the voices of people with ‘learning difficulties’ themselves.

In 1994, Sutcliffe and Simons reported that the majority of people they spoke with in UK self-advocacy groups (see 1.6 below), said that if they had to be called by any group name, they would prefer the term ‘learning difficulties’. Almost simultaneously, the UK Department of Health (1991 NHS and Community Care Act) decided that the official terminology would be ‘learning disability’, and disabled activists in some
quarters welcomed this, since it allied people thus labelled with the wider disability movement. This tension between two subtly different names again provided fuel for a debate about swapping one label for another, with the people themselves as pawns (although increasingly vocal pawns) in the games played by professionals, academics and policy makers. Some of this tension is reflected in the data analysed in this thesis (see Chapter 9, extract 9:5). The twentieth century saw some dramatic shifts in terminology, and Stockholder (1994) questions whether the continual shifting from one name to another has any value, while others (Eayrs, Ellis and Jones 1993) argue that it does, since a new name can alert the public to new meanings.

None of this challenges the existence of the category 'learning difficulty'. Ironically, in one of the first research projects to engage with people who had been institutionalised Edgerton (1965) argued against what his research participants told him, and concluded that there was a concerted attempt on the part of people with 'mild mental retardation' to pass as 'normal' and to deny their true identity. Underlying Edgerton’s argument is the assumption that a true identity, such as 'mental retardation', has a reality. Therefore the statements of people who claimed that they were wrongly placed in an institution were simply self-deceptive attempts to pass as 'normal'. A debate about people’s awareness of their own assigned label has recently re-emerged, but a discussion of this will be left until Section 1.6.3, since the issues arise from the social model of disability, and disability pride issues.

Why do professionals, as Race (1995: 24) puts it, feel a ‘continuing urge […] to classify and categorise’? Race suggests that this is related to the need to plan and provide services. As service provision was a major theme for Research Group members, I will return now to their views about being service users, before considering how this is further reflected in the literature.
1.4 Being a service user

1.4.1 Views of members: being controlled by others

The problem for Research Group members, is not just one about name-calling. Labelling can have a direct effect on other important aspects of social life. For most of them, categorisation as people with 'learning difficulties' means living the life of a service user (see also People First 1989), and this is central to their social problem.

The four people who took part in the discussion in November 1999 each had different experiences of being a service user, but their views were very similar. What they most disliked was lack of privacy, the feeling that they were continually being watched, and indeed controlled by those who are supposed to support them. One member described how he had recently moved into a flat of his own, within a supported living scheme, and had some additional support services, consisting of people who came into his home to help him at regular intervals. His problem had been lack of space. This move was supposed to entail a degree of autonomy and space for his own decisions. He described the situation when he came home from the day centre:

Member: Sometimes I make a cup of tea and think to myself what shall I have on now – shall I have the record player or shall I have the television on? I say to myself, I'd like the television on, and I am doing well.

For most of us, this return to our own private space after a day at work is a familiar scene. We take for granted our right to decide on simple things like tea and television, but for this group member, these decisions had for years to be weighed against the needs and wishes of the other 16 people with whom he had lived. For him, therefore, they assume particular significance. However, his supporters were arriving at his home too early, which meant they were already there when he came home. While he was able to articulate, and solve, this issue, it reflects what is the case for many people with 'learning difficulties': they are continually having to shape their lives to the needs and expectations of others.
Chapter 1: What does it mean to have a 'learning difficulty'?

The concept of control often features in people's own accounts. In recalling life in a long-stay institution, the Hortham Memories Group (1992) spoke of the way residents were treated:

Sometimes they stopped your privileges - that meant no money all week. Or they put you in straitjackets, or you got locked up in a punishment room, in the dark.

(Hortham Memories Group: 12)

In another published account, Andrews reports that work within such hospitals was also treated as a kind of punishment:

I don't know why we had to do it - I think it was just to punish us, because if you did anything wrong, you had to do it even harder.

(Andrews and Rolph 2000: 36)

Even in the community, people with 'learning difficulties' are controlled by others. One group member was angry about the way in which her every movement was watched and monitored by staff members in her residential home. As she said, 'I would rather do it my way and get them off my back'. They feel that their lives do not entirely belong to them - they are continually being expected to achieve, to learn and to perform correctly, and the staff who are supposed to support them in this lifelong endeavour are in fact controlling the game. There is a notion that being human is associated with having certain rights, such as the right to self-determination. These rights are enshrined in law, both at national level through Human Rights Acts, and through international human rights instruments, such as the UN Standard Rules (Lindqvist 1998). As Rioux et al. (1997: 207) argue, 'people, communities and societies hold the principle of self-determination as one of their most cherished values'. However, it would appear that people with the label of learning difficulty in the UK are having that principle routinely denied. In addition to the human, interactional controls, there are structural controls imposed on service users, such as geographical restriction, since a service user in effect belongs to a certain local authority which pays for the provision:

Member: I'm trying to move from one part of the country to another part of the country. There seems to be so much red tape in trying to move - it pressurises you.
1.4.2 Denial of rights

The social problems that these people are describing amount to being denied full rights as autonomous citizens. However, in critiquing their position in the service structure, they are not denying their need for support. As they say, everyone needs some sort of support. This is reflected by the writing of others in similar positions:

What does equal really mean? It doesn’t mean that we’re all the same. If we don’t recognise that, then including people with learning difficulties is doomed to failure.

(Downer, in Atkinson et al. 2000: 23)

What they want is a system which is flexible enough to recognise individual needs. One person said his needs did not figure highly enough to be given any form of support, although he knew he needed it. He put it this way:

Member: I say, I have got learning difficulties, and I do need some support, but I don’t need to be heavily burdened with support.

The system either classifies you as in the group, and provides an over-protective, controlling culture of services, or classifies you as out of the group, and gives you nothing.

What would be a better way of providing the support that people need? What all members agreed on was the need for backup when needed, which encourages people to take responsibility and solve their own problems. One member picked up the word ‘cared for’, and explained that people wanted to be ‘cared about’ and not ‘cared for’, as the latter implies they have the status of children. Further, this support should not need to be contingent on being labelled as someone with a learning difficulty. One of the group members, at an earlier date, discussed this issue in the following terms:

Member: Just because I need help to cross a road, I shouldn’t have to be called a ‘road crosser’.

(Research Group minutes: 12/10/97)

Everyone has individual needs for different kinds of support. While members have no objections to those needs being recognised and met, they do not want any particular
need to define their whole identity and humanity. They want full rights as individual human beings, and members of society.

1.4.3 The culture of services

The idea that people need services to support their lives only started to gain currency relatively recently. As Walmsley (1999) points out, Learning Disability services came into being with the aim of supporting better those families who had always cared for their disabled son or daughter, and the first occupation centre was opened in 1946 following campaigns by parents’ groups. In the early part of this century, community care was synonymous with family care, and the family was seen as a safe haven. The very idea of community was associated with danger, both dangers to people with ‘learning difficulties’, and the dangers they themselves posed to society. As Walmsley suggests, there are two basic impulses underpinning both institutionalisation and care in the community. These are the twin aims of care and control.

Much of the research with which Research Group members will already have had contact is concerned with practical issues about services, and their impact on the lives of people with ‘learning difficulties’ themselves. This kind of research, with which the present author has been closely connected, tends to start from an assumption that services exist, and that by working together and listening closely to what people say, we can make them better (Williams and Robinson 2000a). Much of the work at the research centre, where the present author works, has had this kind of practical focus; in particular it has aimed to consider aspects of general provision or legislation, in order to see how well it serves people with ‘learning difficulties’ and their families. Practical ways for people to gain more control over their own lives have been given priority, and so in general this work is welcomed by those whom it concerns. For instance, research by Townsley and Macadams (1996) investigated how people with the label of learning difficulties can take part in staff selection, and thus have control over who gives them support. Because this kind of work involves people with ‘learning difficulties’ closely, and is presented in accessible versions (Townsley 1999), it is easy to assume that it fits within the mode that they themselves want. It must be remembered, however, that much of this research is based on assumptions about the
existence of service provision and support, and aims simply to increase autonomy and control within that paradigm.

The label of ‘learning difficulty’ does bring with it a life that is set apart from others, and typical social roles which most adults can enjoy within our community are effectively closed to those who are so labelled. Todd and Shearn (1997), for instance, list marriage, employment, and personal relationships as being absent in the lives of most people with ‘learning difficulties’, and comment that ‘people with learning disabilities seem to occupy a marginal social space typically occupied by the sociological form of strangers’ (Todd and Shearn 1997: 343). Dowson (1991) claims that if the lives of people with ‘learning difficulties’ were measured against standards non-disabled people would expect for themselves, then it would be clear that we have still failed miserably. He claims that ‘the services industry long ago annexed almost all aspects of the lives of people with learning difficulties’ (Dowson 1991: 22).

1.5 Competence

1.5.1 Views of members: skills

Webb (1999) described the lives of people with ‘learning difficulties’ with whom she worked as being dominated by professionals who expected them to be ‘good’ in order to achieve privileges. Being good, in this sense, is about being a competent member of society, and the notion of competence is extremely important to this thesis, since doing research could be characterised as a profoundly competent way of acting. The notion of competence in discussion of Learning Difficulty, however, mostly refers to generalised skills in managing everyday life (Simpson 1995). The social problem faced by members is about their relationship with the rest of society, and this relationship is almost by definition one in which they are the less competent social members, who have to acquire skills to achieve standards set by others.

First, I will turn to what Research Group members had to say about this issue. Both in the discussion quoted here, and elsewhere (Palmer et al. 1999) they have continually focused on their identities in terms of skills acquisition. Achievement is very closely
tied in with the view of others, the way in which they come across to other people.
Achievement has been a way of proving one's very worth and humanity, especially when leaving a long-stay institution, as others have also pointed out:

They think when you've been in them sort of places you need someone to look after you but if we can manage on our own and come out in the community... well they'll realise what we've been through. (Andrews and Rolph 2000: 42)

Taken to the extreme, members see learning and achievement as a way of working their way out of the category of 'learning difficulty':

Member: They don't see me as a person with learning difficulties, they see me as a normal individual, who's doing very well for himself. I don't see myself as having a learning disability, because I think I've overcome that. (Session D 4)

In many aspects of their lives, the student role is paramount. The day activities on offer to most people with 'learning difficulties' are construed as training (in some day centres, the attendees are actually called students), and opportunities to attend further and adult education are sought after and attained by many. One member of the original Research Group did complain about a lifetime of training, and the unreality of being prepared for work, saying: 'What did I want to spend all my life training for, just to get a job cleaning toilets?' However most group members appreciate the opportunities given by skills, as does Souza (1997), who recounts her positive experiences within mainstream education, by contrast with her brief experience of special education, which was marked by low expectations. Instead of moving them away from mainstream opportunities in society, education can give people a commonality with other adult learners.

Throughout the current project, members talked about acquiring competence as part of the solution, rather than part of the problem, and indeed were continually encouraging others to do the same. As one of the Research Group members commented when discussing the data:

Member: It was good because he was trying to solve that for himself. (Session D 5)
1.5.2 Competence and normalisation

It is in this area of skills and competence that there is perhaps one of the biggest divides between the voices of people with ‘learning difficulties’ and what is discussed in the academic literature. Is the process of learning to be construed as an opportunity for people, or as part of their oppression? This is a central issue for the current project. There have been some strong arguments about the issues of competence in Learning Disability, and the effects this has on people’s lives. Simpson (1995) for instance, argues that every aspect of the life of a person with ‘learning difficulty’ is involved with competence, and professional scrutiny, and Nirje (1976: 368) noticed that: ‘almost every situation for the mentally retarded has a pedagogical significance’.

In order to understand some of the concerns about competence, it is necessary to consider the model of normalisation, which has underpinned service provision in the UK and also in other parts of Europe and in the USA, in the latter part of the twentieth century. As Chappell (1997) describes it, normalisation was the mantra of the 1970s and 1980s. Originating in part from the Scandinavian model (Nirje 1969) and in part from North-American interpretations (Wofensberger 1972), normalisation was the theory that supported the move from institutional care to community care. Briefly, it is about achieving socially valued situations, contexts and opportunities for people with ‘learning difficulties’. It is, as Chappell (1997: 47) puts it, about ‘a vision of high quality services creating a high quality life-style’.

From the point of view of many people with the label of learning difficulties, normalisation did represent considerable liberation, since it freed them from institutional care. Documentation by people themselves about what this has meant for their lives must not be forgotten (Hortham Memories Group 1992; Mental Health Media 2001). However, normalisation is now systematically being rejected in the literature.

Normalisation was always a professional model, and came with a baggage of jargon-ridden concepts and tools (such as the programme evaluation tool PASSING: see Wolfensberger and Thomas 1983) which were intended for service providers rather than service users. Despite the conspicuous lack of accessibility of normalisation,
some authors now bemoan the fact that people with 'learning difficulties' are still trapped within normalisation thinking. Walmsley (1997: 65) for instance, states that: ‘most people with learning difficulties have not yet to my knowledge repudiated normalisation’. The kind of discussion held by the present Research Group about repudiating labels, and about gaining skills, is characterised by many as normalisation thinking, even though the model itself was never explained to the people to whom it was applied.

What is the link between competence and normalisation? Instead of finding your own place in society, some interpretations of normalisation can imply that people have to fit into dominant social norms. If the difference which singles out a particular group of people is the difference due to lack of competence, then the onus seems to be on them and their service providers to increase those levels of social competence until they most nearly match the social contexts to which they should aspire. Thus normalisation can be described as a model which aims to fit the individual into society, instead of society to the individual. Simpson (1999) notes the dilemma for people with 'learning difficulties':

People with learning difficulties must demonstrate their competence prior to being granted autonomy [...] Competence is not liberation, although it may form part of it for some individuals.

(Simpson 1999: 154-155)

Normalisation is thus linked with educational thinking, and also has much in common with professionally dominated, medical models. Brechin and Swain (1989: 45) claim that both models create 'the professional in a world of exclusive and privileged knowledge.' Being a person with 'learning difficulties' has been seen as synonymous with being unreliable and incompetent. Accounts told by others, in particular professionals and carers, are believed to a far greater extent, as Walmsley (1996) has pointed out. Researchers have considered it necessary to justify why they would want to listen directly to people with 'learning difficulties', and to treat them as reliable witnesses (Harding and Beresford 1996; Ward and Simons 1998), particularly about personal, family issues (Mitchell 1997).

The premise of incompetence underlies most of the services that are there to support people, as 'service users' embark on a lifetime of undergoing what are seen as
educational assessment procedures (Williams and Robinson 2000b). Breaking out of this cycle cannot be done by simply proving yourself more competent. This may be an individual answer for some, but it cannot, by definition, be an answer at the socio-political level, since it leaves the majority of people with ‘learning difficulties’ still in the trap of incompetence, spending a lifetime trying to jump through the hoops set by society.

1.6 Self-advocacy and the social model of disability

1.6.1 Members taking power into their own hands

What opportunities do Research Group members then see for autonomy and power, both at an individual and at a collective level? Through the 1980s and 1990s, some members of the Research Group and their colleagues took action to form a social movement of their own. This is known as the self-advocacy movement, and includes People First groups. It is this movement in which the current project is embedded. In the self-advocacy movement, people do not only speak up about their own issues, but they can define those issues for themselves, and in the process can define themselves too:

It takes a lot of courage and strength to fight against people who have the power to define who you are.

(Souza 1997: 6)

Being a **self-advocate** for members is about power and control over their own lives. For instance, one member suggested that: ‘People First is […] also to do with other types of advocacy, and other types of projects set up by the organisation People First. We are responsible for all types of services being set up’ (D 6). People in the self-advocacy movement support each other, and help each other to find their own solutions:

Self-advocacy is about independent groups of people with disabilities working together for justice by helping each other take charge of their lives and fight discrimination.

(Nellis 1994: 1)

The nature of the solution, in some ways, defines the problem. The problem for people in the Research Group, as we have seen, is a social problem. It is about lives
that are not valued or respected within society and within service provision. However, through taking control of their own solutions, people with 'learning difficulties' enter the arena as competent social actors:

> We want to be seen as people who have something to offer and skills to share, rather than be seen as people with handicaps or limitations.
> (People First of Washington 1995, cited in Cone 1999: 309)

Self-advocacy can completely change the balance of power, by including people meaningfully within the debates concerning their own lives.

### 1.6.2 Professional and academic reflections on self-advocacy

In the discourse of professional knowledge about Learning Difficulty, 'self-advocacy' is a term that has received much attention since the late 1980s. One common-sense view would be that all ordinary members of society advocate for themselves, whenever they speak. Why, then, do we need to talk about 'self-advocacy' as a marked term? Is the term 'self-advocate' becoming yet another label, as Collins (2001) suggests?

Some authors (Goodley 2000; Danforth 2000) have considered these issues in the context of Foucault's concepts of power and knowledge (see 2.6), and in particular his reference to subjugated voices. Foucault (1980: 81-2) claims that: 'it is through the reappearance of this knowledge, of these local popular knowledges, these disqualified knowledges, that criticism performs its work.' The voices of people with 'learning difficulties' constitute an extreme form of disqualified knowledge, since the dominant social view is that the impairment itself is defined by a lack of ability to represent oneself. By using the term 'self-advocacy', we are marking the assumption that these are people who have not previously been able to advocate for themselves, as Goodley points out:

> The term self-advocacy has been applied to account for the self-determination of minority groups who have historically been denied a 'voice' [...] the self-determination of people with learning difficulties is emphasised and members of this labelled group are referred to as self-advocates.
> (Goodley 2000: 7)

'Self-advocacy' is a term of the oppressed, a political weapon, which people can grasp in order to make their own voices heard.
The UK movement started during the 1980s (Dybwad and Bersani 1996), and was at first supported by non-disabled partners such as CMH (Campaign for Mental Handicap, now Values Into Action) and MENCAP. The model for self-advocacy in this country drew largely on the movement already establishing itself in the US, and statements about this by self-advocates themselves are often included in academic publications (Sutcliffe and Simons 1994; Goodley 2000).

Currently, self-advocacy is a theme of prime importance throughout the White Paper Valuing People (Department of Health 2001). In addition to the personal, individual meanings of self-advocacy, there is a political need for self-advocacy to provide the context for what is often termed 'empowerment' (Ramcharan et al. 1997). If people can represent themselves, then they can be expected to be meaningful partners in government policy making. Additionally, self-advocacy is increasingly referred to as a social movement (Goodley 2000: 3). By making a parallel with the struggles of other minority groups, such as Black people or women, Goodley positions self-advocacy as a collective, political movement which belongs to people with the label of learning difficulties. Authors such as Goodley (1997) and Brechin (1999: 65) express the hope that the control exerted by self-advocates over their own affairs will result in an 'emancipatory politics of identity'. The term 'self-advocacy' has attained such prominence that it featured in an article in the Guardian (Mack 2001: 23). The author states that the most important element in this radical movement is the fact it re-positions people with 'learning difficulties' in the social hierarchy, which has always assumed that 'people with learning difficulties by definition cannot really think or speak for themselves'. The picture of Andrew Lee (self-advocate from London People First) on this same page of the Guardian article shows him in the context of a busy People First office, leaning forwards with one hand raised in front of him, and a positive, faraway expression on his face. The public portrayal and hopes for the self-advocacy movement have reached a new strength, and it is talked of as a new political force.

An important issue within this movement is that of the non-disabled supporter. Most self-advocates have had supporters to help them, and their role is discussed by many authors (Brechin and Swain 1989; Walmsley 2001). The involvement of non-
disabled people is contested in the disability movement generally (Branfield 1999; Duckett 1998), and is fraught with many contradictions and tensions (see Worrell 1987; Dowson and Whittaker 1993; Iles 1999; Mack 2001). Many authors have considered what makes good support. Goodley (1997) for instance, suggests that the key lies in underlying understandings of disability, while others maintain that no model is sufficient to guide the supporter and that the only solution is to maintain critical self-reflection and build theory through practice (Iles 1999). The skill of supporting people to take power is explored by Dowson (Whittaker 1991; Dowson 1997), and in Chapters 7 and 8 of the present thesis.

On the whole, the texts referred to in this section are more accessible than the rest of the literature. Many in the movement, for instance, are aware of the Guardian article, and even the Government White Paper Valuing People (Department of Health 2001) has an accessible version, which features on notice boards and discussion groups in People First organisations. However, there is a certain undeniable irony in professionals and academics once again rushing into print about a subject which, if it is to have any value at all, must belong to the self-advocates themselves. Although self-advocacy must be considered part of the solution, rather than part of the problem, there are still social problems within it, when it becomes marshalled for the purposes of powerful others.

1.6.3 The social model of disability

As mentioned in the opening paragraphs of this thesis, ideas about disability as a form of oppression pervade this thesis, not only in my thinking but also in that of Research Group members. The social model of disability (see Oliver 1990; French 1994), asserts that people are disabled by society, and not primarily by their individual impairments. However, the model as it stands has not been developed or owned by people with the label of learning difficulties. Although it provides a rationale to the social problems they describe, it raises two more important and problematic issues for them:

- The theory belongs to and originates from disabled people generally. The question must then be posed: ‘do we (people with ‘learning difficulties’) consider ourselves disabled?’
If self-advocates consider that they have their own individuality and their own movement, then they want to develop our own theories. Yet again, here is a group of people, disabled people, who are going to tell them what they ought to be thinking.

The wider disability rights movement emerged during the period 1980-2000. Documented in Campbell and Oliver (1996), this movement has been formed by disabled people themselves. They define themselves as disabled, not by their impairments, but by ‘physical and social barriers’ (Finkelstein and French 1993: 28). Associated with their use of the word is a new theory of disability, the social model of disability, which they own and which springs from their experiences (Oliver 1990, 1993). There is a whole set of key terms (‘disabled’, ‘impairment’, ‘social barriers’) used within the social model which are produced and defined by disabled people themselves. This is a strong and self-defining movement that has changed the way people think about disability.

The disability movement, however, was formed and owned almost exclusively by people with physical or sensory impairments (Campbell and Oliver 1996); as Chappell (1997) noted, at that time people with ‘learning difficulties’ still had very little foothold within the movement, and neither were their issues generally acknowledged (see also French 1999). One of the key issues for disabled activists within this tradition is the power of a name. Choosing and embracing your identity as ‘disabled’ has been likened to ‘coming out’ (Swain and Cameron 1999: 68), and many of these writers describe a feeling of pride in their identity (Caras 1994; Corbett 1991). Moreover, their adoption of the very term that oppressed them is significant, since the word has been re-defined through the social model of disability.

What does this mean for people with ‘learning difficulties’? Some authors, such as French (1999) have pointed out how important the social model of disability is for people with the label of learning difficulties, who face oppression which is primarily social and attitudinal. She claims that:

The social model of disability has done much to undermine the principle of normalisation. An important tenet of the social model is that disability resides within society, not within individuals. (French 1999: 85)
One of the most oppressive experiences for a disabled person is the assumption that they would want to make themselves different from how they are (Morris 1993). For instance, people who have impairments such as deafness sometimes now describe themselves as Deaf (with a capital D), signalling pride in their impairment. Being impaired is part of identity, and those who view themselves in this way treat as oppressive attempts to change that identity, for example by cochlear implants for people who are Deaf, by surgery for those with a physical impairment, or by genetic manipulation (Ward 2001).

It is from this perspective that disabled academics and activists look towards the field of Learning Difficulty. They see that their own struggle for equal rights depends on solidarity, which is based on foregrounding disabled identities (Corker and French 1999). Therefore, the logic goes, people first have to acknowledge that they have a 'learning difficulty', that they are in fact disabled (in the sense of being disabled by society), in order to undertake collective action and to achieve a strong political voice (Harris: 1995). Finlay and Lyons (1998) in fact set out to investigate the hypothesis that:

[…] collective action by any group which aims to improve conditions for that group requires that the group members actually identify with the group, and that this identity is salient.

(Finlay and Lyons 1998: 39)

They found, however, that people in the self-advocacy movement seldom evoked the concept of 'learning difficulty'. For them it had little salience. They concluded that this is not simply a feature of denial, but that the vast variation amongst people who have been labelled as having a learning difficulty will naturally preclude identification as a whole group.

These debates coincide with renewed interest in the literature about whether or not people who have been labelled as having a learning difficulty are aware of that label. Davies and Jenkins (1997) examined data from a three-year study of attitudes of young people with that label, which showed they were 'profoundly affected by experiences consequent upon their being categorised' (1997: 96) but were unaware of the discourse about their assigned category. This finding is based on data in which interviewees
were asked questions about whether or not they understood the term 'mental handicap'. Todd and Shearn (1997), moreover, argue that people who are leaving special schools are unaware of their identities. They show how the gatekeepers of this information, notably parents and carers, seek to minimise the effects of a 'toxic identity' by engaging in a conspiracy of silence and secrecy. In both these studies, the model of identity is a psychosocial one, which assumes that the individual self concept is unproblematically revealed from what the person says about him/herself. It is also assumed that others' expressed opinions (or lack of them) are profoundly influential on the person.

In contrast to the above studies, Rapley, Kiernan and Antaki (1998) present an analysis based upon the assumption that all people (including people with 'learning difficulties') work up their identities in specific, local contexts. Using some of their own data, and also re-analysing the data presented by Todd and Shearn (1997), Rapley et al. (1998: 807) were able to describe how interviewees could: 'avow or disavow such an identity according to the demands of the situation in which they find themselves'. In such an interview the researcher is often a professional, outside expert, and so a direct question such as: 'Do you have a learning difficulty/ mental handicap?' may be construed as a challenge, or a threat. Rapley et al. found that people with 'learning difficulties' could be quite subtle social actors (see 2.4.3), in managing this kind of talk.

In view of these findings, we must remain aware of the danger that the social model of disability may sometimes be served up to people with 'learning difficulties', with all its side issues such as pride in identity, as yet another discourse of power. Goodley (2001) argues that people with the label of learning difficulties have not embraced a collective identity, and feels that the social model of disability has not yet taken account of their issues. One of the Research Group members attended a conference entitled 'Doing Disability Research' in September 1997, which was led and almost exclusively attended by disabled academics and activists. It is vital to include people in such theory formation about their own lives. These recent debates will be very relevant to the current thesis, since the question of people's own attitude towards the label 'learning difficulty' was handled in an admirably subtle way by Research Group members themselves (Chapter 9). It was with the aim of constructing their own
knowledge that the Self-Advocacy Research Group was formed, during 1997, by four people with the label of learning difficulty.

1.7 Doing research

1.7.1 Research as a skilled activity

Becoming researchers was a way for the current Research Group to tackle their own social problems, and the power of their talk and interaction will be traced through the pages of this thesis. However, their tool (doing research) also held social barriers for them. Many authors question whether people with 'learning difficulties' are able to take their place in the community of researchers, since the very nature of their impairment might exclude them from the task (see for example Walmsley 1997; Stalker 1998; McClimens 1999). Sometimes authors speculate on whether people with 'learning difficulties' can only be active in certain constituent parts of research. For instance, the co-researchers with Mitchell (1997) only took part in the planning and discussion of issues: they did not do the interviewing (March et al. 1997). Stalker (1998) wonders whether doing analysis may be a step too far for most people with 'learning difficulties'. Although I would agree that research is a skilled activity, it should be emphasised here that this thesis is not about skills: it is about generally available conversational strategies, and the way these are used in a particular social context, to challenge societal expectations. The reader is referred to Chapter 2 for a fuller exploration of this methodology. Doing research is seen as an instance of social challenge, which has particular interest because of the constitutive nature of what is going on.

In the more general field of qualitative research, only a few authors have attempted to study interview data as talk, but there have been some important precedents. Suchman and Jordan (1990: 232) revealed how 'many of the interactional resources of ordinary conversation', such as repair or re-interpretation (see 2.5.2), are disallowed in survey interviews, and how this can cause what conversation analysts describe as interactional troubles (2.4.1). Silverman (1973), likewise examined interviews as discursive accomplishments to see how they were brought off (see 2.7.1
Chapter I: What does it mean to have a 'learning difficulty'?

for a fuller explanation), and noted the asymmetries between the interactional rights (2.7.1) of the interviewer and interviewee. The former has rights to ask the questions, to define what is a good answer, to set time limits and boundaries for the event, and importantly, not to reveal anything about him/herself during the talk.

Models of research interviewing have considerably changed in recent years, with new paradigms of qualitative analysis, such as grounded theory (Glaser and Strauss 1967). Both in order to produce rich data, and also in order to pursue value-based research, authors sometimes defend an interviewing stance which is far from neutral. For instance, Gluck and Patai (1991) explore some issues in feminist research, where very personal and intimate details might be revealed in an interview context. As King (1996) notes, the task of respondents in an interview is to work out what is expected of them in this context, and this will depend on how they perceive what the interviewer is doing. Respondents 'simultaneously and continuously monitor who they are in relation to the person questioning them', (Holstein and Gubrium 1997: 122). Instead of the interview being seen as a kind of telescope to view the social world, many authors (Miller and Glasner 1997; Baker 1997) now see it as an interactional event. It follows that interview questions can never be neutral. The force of a question during an interview (as during any encounter) is related to the local interaction. In order to do this kind of in-depth research, the interviewer must reveal who she is, in order to provide a supportive listening environment for the respondent to talk. Holstein and Gubrium (1997: 114) note, 'interview data are unavoidably collaborative'. As will be explored in this thesis, that collaboration is something that had to be worked up, and is at the heart of the identity work that was accomplished.

1.7.2 Emancipatory and participatory research

In the early 1990s a new and tremendously important revolution took place in disability research: disabled people themselves started to take control of the agenda. In 1992, a special issue of Disability, Handicap & Society was devoted to the new ideas of emancipatory research (see Oliver 1992). Fuelled by anger with traditional, oppressive research methods, which positioned the disabled person as a research object and a problem, the new ideas set disability research on its head. Emancipatory research is based on the social model of disability (1.6.3), and aims to identify social
barriers and to break them down. It is about challenge and change, and springs from the concerns of disabled people themselves, with the aim that research can be used as a tool for improving their lives. Essentially, this model is about control. Disabled people may or may not wish to do the research themselves, but the important point is that their own democratic organisations are able to both commission and fund the research (Lloyd et al. 1996). All researchers should be accountable to disabled people and their organisations.

In 1997 Oliver returned to his emancipatory project, and attempted to evaluate his own work against the criteria he had set. These are the six standards, which he felt should be achieved by emancipatory research:

1) A description of experience in the face of academics who abstract and distort the experiences of disabled people;
2) A redefinition of the problem of disability;
3) A challenge to the ideology and methodology of dominant research paradigms;
4) The development of a methodology and set of techniques commensurate with the emancipatory research paradigm;
5) A description of collective experience in the face of academics who are unaware or ignore the existence of the disability movement; and
6) A monitoring and evaluation of services that are established, controlled and operated by disabled people themselves.

(Oliver 1997: 20)

It is useful to bear in mind such criteria when analysing what occurred within the present project, and I return to them in the final chapter.

When we turn to research in which people with ‘learning difficulties’ have been involved, the word participatory rather than emancipatory is often used. Much of the literature contemplates the correct placement of this type of research (see Chappell 2000; Stalker 1998) within a larger field of methodologies. It is true that most research projects in this field have been initiated by non-disabled researchers, who have involved people with ‘learning difficulties’ in their work, as co-presenters (McClimens 1999) as co-researchers (Minkes et al. 1995; Mitchell 1997) or as consultants (Rodgers 1999). Participation in this sense can lead academics to consider disabled researchers as a group (see McClimens 1999: 221 ‘a group of learning disabled co-researchers or participants’; Ward and Simons 1998: 130 ‘co-researchers’, ‘people with learning difficulties’; Williams 1999: ‘disabled participant’, ‘the group’). There is an assumption here that anyone who has the label of learning difficulty has a right to
become involved in research (Stalker 1998), simply on the grounds of their group membership, but that they are essentially interchangeable and anonymous individuals.

The very language of involvement reflects the power of the (non-disabled) researcher as the actor, who does the involving. Swain (1995: 89) argued that participatory research can be ‘more to do with strengthening dominant ideologies and the illusion of change than real shifts of power’. Walmsley (2001) also points out that this type of research originally used models that had been developed by non-disabled people, such as service evaluation (Whittaker et al. 1991). Only recently have a few researchers with the label of learning difficulties come to be known by individual names, such as Aspis (1997), and this is because they have published in their own right. It is difficult for these researchers to have a career in research, as the academic paths to reach these positions are effectively closed to them. As McClimens (1999: 221) notes, they remain ‘outside the loop’.

However, even when the research could be said to be owned by people with ‘learning difficulties’, and to spring from their goals, there is an issue of support. At the least, most researchers with ‘learning difficulties’ have needed a working alliance with non-disabled allies, as Brechin and Swain were already describing in 1989. In the literature generally this is either seen as a watering-down of true ‘emancipatory research’, or as a step on the road towards emancipatory research (Zarb 1992). For these reasons, Walmsley (1997) has drawn attention to the under-researched role of the self-advocacy and research advisor, and Lloyd et al. (1996) also examine the intricate and problematic nature of the relationship between professional researcher and disabled participant. The work carried out by the advisor is of critical importance to many authors:

If people with learning difficulties need non-disabled allies in the research process in order to convey their experiences in a way which is acceptable to the research community and its gatekeepers, how can the integrity of their accounts be maintained?

(Chappell 2000: 41)

It must be recalled, however, that Oliver’s (1992) paper did not suggest that disabled people had to manage research projects entirely alone. What he emphasised was their control of the research agenda.
The present project (Williams 1999) is now itself an object of consideration in these debates, and Walmsley (2001) characterises it as a team approach, which put self-advocates in the driving seat in methodological terms, but ‘did not engage them in exploring and identifying appropriate avenues for change’ (Walmsley 2001: 197). It is my hope that the present work, and the data on which it is based, will both challenge and flesh out some of these assumptions. Unlike most academic writing in this area, this thesis returns to hard data on what actually happened (see 2.5), and aims to revisit issues of power and ownership by analysis of these data.

The present project is only one amongst a growing number of very different models, and as Mitchell (1997) observes:

> It is important not to raise up one particular level of involvement as a pinnacle. For many people full involvement in a research project may be liberating; for others it may be daunting, for others it may just be plain tedious.

(Mitchell 1997: 8)

This is still a developing field, and it is vital now that people with ‘learning difficulties’ are included within its theoretical development. Walmsley (2001) refers to it as inclusive research, a more easily understood term that does not make assumptions about its emancipatory status, hence my use of that term in this thesis when it is necessary to distinguish it as a genre. However, it must be emphasised that the Research Group members themselves simply referred to what they were doing as ‘research’. Some writers (for instance, Chappell 2000) have started to perceive the participatory paradigm as a new and different type of research with rules of its own. Goodley (2001) describes research by self-advocates which consists of individual and collective action, and he proposes that this type of research should be setting its own agenda, rather than aping old paradigms of academic research. It was precisely those insights that provided the impetus for the present thesis.
1.8 Aims of this study

As I have described, Research Group members set out to tackle the problem of labelling and the effect that it had on their lives. My own aims in setting out to support the Research Group were diffuse, and I was largely at the disposal of members, supporting them to achieve whatever it was they turned out to do. Through the course of my own work on this study, my aims have become more precise. My initial research questions were also to do with labelling, since I was interested to investigate how the category of learning difficulty was constructed in talk between self-advocates. However, in carrying out the work together with members, it became evident that their project challenged received social status. My aim thus became to examine in detail the ways in which talk-in-interaction works within inclusive research. If the social problem is that people with the label of learning difficulties do not have full membership rights, then the research question is:

- **How can people with the label of learning difficulties (and those who work with them) use talk within situations that have the potential to challenge that social oppression?**

As the site for their challenge was a research project, this thesis aims to describe the talk that went on during their Finding Out project, and the question becomes:

- **What exactly is it that we did? How can this particular Finding Out project shed light on what goes on within research carried out by self-advocates more generally?**

The methodological insights that underpin this shift in focus will form the subject of the next chapter.
Chapter 2
Tools for analysing talk

2.1 Chapter overview

The current chapter aims to position my methodology within the network of developing approaches to analysis of talk. Readers may come to this area with different backgrounds and expectations, and so the chapter also attempts to make sense of this type of analytic method in general, and to show why it might be worthwhile.

Section 2.2 starts with some comments about the stance taken towards talk, and some initial definitions, to position my methodology, which is then presented in summary in section 2.3. This provides a reference point for other parts of the chapter. Taking this model, I then explore and discuss the various parts of it, with reference to the theoretical literature. The approach I take is a ‘bottom up’ approach, starting with the talk that actually happened, and so approaches to producing and selecting data are discussed first (2.4). The following section (2.5) then deals with the methods I used for textual description, which draw heavily on a conversation analysis approach. However, this study is an ideological and socially committed one, that depends on a level of social criticism. The following section (2.6) therefore jumps to the top of my own model (see p.35), and considers how discourse can contribute towards social explanation. The problem for any analysis is how to fit these two levels together – how to get from texts to an insightful social explanation. Section 2.7 therefore explores the tools for moving from a textual to an explanatory level: interactional rights (2.7.1), the use of membership categorisation devices (2.7.2), the working up of identities (2.7.3) and interpretative repertoires (2.7.4). The final section, 2.8, re-visits the methodology for analysis that I have arrived at, and considers the fit between the participatory element of this project and the discourse analytic method. Throughout this chapter, I use extracts from the data for illustration, since the choice of any methodology must relate to the nature of the data and the research questions. These extracts are also intended to bring alive some of the issues and debates in analysis.
2.2 The analytic perspective adopted towards talk

Although communication is all around us, and to a large extent constitutes our lives, it is notoriously hard to define talk, discourse or communication. Van Dijk (1997) suggests, rather tautologically, that discourse is defined by the cross-discipline of discourse studies. We have to start somewhere, and Taylor (2001: 5) starts with a loose definition of discourse study as: ‘the close study of language in use’. I have chosen to use the term talk to refer to what goes on between people when they engage in communicative events. I do this for three reasons:

- Discourse can also refer to philosophies or bodies of ideas, and so has some ambiguity (McHoul and Grace 1993).
- ‘Talk’ aligns what I propose to do with the methodologists who want to study as closely as possible naturally occurring interactive data (see 2.4.1 below); because of the emphasis on talk in real situations of use, the term talk-in-interaction is also frequently found.
- The word ‘talk’ is simply shorter and easier to relate to those with whom I have been working, namely Research Group members.

This study takes a social constructionist view of talk, as opposed to a positivist view. Rather than study talk as a transparent window on some objective truth, I am interested in talk precisely because it has the power to construct afresh what is happening, on each occasion people communicate:

Social objects are not given ‘in the world’ but constructed, negotiated, reformed, fashioned and organised by human beings in their efforts to make sense of happenings in the world.

(Sarbin and Kitsuse 1994: 3)

This does not mean that each communicative event is totally fresh, and has nothing to do with any other such event. As communicators, we draw on resources of languages (systems of rules, vocabulary and speech sounds), as well as knowledge (bodies of ideas and information). Any single communicative event is a site to which speakers and listeners bring their own resources, and simultaneously re-create a new version of reality. Talk does not merely mirror actions, attitudes or events (Potter and Wetherell
Two more sets of terms are introduced here. Firstly, in common with Chouliarki and Fairclough (1999), I see talk as just one aspect of social life. Therefore the people who take part in talk, the speakers, are frequently referred to as members (Sacks: 1995), since they come to the interaction as members of society. The term ‘member’ is used in this general sense; where I refer to members of particular groups, I try to make this clear. Secondly, there is a set of terms which refer to talk, as it is used in interactions, as if it were a craft or a work skill. This seems particularly appropriate, since my aim is to describe the social object of research, as it was ‘talked into being’ (Heritage 1997: 161) by Research Group members. Like other analysts in this tradition (Antaki 1988; Edwards 1998) my interest is in uncovering patterns, which can be described as strategies or tools, which were available to members for the work they set out to do.

2.3 Overview of methodology

Instead of starting from the outer theoretical issues of ideology (see 2.6.1) and power and working in towards the detail of exposition, as proposed by van Dijk (2001), I have chosen the opposite route of working from the text first (transcription of recorded talk), and then extrapolating to wider issues of identity, discourse and power. Schegloff (1998: 416) recommends that a conversation analysis can lead on to ‘issues of cultural constructions, ideological formations…referred to the context in which they were produced’. This is what I have attempted to achieve.

The schema therefore starts at the bottom with the production and selection of data for analysis, while the following three sections follow Fairclough’s (1989; 1995) tripartite division into textual description (see 2.5), interpretation (see 2.7) and social explanation (see 2.6). The point of the schema is to clarify for the reader the various activities involved in analysis. The items outside the main circles, including the Research Group’s own analysis, are all input, which fed into the discourse analysis.
Schema for ANALYSIS

SOCIAL EXPLANATION

Mini conference

Elaboration

INTERPRETATION
Analytic tools:
- Interactional rights,
- Membership categorisation devices,
- Identities,
- Interpretative repertoires

Tapes of return visits to groups

TEXTUAL ANALYSIS

video extracts

transcripts

PRODUCING AND SELECTING DATA

Audio and video tapes from group’s interviews

Audio tapes of group’s own sessions

group’s own analysis

Tapes of GROUP discussion sessions
The diagram given on page 36 is an abstraction, and it is not intended to imply that these activities could or should happen in a linear order. Rather, like Fairclough, I found myself moving backward and forward between the analytical activities. In particular, the activities of Research Group members and myself were interrelated at many points and in multiple ways, and so arrows could be drawn to connect almost every part of the diagram with every other.

2.4 Producing and selecting data

2.4.1 Transcription

The first stage of analysis is to produce data, and it might be thought that was completed in the bottom two bubbles of my schema, when we made our tapes. The recording and preserving of these raw data (both audio and video tapes) is vital to the process. When Harvey Sacks (1995) started to discuss the possibility of examining how social life actually works, he turned towards naturally occurring data, in the form of tape-recorded episodes of talk. As Silverman (1998) points out in his discussion of Sacks’ work, what attracted Sacks to talk was the fact that it could be recorded, transcribed and studied. It was one of the few aspects of social life that was amenable to being preserved and re-examined. Sacks wrote (1984: 26-7): ‘We are trying to find the machinery. In order to do so, we have to get access to its products’. The data of other related disciplines, such as ethnography or anthropology, were simply not so revealing, depending as they did on field workers’ memory and retrospective note-taking, while theoretical linguists almost universally (Chomsky 1966) used invented examples of language to illustrate their points.

However, in order to work with the raw data of tape-recorded talk, some method of transcribing must be used. As Ochs (1979: 43) maintained: ‘transcriptions are the researchers’ data’. The level of detail included in the transcription is a vital part of the analysis, both reflecting and helping to formulate the analytic assumptions.

One of the first tasks for analysis, then, was to create a transcription system. Although I had roughly transcribed most of the material for the group’s own analysis, I wanted to obtain a level of detail which permitted me to observe how each turn (each time a
new speaker started speaking) was linked with preceding and subsequent ones, including overlaps and interruptions. Hesitations and pause lengths are also important, since all these could be indications of trouble in the progress of the interaction. Ten Have (1999: 116) refers to such troubles as mishearings or misunderstandings, and I use the term 'trouble' in that sense of interactional trouble. However, I was not interested in the idiosyncrasies of each person's speech style, and so some of the variation of individual speakers in terms of intonation, pace or clarity of pronunciation, is not included. The transcription system I arrived at is given in Appendix A, and was adapted from Jefferson (1979), drawing also on Atkinson and Heritage 1984; Schiffrin 1994). The following is a brief example to illustrate its use:

Extract 2:1 (V 3)

16. Angela: do you like going to a training centre every day or do you find it - or  
17. Harry: do you find it boring/ → Harry  
18. Harry: no I think Marland is in our area because ( ) cause I get the -  
19. Angela: no no what I'm saying to you do you like going every day five days a week†  
20. Harry: five days a week yeah/  
21. Angela: do you find it boring/  
22. Harry: no/ what I - well I LIKE going to work/

Explanation of symbols used in above extract

↑ upward intonation
→ gaze direction
- interruption
/ end of tone unit (usually indicated by drop in intonation)
CAPS segment of talk that is louder than surrounding talk
Underlined word: emphasis
(.) short pause

12. Line numbers are given to refer back to original full transcript.

In the text I will use the convention of referring to lines in extracts by simply citing the number.

One speaker here dislikes the idea of a training centre, while the other says he likes it. Without the transcript, this is perhaps all we would retain from this bit of talk. However, by being able to examine the detail of the talk, we learn far more than this. We learn, for instance, about how Angela herself constructs the object of 'training
centre' (17). Where Harry refers to his five-day attendance as 'work' (23), Angela constructs the centre as 'boring' (17) and repeats this word (22), the emphasis indicated by underlining. At 18-19 she interrupts Harry, (as indicated by the single dash), cutting short what he was starting to say, about his route to work, and by it she is enabled to force from him an admission that 'I LIKE going to work'.

Much more could be said, even about this short extract; however, just from these few comments, one can appreciate how transcription conventions are linked with analysis, since they reveal and mark out features that may turn out to be important. The attraction of studying the details of real talk is that they both reflect and constitute social realities. The social reality constructed by Harry in the above example is very different from that constructed by Angela, and by doing this bit of talk, they add to the possible meanings and stances about training centres. As Heritage (1997: 161) puts it: 'Social worlds are evoked and made actionable in and through talk'.

A further point about working from transcribed data is that the analyst is enabled to situate the talk in that particular occasion, as it unfolds. Antaki and Widdicombe (1998) refer to this as occasionedness:

A good part of the meaning of an utterance [...] is to be found in the occasion of its production – in the local state of affairs that was operative at that exact moment of interactional time.

(Antaki and Widdicombe 1998: 4)

This might not seem remarkable, until one considers that much analysis in social research (e.g. Williams and Robinson 2000a) proceeds by taking quotations, out of context, as illustrations of an argument. This point is spelt out in Potter and Wetherell (2001). These authors compare an attitudinal survey about racism with the kind of information gathered by a discourse analyst. In the former, it is assumed that a range of people can take up a range of attitudes, towards essentially the same object. As soon as one examines the talk in more detail, however, it is clear that each speaker is actually re-constructing the object through that particular bit of talk:

[...]different kinds of explanations assume different kinds of objects or supply the social world with varying objects.

(Potter and Wetherell 2001: 209)
The word **local** is often used to refer to this aspect of discourse analytic research. The analyst is not interested in talk as an exemplar of some world view or general philosophy of life, but in how this particular bit of talk was produced in this particular situation (see ten Have 1999; van Dijk 1997).

Within participatory work, transcribed talk is a concrete and accessible format for approaching what happened in the project. Instead of making abstract theoretical assumptions about inclusive research, we can continually return, both to the version of events in the transcriptions and the original tapes. This stance seemed to me to be entirely compatible with my ethical priority to move forward with the understandings of Research Group members themselves. As noted in 1.2.2, people with 'learning difficulties' all too often have their words taken away from them, and fitted into some grand theory. As Schegloff (1998) observes:

> What is needed is not readings in critical theory, but observations – noticings - about people's conduct in the world and the practices by which they are engendered and understood.  

(Schegloff 1998: 414)

### 2.4.2 Transcription of video fragments

When the Research Group conducted their visits, I agreed to make video recordings, so that they could afterwards look back and remember what had been said. Therefore the video recording was selective, since I was attempting to focus the camera on the person talking. I did on one occasion (Visit 6) try a fixed camera position, but found the resulting data much less revealing. My first use of this data in my own analysis was simply to clarify points in the transcription of audio data. I found that there were many occasions when something was clearer on video than on audio, because of many different clues, such as lip movements, facial expression and simply being able to see who was talking, which was a problem in transcribing the larger gatherings such as Visit 2.

Inspired by Heath (1997), Kendon (1983) and Goodwin (1984), I then became aware that there might be useful information in the video tapes which was not available from audio. My eventual method for transcription of video extracts (or fragments) is detailed in Appendix B, and in 2.5.2 below I discuss briefly how these
data were used for analysis. What I decided to do was to use the video material as a back-up to the audio recordings, when analysing particular extracts. This enabled me to reveal the detail in the interplay of events and actions that accompany speech.

In attempting to transfer the information on screen onto paper, I found I was able to notice three types of behaviour, which all needed continuous tracking: eye gaze, hand gestures, and facial expression. Occasionally also there were head movements. Sometimes these were discrete items, occurring at a particular point. But often a particular movement became static over the next few seconds – for example, a hand gesture that was then frozen and the hand kept in place. The level of detail required in transcription is very time-consuming, but, perhaps fortunately, the raw data I had available only lent themselves to interaction analysis when the interacting members were both visible on screen. Thus the sampling problem was eased.

In the following example, each line represents six seconds of talk, and the words are written along a time line, showing how they were spaced within this six seconds.

**Extract 2.2 (V 1)**

M: gaze→........................................→W........→J (+head tilt)........................................
Smile..............................................................................................................
2 hands open..........................................................folds hands..........................
    leans forward..........................................................................................


J: gaze→Mark..................................................../*glance→Mark..........................
Slight frown..................................................................................................
Arms folded................................................moves one hand/ folds again..............

I will return to this extract below (2.5.2) in discussing the methods used in video interaction analysis.
2.4.3 Selection of data for analysis

Finally, before moving to the methods for analysis of talk, I will say a word about how the extracts for analysis were selected. Ten Have (1999: 102) discusses an approach known as unmotivated looking. Many analysts (e.g. Schegloff 1996) maintain that it does not matter where one starts in the data; Sacks (1995) claimed that social order was so pervasive that there will always be something interesting to be found.

This may be true, if one’s goal is to describe conversation in general, but it was not entirely true for my data or purpose. The extracts I have analysed and presented throughout the thesis are chosen for a purpose, not randomly. In the main, they were chosen by recourse to the group’s own interests and concerns. For instance, in Chapter 9, I examined all the instances of responses to the first research question posed by the group, and then chose two extracts. They were the examples which seemed to give a purchase on the concepts that I had perceived the group to be interested in – namely the problem about reference of the label ‘learning difficulty’, and how people saw themselves.

2.5 Textual description

2.5.1 Making things strange

Prior to the 1960s, one of the driving forces in sociology was a positivist view of social life, in which research was seen as a neutral, value free tool to generate knowledge (Taylor 2001: 11), to label and categorise perceived experience (McHoul and Grace 1993). As Taylor points out, much social science proceeds to this day on the same basis. Even qualitative methods, such as grounded theory (Glaser and Strauss 1967; Pidgeon 1996) are fundamentally interested in categories, or themes, even though they may arise from the data. Indeed, categories and ordering underpinned the way in which the Research Group members approached their task of analysis, by looking back at the raw data (video tapes) and picking out the sections they felt were interesting, which then became the main themes for their analysis.
In the late 1960s, however, a fresh view was taken, with the emergence of ethnomethodology (Garfinkel 1967). Instead of using given categories from sociology to categorise social phenomena, Garfinkel aimed to turn his analytical gaze onto the way in which social orders themselves were created and maintained. Heritage (2001: 50) describes ethnomethodology as the study of how 'socially shared methods of practical reasoning are used to analyse, understand, and act in the common-sense world of everyday life'. Where previous ethnography had sought unknown cultures or primitive tribes for its focus of study (Whorf 1956), Garfinkel's work led the way to a realisation that the social activities all around us are also worthy of attention. Ethnomethodology represented an attempt to bring method to a field that is taken for granted, and to do that by standing back from the assumptions we ordinarily make, to examine them analytically.

Goffman both developed Garfinkel's insights, and made his own unique contribution, by turning his attention to the way in which ordinary interaction was patterned and achieved in face-to-face encounters, by reference to what he termed (Goffman 1983: 2) 'the interaction order'. Prior to Goffman, the domain of ordinary interaction was taken for granted, as if it 'did not need to be defined' (Kendon 1988) but for Goffman it was precisely these ordinary interactive practices that were at issue. Many of the insights that Goffman brought to this domain are now deeply embedded in the ways in which discourse analysts approach their task. For instance, much of his work is to do with self presentation and identity (see below 2.7.3), and he led the way in making analysts realise that these were not fixed, a-priori assumptions about people, but instead they are played out on the stage of human life (Goffman 1959). His analogy of social interaction as a performance, and related metaphors such as social actor, and audience, has had a pervasive influence on subsequent work.

Many theorists still return to the importance of this analytic stance. For instance Janks (1997: 331) urges us to 'read against the grain'; by simply re-iterating commonsense knowledge about a situation, an interaction or a text, one is not adding any analytic value. A short example might illustrate how important this approach is:
Extract 2:3 (V 2)

333. Dawn: Adrian wants to say something =
334. Adrian: = wa what I’d like to say(1) I agree on some of the um key issues on
what my fellow friend has said/ and I (.) was thinking myself if we can
335. help those who are disabled (. ) like help them to um - to reach out
336. and speak up for themselves ↑/
337. 338. Mark: yes yes/ (3)

One way of dealing with an extract like this would be to use it as an example of the
way people in self-advocacy groups are trying to support each other, and are aware of
the importance of speaking up. The researcher would then go through a larger corpus
of data, collected by visiting self-advocacy groups, and find other examples which also
handled the same theme. This forms the basis of a grounded approach to analysis.
However, at the end of it, we would still not have addressed the fundamental question:
‘how is it that members here are doing the business of “being self-advocates” ’? In the
grounded approach, however faithfully the analyst follows the members’ own concerns
and words, he or she is taking for granted the category of ‘self-advocacy’. It is only
when we make strange what is ordinarily taken for granted, that we can start to work
out what is going on in the talk.

For instance, in the above example, the analyst might notice the use of specific
vocabulary choices (‘disabled’, ‘reach out’, ‘speak up’), the use of the rhetorical device
of agreeing with a previous speaker (334) or the way in which people respond to each
other, with the ‘yes, yes’ (338). Could these strategies be part of what we mean by
self-advocacy talk? In approaching the task of analysis, then, I did not start by
assuming that these are people with ‘learning difficulties’ who are doing research. All
these things had to be worked up, and it is the analyst’s task to demonstrate how this
occurs. As Pomerantz and Fehr (1997: 65) explain, this represents ‘a shift away from
the search for causes of human conduct and towards the explication of how conduct is
produced and recognised as intelligible and sensible’.

People with ‘learning difficulties’ have frequently had research done about them,
starting from the assumption that they display deficits (specifically communicative
deficits); in the same manner, the communication of older people who have been
labelled ‘confused’ (Shakespeare 1998: 3) is also assumed to display deficits that are
attributable to their condition. As Schegloff (1992: 129) observed, the category can be used as a warrant to focus on details of conduct and: ‘what [is] found [is] then generally attributed to the license under which one found it’. Consequently, I wanted to throw out all prior assumptions, and to observe in detail what was happening. By the time of our discussion sessions (see Preface: sixth stage), I was clear that this approach was very important to what I was doing. I explained it to the group members, and Appendix F gives part of the handout I produced for our discussion sessions, which members subsequently used in their own presentation at our mini conference.

2.5.2 Conversation analytic approaches

The original aim of conversation analysis (CA), as developed first by Harvey Sacks and his associates in the 1960s, was to discover the way that social interaction works – the machinery of talk. To this end, conversation analysis starts and ends with text, and is value neutral. As ten Have (1999: 135) states, ‘the ultimate “results” of CA are a set of formulated “rules” or “principles”.’

In his early work, Sacks addressed himself to common problems of everyday interaction. These are not social problems, in the sense of large societal notions such as oppression or dominance, but they are mechanical problems that face us all when we want to do the ordinary things that keep social life going. Sacks, as Silverman (1998) put it, invented the study of conversation. In his first lecture, which is now published posthumously (Sacks 1995), he talked about the rules of conversational sequence, and used data from telephone calls to a suicide prevention centre, to start exploring the regularities that he observed. One of these, for instance, he formalised as the theme of paired actions (adjacency pairs), where one utterance creates a slot that is filled (in various ways) by a second action. Sacks’ approach, as ten Have explains, was to:

\[\ldots\] take what people are doing, that is, saying, not-saying, saying something in a particular manner, at a particular moment, etc., and try to find out the kind of problem for which this doing might be a solution.

(ten Have 1999: 15)
This is pure conversation analysis, exemplified by classic works (Sacks, Schegloff and Jefferson 1974; Schegloff 1968). The former explored a system to describe rules for turn taking in conversation. It is in this early work that some of the basic concepts originate, such as adjacency pairs, and the very fundamental notion of **sequential organisation** – that one thing is related to the unfolding sequence of events. This kind of work concerns itself with the rules that constitute conversation in general, and not with any particular context or purpose.

It might appear that pure conversation analysis holds no real attraction for my study, which is couched in a particular and important discursive achievement by a group of people, and is informed by a widespread social problem. My primary interest in this data was not to discover new rules about how language works. Is CA then irrelevant to my project? I found that it was not. Take, for instance, the following extract from our data:

**Extract 2:4 (V 4)**

524. Angela: what are you learning↑
525. Mark: do you get -
526. Jenny: [(........................ at school)]
527. Keith: [all to do with our work/ to do with our working placements/]
528. Jenny: at school. I went to (...) school and I didn’t [learn much] but I’ve learnt
529. Mark: [come back to you (WH)]
530. Jenny: I’ve learnt far more since↑/
531. Mark: right (WH)
532. Jenny: with Helen Tyne on a computer course/ and learnt far more since/
533. Mark: right come back to you/ WH → Keith
534. Jenny: cos I was kept down/
535. Keith: hand gesture with right hand, patting downwards, knee level
536. Keith: yeah on the workwright course with Helen Tyne on a Friday/ but
537. she’s off sick at the moment we’ve got somebody else in charge/
538. Mark: right
539. Keith: with us/
540. Mark: right do you get – do you get on with that other person↑
541. Keith: yes/
542. Mark: you do↓

Looking carefully at this extract, one can see how important turn organization is. The first question (Angela: ‘what are you learning↑’) appears to receive responses both from Jenny and Keith. One could say that Angela had created a slot for **self-selection** amongst a sub-group of the participants who had been talking about their college courses, and both Jenny and Keith try to take that slot. However, Jenny’s turns (526 and 528) sound like an interruption, certainly a self-selection. She interrupts
Mark at 526, and then comes back in at 528. Other members hear 528 as an interruption, since Mark (529) whispers to Keith: ‘right come back to you’. Jenny then finishes her turn and Keith immediately comes back in at 536. We know he was selected by Mark for this turn because of the previous procedural work Mark had done at 533. Mark not only accepts Keith’s turn as relevant (‘right’) but then (540) asks a follow-up question, thus confirming the interpretation that Keith was the chief respondent in this passage.

It is immediately apparent how many very useful observations can be made about this organisation. For instance, Mark and Angela both appear to have the rights to allocate turns, and moreover to judge whether those turns are relevant. It is in this way that they contribute to their status as interviewers – they are doing the conversational work of interviewers. Moreover, it is apparent that one needs to pay careful attention to the sequential context, the fluidity of the talk, in order to judge what turn-work members are doing. The intervention by Jenny (528) would not necessarily have been heard as an interruption, were it not for Mark’s subsequent remark. The sense of what is appropriate is built up, produced by the interaction (see Silverman 1998: 35). In the present case, we cannot assume in advance that members are doing an interview. This fact has to be achieved by their talk, and one important way in which this is done is by the turn structure itself.

In terms of sequence structure, it is also useful to note that the first pair of turns creates an adjacency pair, in which one turn provides a slot for the next. An elaboration of this basic structure is to provide a third part, and this is particularly useful if one is doing interviewing, since in the third part, the interviewer can acknowledge the interviewee’s response. Mark eventually gets to give his third part utterance at 538. One can now appreciate that Jenny (528) took the slot where he would have originally given this third part, and therefore this could be a strong reason for his move to sideline her contribution. As CA analysts observe, one event in a conversation is occasioned by another. There are internal links between what happens, and it is the analyst’s task to uncover these. Sequential positioning is a key concept in CA, as Heritage (2001: 52) explains: a current action, or turn at talk, can ‘project the relevance’ of a particular range of ‘next actions’. The following speaker can choose a preferred option, acknowledging and fitting in to previous turns. If a
dispreferred option is chosen, then as ten Have (1999: 120) observes, participants will have to account for that in some way.

Schegloff (1998) argues that conversation analysis must proceed by grounding the analyst’s observations in what is ‘demonstrably relevant to the members’:

For CA, it is the members’ world, the world of the particular members in a particular occasion, a world that is embodied and displayed in their conduct with one another, which is the grounds and the object of the entire enterprise.

(Schegloff 1998: 416)

Schegloff does not mean thereby to claim that members themselves talk in terms of turn allocation, adjacency pairs, self-selection, and so on. The analyst’s task is to show ‘that the parties are oriented to it in doing whatever they do’ (Schegloff 1999a: 570). In the above extract, I would argue that Mark is oriented to the business of allocating turns, and keeping order in the talk.

Therefore, several aspects of CA are attractive for this project. It provides a systematic way to study what is going on in the text, and some tools for starting to look at this in detail. The detailed looking, in itself, I find productive. Moreover, it is not a cold, mechanical type of analysis, but returns continually to what the members themselves were doing at the time, and their demonstrated understandings. This accords well with the project, not only because of the analytical gains it produces, but also because it feels comfortable to be continually returning to members’ own concerns. Ten Have’s (1999: 101-128) guide to doing CA was particularly useful in developing my own method. He recommends four basic stages in examining a text:

- **turn taking organisation**: the way in which members take turns or allocate turns to each other
- **sequence organisation**: the way in which utterances are linked – for instance, into adjacency pairs
- **repair organisation**: where members correct what they are saying, re-phrase, or help each other
- **organisation of turn construction**: for instance through preference organisation (see above).
I found it useful to follow this procedure, although it was hard to formally distinguish one stage and the next at times. For instance, it is often difficult to comment on sequence organisation without immediately going into the ways that turns are constructed. The presentation of analysis in this thesis is even more fluid, and brings together the themes and the main issues as they arose from the detail of turn and sequence structure. Nevertheless, I did find the discipline of separating out each phase of analysis useful, and I hope that the thesis reflects some of the rigour of CA.

2.5.3 Video interaction analysis

As mentioned above (2.4.2), there were two initial uses of the video data in this project, firstly for group members to return to the data and conduct their own analysis, and secondly to clarify any unclear passages when transcribing from audio. However, I then became aware that the video evidence could have an analytical purpose in its own right. Kendon (1983) for instance, claimed that gesturing could be a part of meaning, and that a hand/arm or a facial/head gesture could be seen as a meaningful unit, just as a speech act could. He coined the terms gesture stroke and gesture phrase, and described the different ways in which such gesturing could both accompany speech (helping recipients to understand and remember) and could achieve meaning in its own right.

Goodwin (1984) similarly uses evidence of body movements and gaze, to show how members jointly work towards constructing a story. Like CA, video interaction analysis can be a very detailed and technical approach to data. Heath (1997; 1988) bases his approach on repeated watchings of very small fragments of video data, and like CA analysts, is intrigued by the technique of unmotivated noticings. The analyst does not come to the data with pre-conceived categories, but is open to see what is happening on screen. In particular, Heath has revealed how one action can be occasioned by another. Video evidence seems to be particularly able to reveal such interconnections.

As an example of analysis, I return to extract 2:2 given above. I found that the more I looked back at the tape, in order to record each person’s actions, the more I noticed. For instance, I started to notice how John’s and Mark’s mutual gaze behaviours were
linked. Even the way Mark looked down at a particular moment appeared to have some significance in terms of how they achieved their turns. In particular, Mark’s three co-ordinated actions, in smiling, leaning forward and tilting his head, appeared to be directed towards bringing in John as a respondent.

Being a researcher can involve all these fine details of non-verbal behaviour, and the same tasks that have been identified through audio analysis (e.g. keeping control of the topic, collaboration with other participants) are observably achieved also through non-verbal means, such as gesture and facial expressions. The decision to include some measure of video analysis within the project has perhaps emphasised the detailed approach to analysing what is actually there. It certainly has had the effect of bringing this analysis continually back to the text.

2.6 Social explanation

2.6.1 Critical approaches to discourse

I will now move to the top of the Schema (p. 35) in order to consider aspects of social explanation. Despite the primary focus on text and talk, the present study aims to look beyond the local situation. Indeed, it aims to look beyond the mechanics of talk-in-interaction, and follows Fairclough (1989) in assuming that an adequate explanation of what is happening in any interaction includes an analysis of social forces beyond the text:

The situational context for each and every discourse includes the system of social and power relationships at the highest, societal, level.  

(Fairclough 1989: 152)

Additionally, it will be recalled from Chapter I that this study is socially committed, intending both to document social challenge but also to support it, as does critical methodology, or critical discourse analysis (CDA) (Fairclough 1992, 1995; van Dijk 2001). Instead of examining dominant discourses, the present study focuses on the voices of those who are in the oppressed group, the Foucauldian ‘subjugated voices’ (see 1.6.2). As Fairclough (1989: 20) points out, ‘in so far as dominant conventions are resisted or contested, language use can contribute to changing social relations’.
Kress (1996) calls for reciprocity between the cultural resources of different groups, and this study aims to do precisely that – to bring the dominant (professional and academic) discourses together with the subjugated discourses, that belong to people with the label of learning difficulty.

Research is termed **critical** when its central aim is to uncover oppressive or dominant discourses. Fairclough (1989) puts it in this way:

> Critical is used in the special sense of aiming to show up connections which may be hidden from people - such as the connections between language, power and ideology [...].
> (Fairclough 1989: 5)

Such research does not have to focus exclusively on texts originating in dominant groups, since a dominant discourse can be **naturalised** (accepted and internalised by those whom it dominates). This is referred to as **hegemony** (van Dijk 2001), and as critical discourse analysts observe, it is by these means that **ideologies** do their work. As Billig (2001: 217) explains, 'ideology is the common-sense of the society'. The present data are not chosen for the fact that they exemplify dominant discourses. On the contrary, the act of doing inclusive research is potentially new and represents a form of counter-power. However, there are senses in which dominant discourses underlie parts of the data; tensions between the dominant discourse of Learning Difficulty, and the new discourse of self-advocacy, were one of the first aspects of the data that interested me. For instance, there are many occasions when members ask questions that imply they are not competent to make everyday decisions ('When is something going to happen?' 'Are you taking us to Wales?'), constructing themselves as incompetent. At other times, those non-disabled people present may also make assumptions that undermine the attempts to establish autonomy and power.

The power that CDA is interested in is asymmetrical (Fairclough 1995: 17), unlike the Foucauldian interest in the power that is by nature inherent in any discourse. The CDA type of power, as Fairclough maintains, is often revealed by the very way in which social domains are structured. Power relations are embedded via institutional practices which 'directly or indirectly legitimise existing power relations' (Fairclough 1989: 13). In his more recent work (Fairclough, 1995: 27), he argues that the 'orderliness' of interactions depend in part upon 'naturalised ideologies'. For instance,
in the present context, a part of the naturalised ideology of Learning Difficulty is that there will be non-disabled supporters present, whose responsibility for things like basic safety, arrangements for transport and so on, go unchallenged. These assumptions are embedded deeply into the data, and it is part of the analyst’s task to de-naturalise and unpick that order.

How does this notion of power relate to my own research? Through their own action in doing research, members were disrupting the taken-for-granted consensus on ‘learning difficulty’, for instance by taking control of agendas and speaking for themselves. My analysis of this data, then, has to take into account how people labelled as having a learning difficulty are usually expected to behave, and how they are treated socially, in order to start noticing the significance of what members were doing. Further, I am interested in the wider consequences of their work, which requires a level of explanation beyond the text itself, and which takes into account some of the prevailing ideologies of the late twentieth century in the field of Learning Difficulty.

To this extent, then, I would agree with Fairclough (1995: 11), who argues that ‘social categories which do not have [...] manifest consequences may nevertheless be necessary to the analysis of a text’. In recent debates between CDA and CA proponents, this has proved to be one of the key issues, with Schegloff (1999b: 579), for instance, arguing that the analysis should be about what ‘the parties to the interaction [...] demonstrably orient to as relevant’. Schegloff is critical of the CDA approach, which tends to start with presumptions relating to ideology, power and oppression, and then seeks to find examples for them in the data. The sampling is principled – it is structured by the analyst’s concerns. Billig (1999: 576), however, defends the CDA stance, claiming that ‘all analysts bring presuppositions to the analysis’, and naivety is impossible. Moreover, ‘CDA [...] explicitly wishes to incorporate insights from social theory and other social sciences, including macro social science, into the analysis of particulars.’ Such debates risk producing, as Wetherell (1998: 405) fears, two opposing camps of discourse analysts; she proposes instead an ‘eclectic’ approach, which can bring together the insights both from text-based methodologies and from wider, critical traditions. Therefore she argues that the analyst’s work should be concerned not only with empirical demonstrability, but also
with ‘[...] the social and political consequences of discursive patterning.’ Wetherell goes on to demonstrate what such an approach looks like in practice, by considering data relating to young men’s talk about sexual prowess. The analyst can be concerned, both with the local unfolding of the talk, but also with the various discursive positions open to members, which go beyond the talk.

My methods draw heavily on some of the basic presuppositions of CDA, but there are also significant differences in approach, due to the nature of my task and the data. Like Wetherell, I aim for a more synthetic approach, and to move from a grounding in real data, towards ideology and power issues. To summarise, the similarities with CDA include the fact that the ultimate goal here is about a real social problem. I am involved with people, whose lives are actually affected by the discourse that surrounds them, but who challenged it through their own talk, and the research is participatory in the sense that Fairclough (1989, 1995) recommends. The later model of CDA (Chouliarki and Fairclough 1999) also seems to accord well with the current approach, since it is based on a sharing of knowledge. The key to CDA is to denaturalise; the analyst’s task is to reveal things that are taken for granted, that are not apparent to the participants. This process is intended to add to their empowerment.

2.6.2 Reconciling social commitment with the constructionist view

As I stated at the outset (2.2), the view of talk taken in this thesis is a relativist or social constructionist view. How can this be reconciled with a commitment to change things? For Foucault (1980), power was produced by all discourses, a very generalised force in which we are all inevitably caught up. To that extent, his approach was value neutral. As Wetherell (2001: 396) remarks, there is a logical tension between the extreme relativist position, in which the analyst’s results are simply ‘narrated into being’, and social commitment. Can one discourse be better than another, in terms of the difference it might make to people’s lives?

The tension between value-driven research and the social constructionist approach is still not resolved. For instance, Chouliarki and Fairclough (1999) discuss the fragmentation and instability generated by the multiplicity of discourses in modern life, and the loss of a sense of identity. What they conclude is that discourse is just one
part of social life – it is one type of social practice – and our own deconstruction of discourse (as analysts) is also a particular type of social practice. Therefore, if we want our analysis to bring gains to particular groups of people in society, our best option is to develop an open relationship between the theoretical practice of the academy and the social practices of non-academic life. As McHoul and Grace (1993: 35) concede in their exposition of Foucault’s theories, ‘discourses might be tested in terms of how they can actually intervene in local struggles’. In other words, a partnership approach to enquiry, such as the one practised in the present project, can at least provide a basis for mobilising people and enabling them to act. As Bloor (1997: 234) commented: ‘the real opportunities for sociological influence lie closer to the coalface than they do to head office’. The measure to judge socially committed research becomes usefulness, rather than some positivist notion of truth. In the end, in order to be socially committed, we have to argue that the analyst’s findings do have something to offer to society at large (Wetherell 2001: 397). The analyst’s task is not only to do the analysis, but to ensure that it has a place in the wider social context.

In the current study I have attempted to work with members throughout the various stages of analysis, including the final social explanation phase. It is hoped that the accessible version of this thesis will help to make a difference, in ways that are spelt out in the final chapter (10.5), as will our joint conference presentations (with members of the original Research Group, and with self-advocate researchers who have worked on subsequent projects). It is through critical engagement with each other’s ideas that the usefulness of the current work should be evaluated.

2.7 Analytic tools for interpretation

The problem for analysis is how to reconcile the micro arguments about what is going on locally in the talk-in-interaction with macro arguments about power and ideology (van Dijk 2001). In other words, the issue is how to get from the ‘textual analysis’ bubble in my schema, to the ‘social explanation’ bubble. As will be seen, the intervening space, labelled ‘interpretation’ is fairly large, and contains several devices and analytical tools that I have found extremely useful in helping to make this leap. In essence they are all ways of asking further questions of the data, based on the
outcomes of the textual analysis. The analyst needs to move beyond mere noticings, towards an understanding of the pattern that underpin and characterise them, so that wider themes can emerge.

### 2.7.1 Interactional rights

Conversation necessarily involves all social members in taking part in a pattern of talk that has underlying rules. CA's contribution is to describe that pattern – for example, the way in which one turn occasions another, or provides a slot for it. However, particular slots are not necessarily distributed equally between all members. Schegloff's (1968) classic paper on calls to a disaster centre noted that it is the answerer's place to speak first. When this does not happen, then the caller has to do specific work in order to produce an identification. Thus, from the very beginning CA has been concerned to unpick issues about specific **interactional rights**.

Subsequently, some authors have taken a particular interest in how interactional rights are distributed in certain social situations, such as classrooms (Sinclair and Brazil 1982), workplaces (Heritage 1997), doctors' surgeries (Heath 1988) and the family (Ochs and Taylor 1992). Most of these studies are concerned with the asymmetrical distribution of talking rights within certain situations, and are part of a wider body of work now known as **institutional conversation analysis** (Heritage 1997). Ochs and Taylor (1992) for instance note that children within the family typically are allocated certain **interactional roles** (as narrators) but are denied others (e.g. problematisers or elicitors).

There are some obvious connections between this type of work and the present project. People with 'learning difficulties' are often in the same situation as children, in being denied interactional rights, and the power of self-advocacy is precisely about the re-distribution of these rights (see 1.6). It should be noted that this approach to analysis does not assume that certain institutional roles, such as supporter or self-advocate, bring with them corresponding rights, nor that particular verbal practices are **category bound** (exclusively part of certain roles). Instead, the aim of institutional CA is to analyse the 'verbal practices and arrangements' through which such institutional roles are 'talked into being' (Arminen 2000: 436).
2.7.2 Membership categorisation devices (MCDs)

Categorisation of people is a very widespread feature of talk, and Sacks (1995; see also Silverman 1998) was particularly interested in describing how such categories were used within talk. What he proposed was that members shared 'collections' of categories, and rules for their application within talk. For instance, when a word such as 'mother' is used, we take it to be from the collection relating to family. One of the rules he proposed, (see Silverman 1998: 80–81) was that once one member of a collection has been invoked, then we tend to hear subsequent categories as members of the same collection. The mention of a 'baby' will be taken to be the mother's baby.

These might appear to be simple mechanical rules about the way language works. However, they have an immediate application in studies of talk, enabling the analyst to describe what is happening in particular social situations. Baker (1997: 131) for instance, in a study of teacher-parent interviews, looks for the use of membership categorisation devices (MCDs) by interviewer and respondent, to 'show how both are involved in that generation of social reality built around categories and activities'. MCDs are intricately linked with the concept of interactional rights, as detailed above, since a strong clue to how to categorise a person within any situation is provided by the interactional rights he or she assumes. In the absence of any other clues, for instance, a person who walks into a room of 30 people, and raises his voice to tell them to 'sit down and be quiet' is likely to be the new supply teacher, rather than a student.

Again, the concept of membership categorisation proved an extremely useful way of summarising what was happening in some extracts, particularly in relation to the way in which interviewer and interviewee not only worked up their own membership categories, but also worked with versions of the other's membership. The reader is referred to Chapter 9, extract 9:6, in which the following exchange occurs:

**Extract 2:5 (V 1)**

88. Mark: er what do you think about people being labelled/ like
89. being um (. ) like (. ) like with a learning difficulty =
90. William: = like like like us you mean†
Chapter 2: Tools for analysing talk

Mark asks a question, and the response slot is taken by William. However, instead of providing an answer, he questions the basis on which the question was posed. He is asking how (in what category) he is expected to respond. This is discussed further in Chapter 9.

2.7.3 Doing identity work

Instead of considering identity as something permanent and immutable about a person, I was interested, in common with Antaki and Widdicombe (1998), in seeing how members made relevant various identities in the course of the talk. Since being labelled as ‘someone with a learning difficulty’ was such a central feature of the members’ own research, insights about identity work became an important analytical tool for me.

Zimmerman (1998), for instance, distinguishes between three levels of identity work: ‘discourse, situational and transportable identities’. To explain these concepts, again I will give a short example from the data:

Extract 2.6 (V 4)

80. Sarah: can I ask you something/
81. Mark: of course you can/
82. Sarah: um are there times perhaps when it is useful (0.5) are - are there
83. times when it is useful to actually have a label so that you can
84. actually get things specific to your needs/
(→ Mark: narrows eyes at end, head on one side)
85. can you think of a time (1) is labelling totally wrong or could it be
86. right if it meant that you could get access to more resources/
head still on one side slightly
87. Mark: u::m (1) are you referring to people’s needs/
88. Sarah: yes

Sarah’s request for permission to speak (80) and Mark’s granting of that permission (81) are interesting, since by doing this bit of work, they are both telling us something about the nature of that particular conversation. In Zimmerman’s terms, this work is about discourse identity. Discourse identities, such as questioner and respondent, are the identities participants take up in order to make a conversation happen. They are the basic building blocks of conversation.

However, why is it that Sarah feels the need to ask permission before she speaks? Mark, in effect, has a power to assign turns in this conversation, and this is a right
recognised both by him and by Sarah, in fact jointly worked up by them both. This is what Zimmerman refers to as situational identity. Mark’s situational identity is the identity assigned to him by virtue of the particular situation of group interview. However, he is not simply a passive recipient of this identity – he is actually helping to create the situation by the things he does (e.g. giving permission) in his discourse. It is clear that that discourse identities and situational identities are closely linked. By doing this work, Mark and other members are jointly creating the situation of an interview, in which one person (the interviewer) has the right to assign turns. As Edwards (1998: 31) puts it, ‘categorisations feature in actively worked-up versions, that constitute the sense of the very circumstances in which they are used’.

Finally, I would like to consider Sarah’s longer turn starting at line 82. The subject under discussion is the issue of labelling, and Sarah puts forward an argument that labelling could be useful, if ‘you can actually get things specific to your needs’ (83-4). Sarah, it will be noted, does not include herself in the category of labelled people – she is talking to Mark about ‘your needs’. She implicitly portrays a situation in which she and Mark have what Zimmerman would term different transportable identities. They have different statuses with regard to being labelled, and it is this status difference which she is making relevant. Other authors have studied how speakers make relevant aspects of various possible identities, such as ‘woman’ (Edwards 1998) or ‘gun owner’ (McKinlay and Dunnett 1998) according to the needs of the conversational context. As Gergen (2001: 259) notes, our accounts of ourselves are ‘suspended in an array of precariously situated relationships’.

What is interesting, further, in this example is that in the course of her turn (82-86), Sarah does some quite specific work, asking Mark to give an example of the situation she is proposing to him, and pausing to wait for him to think of an example. This can be heard very much as the kind of thing a teacher might do in the classroom (Stubbs 1983), in bringing pupils into classroom discourse. She is offering Mark the opportunity to subscribe to her own conceptual framework, that ‘labelling could be useful’, by making it relevant to his own life. In the event, she is not successful, but what I want to comment on here is that the very nature of what she does helps to constitute her own (transportable) identity as a professional. It is apparent how closely discourse and situational identities are entwined with transportable identity. It is
precisely this fluidity and interconnectedness which make multi-level identity work so useful as a concept.

Identity is something which can be worked up and achieved: at the same time, it is something which can be rejected or challenged (Baker 1997: 132). My interest in these data was precisely the way in which members challenged their own social status through the fine intricacies of talk-in-interaction, how they ‘invoke or accept or contest the relevance of identities on a moment to moment basis’ (Greatbatch and Dingwall, 1998: 131). The tripartite concept of identity provided a useful tool to untangle some of these complexities.

2.7.4 Interpretative repertoires

In attempting to interpret what is going on in the data, the analyst is primarily interested in the way in which members themselves make sense of it. The aim is to uncover their own interpretative devices, since, as Antaki (1988: 12) pointed out: ‘much of what is said is only sensible against a background of silently agreed knowledge’.

In this particular case, I was also a member, since I was present during all the sessions (except for two brief interludes), and had been instrumental in helping the group to get established and under way. Therefore my own understandings of what is going on are also treatable as part of the data (c.f. Rawlings 1988). What I have found very useful is the back-step, not just to describe what I think is going on, but then to stop and ask myself ‘how do I know?’ What I often find is that I am drawing on repertoires which to some extent I share with the members (repertoires drawn from the lives of people with ‘learning difficulties’), although I also have access to others, such as the repertoire of what researchers do.

Wetherell (1998) used the term ‘interpretative repertoire’ to show how the positions the young man in her example (Aaron) takes up can be referred to repertoires available to him:
An interpretative repertoire is a culturally familiar and habitual line of argument comprised of recognisable themes, common places and tropes [...].

(Wetherell 1998: 400)

An example of how useful this tool is can be given from Extract 2.6 above, when Sarah says to Mark: 'is labelling totally wrong or could it be right if it meant that you could get access to more resources†' (85-6). What are we to make of this remark? It might appear quite opaque to some readers. What are these 'resources' of which Sarah speaks? The first step might be to see how Mark himself takes it, since he is the audience to the remark, and helps to construct its meaning in this context (Duranti 1986). He actually questions her intention, narrowing down the question by the word 'needs'. This could appear even more mystifying to the analyst. What is the link between 'resources' and 'needs'?

This passage could have passed unnoticed for me, so naturalised is the knowledge it draws on. The words 'resources' and 'needs' are both social services terms, which are used within assessments provided by professionals for users of social services. It is only by stopping to consider what knowledge I am drawing on that I can start to describe what is happening in that extract. Sarah is pulling into the argument a recognisable theme, and in so doing is invoking the whole service world in which people have to label themselves in order to receive support in the form of 'resources'. The analyst is able to describe how such shared understandings are made visible in actual social practices. The step from here to the unearthing of ideologies, the common-sense beliefs of a society (2.6.1), is but a short one.

2.8 Bringing it all together

2.8.1 Elaborating the analysis

I have now covered the main stages in my Schema on p. 35. For completeness, I should mention here that a final stage of the interpretation level is the elaboration of the analysis (ten Have, 1999: 129). CA is often accused of being arbitrary and ungeneralisable, based as it is on single extracts of talk. Therefore it is important to broaden the conclusions, by finding other similar examples in the whole corpus of data. In conducting this trawl through the data, I followed ten Have's advice in broad
terms. The analytic method is to describe and interpret what is happening first within one or two chosen extracts, until one has something interesting. Then one searches both for similarities to confirm the findings, or indeed for counter-examples which might add something new or different. Deviant cases can often provide insights, by revealing what went unnoticed in the original analysis.

What one searches for will depend on the nature of one’s findings. In classic CA methodology, the findings may be about a particular conversational device, and so this can be confirmed or disconfirmed by systematic searching. For instance, Woofitt (2001) looks at the phenomenon of reported speech as used by a spirit medium in sittings, in order to frame the speech of the dead. He then goes on to take examples from the whole corpus of data, in order to investigate variations on the way this phenomenon is used.

In the present study, I was interested in the patterns emerging about strategies to do the work of researchers, the ways in which members did ‘being researchers’. For instance, in Chapter 5, having analysed one extract which contained examples of collaborating in interviews, I then checked through the entire data set for other examples in which members appeared to be demonstrably doing the work of interviewing. What I found was a set of other strategies, presented at the end of Chapter 5, and also some notable counter-examples, which I became interested in as they constituted threats to being researchers. In fact, the theme of threats became so important that the whole of Chapter 6 is given to it. Throughout the process, one part of the analysis was built on the back of another, and as analyst, I was constantly moving between one part of the model and another. However, the greatest challenge was to keep taking these insights back to group members, and I will conclude this chapter with a brief discussion of their continued participation.

2.8.2 Continuing our joint work

The final word in this chapter must go to the issue of power, which is both an object of theoretical consideration, but also a practical issue for our project. Throughout our work together, I have been aware of inevitable inequalities, due to my professional status, and greater access to knowledge, information and other resources.
My relationship with Research Group members did not start and finish with the collection of the data. This analysis aims to engage with members themselves in the formulation of knowledge, and to recognise their voice, not just as a voice subjugated by dominant ideologies, but as a voice which can challenge and produce change (Chouliarki and Fairclough 1999; Kress 1996; Nunkoosing 2000). I am aiming throughout to engage with participants, and recognise their right to create their own form of knowledge for themselves. Rather than take away this analysis and make it exclusively part of the academic discourse, I chose to take the findings back to group members, in order to help them understand the issues.

Group members referred to these sessions as ‘PhD work’, and one of the hottest topics at the first session was the issue of what a PhD is. To distinguish them from the group’s own analysis sessions, I refer to them on the Schema as ‘discussion sessions’. I approached the first session with some trepidation, with the aim of explaining and sharing some of the aims and ideas in this research. One of the members suggested that the outcomes of this first session could be made into a document (see Appendix G) which is entitled ‘Talk’. It was this document that I took back to the participating groups, in order to explain to them what I was doing with their data, and to seek informed consent. The contribution of group members, at every stage, cannot be overstated. The subsequent series of six discussion sessions which we held between September 1999 and June 2000 were funded by a bursary from the Open University, and so I was able to pay members on a sessional basis for their work towards my PhD. We had turned the tables, and they were now helping me.

These discussions were all tape recorded and roughly transcribed, so that I could analyse the data thematically. This was a way of gaining some access to the members’ own analytic insights and theorising of their own lives. The themes emerging from these data inform Chapter 1, and also helped with the formation of some overall structures in order to select extracts for analysis. For instance, one discussion was specifically on the topic What is self-advocacy? and provided a framework for Chapter 4, while a discussion on What is research? underpins the analytical structure in Chapter 5.
I have tried to be honest with Research Group members about the advantages I will gain from getting a PhD, and their natural rejoinder to this has often been ‘Why can’t we get one too?’ I am therefore seeking accreditation for their achievements during this whole process, by developing a Research Skills curriculum, in conjunction with them and with another team of self-advocates with whom I presently work. Similarly, I continue to support them in developing their own work and interests, recognising that these are not entirely going to coincide with my own. A recent interest, in 2001, for instance was to network with other self-advocate research groups, and I have recently supported them on a number of visits. However, they maintain an interest in what I am writing, and my hope is that the work will also be of value to other self-advocates, particularly those who are embarking on their own research. This is the reason for the accessible version of the current thesis.

At a theoretical level, I have also needed to remain aware of my own relationship with the group, and the power implications within the support role. Therefore a final aspect of my own analysis has been critical reflexivity. I cannot, and would not wish to, deny my own role in the Research Group’s project, in practical, ideological and analytical terms. Throughout, I have supported them in conceiving of the work, in realising its import, and in analysing. Therefore I am bound to have occupied a powerful position. This is dealt with as a topic in Chapter 8, but throughout the analysis, there is an attempt to take an honest look at the distribution of power and how we can jointly re-distribute it within inclusive research. Rather than start with assumptions about that power, I have attempted to demonstrate from texts how it can be constructed and shared, and specifically the strategies that supporters (including myself) can use during projects such as this one.

As an example of one instance of this kind of talk, I will conclude this chapter with a brief exchange that occurred between Mark and the member of staff of the first group we visited:
Extract 2:7 (V 1)

987. Mark: yes and the research group/ which we are research visit - having the research group/ and what we're trying to find out is different things to do research on (2) which I think is very exciting/ I don't know how we do it but we do it/
988. June: oh you're doing it you're doing it/
989. Mark: yeah LF
990.

Research Group members constituted what they were doing as research precisely by 'doing it', and my hope is that this thesis will help them appreciate exactly what it is they did.
Chapter 3

Doing introductions

3.1 Chapter overview

This first analytic chapter will function as an introduction to the research project undertaken by members of the Self-Advocacy Research Group, by examining occasions on which they introduced themselves to other members. The chapter is about how the group members answered questions about their own identity and intentions, in the events that I have called in the preface the ‘fieldwork for Finding Out’. The general purpose is to start to explore the resources or strategies that were available to them for creating these events as research interviews, and this chapter will set the methodological foundations for the rest of the thesis. By addressing the question ‘who are we?’ they also started to answer the question ‘what sort of thing are we doing here?’

The chapter starts (3.2) with an extract from the second visit (see Appendix C for details of visits). This visit was exceptionally open to counter interpretations, due to contextual circumstances that are sketched out in 3.2.1. The textual analysis (3.2.2) considers members’ methods for bringing together the two slightly different repertoires of self-advocacy and research. In order to explain their purpose, members had to do joint work in aligning as a group, but this joint identity was not always solid, as the subsequent extract from the same visit explores (3.3).

The following section (3.4) considers other ways of introducing the events, through the whole corpus of data from the visits. I explore how Research Group members made salient their identity and purpose as researchers, and also demonstrated and marked their ownership of the process. The discussion (3.5) reflects on the interpretative repertoires that are open to all members in making sense of what is happening. In particular I turn to membership categorisation as an analytic device for encapsulating the work that is done in these opening encounters.
3.2 Who are we? Presenting as a group

Both the main extracts to be analysed in this chapter come from a stretch of talk towards the beginning of the second visit, and are chosen because they constitute an occasion on which Research Group members were called to account for themselves as a group. I will start with a lengthy extract at the start of this stretch, to give a flavour of what was happening.

Extract 3:1 (V 2)

77. Mark: what - what we're doing is some research work (.) about
78. Norton Self-advocacy um Research Group and what this relates from
79. to about 1997/ and it um (1) explains what is research/ (shows
80. booklet) can people HEAR me what I'm saying†/
81. Ian: yeah /
82. Mark: yeahT (1) pe- go- we've got (. ) a (. ) leaflet about what is research/ (1)
83. and it goes on right the way through till um (. ) what the Norton Group
84. are are actually doing/ (turning pages of leaflet)
85. Chris: (...that's true)/
86. Mark: right some of - has anybody got any questions on that†/
87. Fred: where do you meet†/
88. Ian: (...) meet†/
89. Fred: where do you meet†/
90. Mark: where do we meet†/
91. Angela: where do we meet† / [we meet at the Brandon Centre/= [um er at Westfield -
92. Mark: [um er at Westfield Business Park (. ) People
93. Fred: (...............)
94. Angela: we meet at the Brandon Centre in Norton isn't it†/

Video starts
95. Chris: (........†)
96. Angela: we meet at the People First office/ [we meet once a fortnight/
97. Mark: [Westfield Business Park (. ) People
98. First office which is in Norton/
99. Chris: whereabouts in Norton†/
100. Mark: er that's er Rowland Road in Westfield/
101. Chris: I [ know (....) Norton/
102. Harry: [yes you get the (....) bus to get there that's right]/ Rowland Road
103. Fred: when do you meet†/
104. Angela: every Friday/ once a week - once a fortnight/
105. Mark: we meet every Friday/ sometime we er - we got two groups going/(. ) =
106. Dawn: have you†
107. Mark: = at the moment we've got the er the newsletter group (. ) and the
108. research group/ and one week it's newsletter group (. ) actually doing
109. the (1) the newsletter/
110. Takes newsletter out and holds it up to show to people
this is our second one/ (looks at newsletter)
3.2.1 Contextual circumstances

Before the analysis, a word or two might be in order about how this visit was set up, from the point of view of Research Group members. The visits in general were arranged by letter, using an address list of participants we had from a recent seminar held in Norton. Group members had dictated their letter to me (see Appendix D), and I had sent these off to the six groups, all of whom responded very quickly. However, on this occasion, the group we contacted had withdrawn their offer, and as we had made arrangements for travel on that particular day, we decided to try and re-arrange a visit at very short notice. As it happened, the People First group with whom we were put in touch was available that afternoon, since they had already booked a large room to meet with a visiting researcher in the morning.

Therefore the identity and function of the Research Group and myself must have been quite obscure to the People First members we visited, since they had just spent the morning with another, non-disabled, researcher, who was still present during the afternoon. This extra visiting researcher became known as a named individual, but what was she doing there? In addition, the fact that the group of people we visited was a conglomerate of many different smaller groups was probably never clear to Norton members. There were several supporters, who did not introduce themselves formally, and the whole situation was imbued with greater confusion by the large numbers of people present (at least 25), and the venue, which was the social cafeteria area of a sports complex, with swimming pool.

Given all this very confusing background to the afternoon, it is evident that various speakers would need to set the scene. However, it was not clear whose agenda we were following, and it was hard for Research Group members to establish that they were going to ask some questions. This was the background to the talk that occurred in Extract 3:1.
3.2.2 Managing the interaction as a meeting

The first feature to note is the organisation of turn taking. First, one speaker has more turns than anyone else. This is Mark, with nine turns, while Angela and Chris have four, Fred has three, Ian two and Harry and Dawn one each. Mark's turns are also longer than the others, and he is not interrupted. When another speaker intervenes, it is often simply to deliver what Silverman (1997) calls a response token (85: 'that's true') or a continuer 'yeah' (81), 'have you†' (106). Following his opening long turn, which, with one short intervention, spans lines 77 – 84, Mark offers the floor to any other speaker. This offer is taken up by members. Fred starts at 87 with 'where do you meet†', repeated at 89, then Christine adds at 99: 'whereabouts in Norton†', and at 103, Fred comes in again with: 'when do you meet†'.

In considering the turn structure, it is also sometimes useful to think about who selects whom (Sacks, Schegloff and Jefferson 1974). For instance, Mark appears to be selected by other speakers (87, 89), whereas Angela self-selects (91, 94, 104). Mark hears her turns as self-selections, since he immediately comes in after each one, sometimes overlapping with her. If one examines the contents of the turns, the first two pairs are ones in which Mark corrects things that Angela said (at 92 and 97). They are working up a degree of competition between themselves. While Angela offers two formulations of place, Brandon Centre and People First office, Mark locates the office in 'Westfield Business Park'.

So far, then, we can note Mark's dominance of the turn structure in this extract. The turn allocation is quite complex. Mark asks for questions ('has anybody got any questions on that' (86), a move by which he then turns the tables and puts himself in the position of respondent. He controls the turn allocation, just as a chairperson or presenter would control a meeting. There are two overlapping sections, in which there is trouble about who should have the next turn, at 96-7 and 101-2. These deviate from the rest of the extract, which on the whole is marked by consecutive non-overlapping
Chapter 3: Doing introductions

turns, reminiscent of the formal structure of a meeting. Such smoothness is a joint achievement – all have to respect the turn allocation rules for it to work.

In the organisation of sequences, there is also a sense of order in this extract. Each time there is an initiation, the preferred response generally happens fairly soon after (see 2.5.2 for concept of ‘preference’). The structure of sequences is therefore fairly straightforward. Mark interrupts his opening turn (77-80) with an appeal ‘can people HEAR what I’m saying↑’. Note how he is continually monitoring his audience’s response. Ian then responds (81) and Mark continues with his original turn (82-4). This is acknowledged in line 85 by Christine’s ‘…that’s true’, and he then takes the opportunity to follow up his turn with an offer to take questions (86).

Questions do follow, as we have seen, and are broadly accepted as topically relevant by Mark’s and Angela’s responses. This acceptance is done by adjacency pairing into initiation/ response (question/answer) throughout. This straightforward pattern is only slightly disturbed by the joint answers provided by Mark and Angela, and an overlapping sub-sequence from 101-2, which springs from Christine’s subsidiary question ‘whereabouts in Norton↑’. This kind of sequence organisation can only happen if:

- People respect the rules of conversation, and follow questions with answers (and produce questions when invited).
- People follow the rule to speak to one relevant topic – sub-conversations would threaten many a meeting.
- People listen to each other, and are open to negotiating their discourse identities or remaining silent; (remember that there were at least 25 people present, so it was not at all obvious who should be answering whom, and who should take initiatives as questioners).

It also ought to be noted that Mark addresses the whole audience in his opening turn, as indicated by his procedural self-interruption ‘can people HEAR what I’m saying↑’ and his self-repair in 105, when he moves to the relevance of ‘we got two groups
going’. Mark’s repair work can be heard as a type of self-monitoring, and he deploys strategies to make sure he is keeping his audience. On both these occasions, he marks his turns as formal speeches by producing written texts that he has brought with him and to which he can refer – firstly, the research booklet, and then the newsletter. These are finely tuned to his identity on each occasion, since they represent the output of each of the groups he mentions. Thus this extract contains evidence of the formal structures associated with a meeting, namely one topic, orderly non-overlapping turns and control by the chair.

3.2.3 Orienting to group identities

Having looked at the structural features of this extract, I move now to the content of the turns. What is Mark doing in his first turn (77-84)? It comes over as a presentation about the identity of the Self-advocacy Research Group. He does this chiefly by means of referring to the booklet about research, showing the booklet, summarising what it is about – and then throwing open the floor for questions. There are many strategies for identity work in this.

Firstly, Mark uses the title of the group, lending it a status and coherence. Secondly, the vocabulary is worth noting. Mark answers the question ‘what are you doing?’ with ‘research work’ as distinct from any other sort of activity. His use of the date (about 1997) gives the group a certain status, as it started its existence at a specific time. The phrase ‘what is research’ (79) implies that his listeners might not know what it is, but that it does have a distinct meaning, which he in fact knows. He takes on a powerful position as arbiter of some knowledge that not everyone present possesses. Not only has he a superior knowledge base, but as a visiting researcher, he is willing to share this knowledge with his listeners.

His mention and production of the leaflet, as noted above, is an important part of his performance. The written word has a status and permanence, especially within a group where at least some participants cannot read or write fluently. Books and leaflets are
often part of a world that does not include people with ‘learning difficulties’. They may be talked about in books, but not be the authors of books, or turn to books themselves for information. The leaflet remains in front of Mark as a symbol of his and the group’s status. This important leaflet leads him back to ‘what the Norton Group are actually doing’ (83-4). If the leaflet gives status to the question of research, then the fact that the Research Group is mentioned in it also gives them status. There are many carefully placed strategies brought together here, which all do group identity work. The very structure of the turn – introduction, naming, leaflet – what the leaflet is about – then the mention of the Norton Group again – is very neatly designed. He puts himself over as committed to research, and on top of his job as a researcher.

Following this, it is interesting to highlight the design of questions that other members use: ‘where do you meet?’ (87) and ‘when do you meet?’ (103). They draw on the relevance of Mark’s group talk: groups often do conduct their business by meetings, that take place in a regular location, and Mark’s use of the word ‘group’ is a warrant for their line of questioning. However, although details of meetings may be relevant in a People First repertoire, they are less so in a research repertoire. For instance, if I had announced myself as a researcher, I would not expect a series of questions about group membership and meetings.

There is thus a slight mis-match between the ‘where do you meet?’ line of questioning, and Mark’s opening explanation of what research is, hearable because of the repair work between 87-90, with Ian’s repeat (88), and Mark’s re-phrasing of the question (you→we) in line 90. This shift of personal pronoun could be a device for making explicit the group membership. He might also be stalling, or playing for time, although repetition of a question is a typical chairperson’s device. In effect, he is marshalling the other group members around him, to enable their response as a group, as can be seen from Angela’s response at 91.

How then do Norton members deal with these questions? After their initial hesitation, they launch into the detail of meeting place names, structure, timing and regularity of meeting. In other words, the questions are heard as requests to talk about
the routine of which they are a part, to expose this to others. At first, as has been noted, Mark and Angela appear to be giving slightly different versions of where they meet, but Mark manages the repair jobs at 92 and 97 without openly contradicting Angela’s contribution. He then uses the term ‘which is in Norton’ (98). What does this do? By introducing the more general geographic term, ‘Norton’, Mark acknowledges the fact that the interviewee members live outside Norton. Although they can be expected to have heard of Norton, they will not know the detail of place names within the city. At the same time, he moves to the relevance of ‘Norton’ rather than the precise location. Norton is relevant because what is being talked of is not the geography of the group meetings, but the fact that the group represents (in an abstract sense) Norton. The question of location is not about: ‘where is it—I might want to get there from the bus station’, but ‘what sort of place do you manage to get your meetings in?’ The reason I deduce this is by looking at the whole range of questions asked subsequently by the interviewee group:

- how did you do it (which becomes: how did you expand) (122)
- how (do) you get to the meetings (142)
- do you enjoy your job (picked up again at line 189 →) (171)
- what do you want to do in the future (175)
- how many ... are you (.) in the meeting (208)
- do you (..) get paid for it (226)
- do you have people in wheelchairs as well or not (+ blind people) (252)
- how do you show the practical out working of self-advocacy (259)

The whole sequence of questions is finely orchestrated. The relevant factors about group identity for them are about finding meeting places and times to meet, recruiting group members and enjoying self-advocacy. Their questions are based on the presupposition that they too are a group, and they are trying to find out the similarities and differences between their group and the visiting group. This is an open display of membership categorisation work. It is revealing that Chris’s focus on the precise geographical location (99: ‘whereabouts in Norton†’), which is taken up by Harry who gives advice on bus routes, is not relevant to this purpose. Christine appears to have a sense of this perceived irrelevancy, since she feels the need to explain why she had asked the question by ‘I know Norton’ (101).
The second question, ‘when do you meet?’ again occasions some slight hesitation. Angela self-repairs with ‘once a week – once a fortnight’ (104), and Mark then continues with a specification, moving back to the ‘every Friday’ but then qualifying this with the explanation that there are ‘two groups going’ (105). Despite this confusion, he and Angela still manage to put over a group identity, and this is largely due to their joint work in the talk. When Angela hesitates, Mark comes in to help her. When he formulates something, she is silent, not contradicting him. There is group work in the talk, matching the picture they are portraying of their group. They put over that group as so productive that it has two functions, each of which takes place at specific times, and the group can produce not only the leaflet with which this extract opened, but also a newsletter, on which it concludes.

In this extract, then, we can see some of the discourse strategies at work, to produce group identities. The general quest seems to be to compare experiences and identities, and in so doing to continue working out who they themselves are. The interesting point is that, although members are drawing on two different repertoires, namely that of the self-advocacy and the research group, these two repertoires can be interfaced without any major trouble or breakdown of communication. Each speaker listens and adapts to the needs of others quite successfully, and they appear to do this through adhering to the genre of the meeting.

### 3.3 Some cracks in group identity

Extract 3:1 is part of a lengthy chunk, in which the format remains more or less constant. The questioning that has been set in motion continues, and produces more interesting identity work. The extract below is from a later stage; my aim here is to see how the talk develops.
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Extract 3:2 (V 2)

208. Derek: [how many – at the meeting/ how many are you in the meeting/]
209. Angela: [er I'm on the committee/ smiles towards Derek]
210. Mark: oh there's -
211. Derek: how many of you in the meeting↑/
212. Mark: you mean how many are there [actually on both groups↑
(Angela looks round towards Mark)
213. Derek: [yeah]
214. Angela: there's me Mark –
215. Mark: oh right/ there's four of us on the research group/ =
216. Derek: yeah
217. Mark: = and six on the newsletter group/ which [(.)] is hard work believe you me/
(smiles and looks down at his papers)
218. Angela: [ that's very boring] WH
219. Mark: actually getting the people there to do the work/
220. Derek: yeah that's true/
221. Mark: say like most people turn up on time (.) most people don't/ it all depends on where – on where it actually is/
222. Elaine: do you do [ you (...) get paid for it↑]
223. Mark: do we get paid [for it↑/
224. Harry: [ that's like me because (..................)]
225. Mark: [we do for the research visit and the research group but we don't for the newsletter group/]
226. Val: [do we get paid for it↑/]
227. Angela: um yes/
228. Harry: [(..............................................................)]
229. Mark: [we do for the research visit and the research group but we don't for the newsletter group/]

3.3.1 Orienting to individual identities

This extract is not so ordered as the previous one. For instance, there are several sections of overlapping speech. Turn allocation, however, still follows the general lines of a meeting between two groups. Members of one group take turns as questioners, and members of the other group take turns to answer. Discourse identities are clearly allocated and adhered to.

However, it is in the repair organisation and turn design that some more complications can be noticed. Both of the main questions produced by host members are subjected to clarifications and revisions. For instance, at 212, Derek’s repetition of his original question ‘how many of you in the meeting↑’ implies that Angela’s reply at 210 had not been an acceptable answer. By repeating the original, a speaker implies that the original had not been heard, or had not been addressed. We can suppose that it
is heard in the latter way by Mark, since at 213 he checks on the questioner’s intention by trying out a re-wording: ‘you mean how many are there actually on both groups’.

The fact that Mark’s interpretation is then accepted by Derek, the questioner, privileges him (Mark) as a respondent, and he then goes on to respond at greater length at line 216, cutting across Angela’s own response in 215. One can see how the detailed sequence of the talk, as it unfolds, can serve to undermine one member’s contribution and privilege another’s. The joint, supportive front of the team is threatened at this point.

In the light of this, Angela’s aside at 220 (‘that’s very boring’) is interesting. It overlaps with Mark’s turn and it is hard to tell if it has been heard. It is not part of any formal sequence, but is an immediate reaction to Mark’s mention of the newsletter group. My interpretation of this is in part due to my prior knowledge of conversations between her and Mark. Angela did not at this stage attend newsletter groups, but only research groups, and this was one of the causes of tension between her and Mark. However, one can also appreciate how such dissent is seeded by the local unfolding of the talk.

There is also some confusion around the choice of vocabulary items, and the way in which they are swapped, one for the other. For instance, the word ‘meeting’ (208) is replaced by ‘committee’ (210), and then by ‘groups’ (213). I would suggest that this reflects the continuing tension between (at least) two different interpretative repertoires, one that is based on various self-advocates coming together on occasions for a meeting, and the other that is based on a small group of people doing some work together. Angela’s use of ‘committee’ is yet another strand, since she is responding in her own right, and in the first person, ‘I’m on the committee’, thereby introducing the beginning of a tension between group and individual identity.

Mark then relates the difficulties of getting a group together. However, this is also a personal story about his own position. The phrase ‘believe you me’ (219), for instance, can be heard as a personal appeal for empathy. Derek clearly hears it that way, since he responds with an encouraging ‘yeah that’s true’ at 222. Mark then continues to
emphasise his own position as a personal, individual one, by referring to other members of the group as ‘people’ (223), and portraying himself as the person who has to worry about getting them there. He is the one responsible for the working of this group, and he backs up this individual identity by his body language (*looking over his glasses, mouth turned down*). His troubles talk here draws responses from both Angela and Harry, although Angela’s at 220 appears to go unheard. Harry’s overlapping talk from 226 is probably occasioned by Mark’s rebuke about not turning up on time, since he mentions the place he has to travel from in order to get to the group. The very fact that he does this supports Mark’s position as a responsible group leader, to whom others must justify themselves. However, their joint performance at this point is somewhat undermined: team members appear to be talking amongst themselves.

The business in this extract differs from the previous one. There is more individualisation, with tensions apparent between various Norton members. They are not designing their turns to support each other, but in some respects to challenge each other, and to respond to that challenge. Members appear to present themselves here more as individuals, Mark the harassed but responsible organiser, Angela the committee member, and Harry the member who has to justify his actions to Mark.

3.3.2 Moving from ‘being researchers’ to ‘doing research’

The extended sequence in which both extracts occur is interesting because identity is directly addressed throughout, through some very clear devices for membership categorisation. One can observe identity being actively constructed during and by the talk, as members show concern for how they are perceived by others in the room. The aspects of identity made salient by participants (being responsible for a group, working co-operatively with others in a group) are precisely those which are being demonstrated through the ordering of the discussion. However, a group is made up of individuals. The aspects of identity referred to in the discussion (being on the committee, having to ensure that other members came on time, writing a booklet about
research...) have an effect on the present conversation. They help participants to orient to the nature of the occasion, and to start moving towards 'what research is'.

In the first extract, (3:1), Mark can be heard as the main spokesperson for the visiting group – he is one person speaking for a ‘we’ (The Norton Group), while in the second extract (3:2), there is some differentiation of opinion expressed, with individuals stepping out of their group membership identities, and putting themselves over as people with individual opinions and positions within the group. An introduction to the group can be done either by presenting a solid group identity, or by a combination of individual positions within the group. However, it is clear that a joint performance leads to a neater structuring of the talk. Further, a structure with one chairperson feeds into the construction of doing research. When Mark finishes his presentation of ‘what is research’, he puts the host group members into the role of questioners, and the Norton members into that of respondents. He is using his identity as group spokesperson to take a commanding position over the course of the conversation and this clearly adds to the picture of himself that he is putting over, as a researcher. Not only is he talking about research, but he is demonstrating by the actual interaction here-and-now, and his control over interactional rights, what it means to be a researcher.

In order to understand what sort of event is about to happen, all members need first to have some kind of grasp of who is who, and the interviewee group tackle this issue head-on with their impressive list of questions. However, by answering questions, the Research Group members adopt a particular discourse identity: that of respondent. This leads, rather confusingly, to becoming interviewees, rather than interviewers. Thus their situational identity has to be built on rather an inauspicious start on this occasion, making it somewhat harder to move on to their own agenda, which is to ask their own research questions. On that particular occasion, they have some difficulty managing that shift; some 50 lines further on there is a five-second pause, followed by a prompt move from myself: ‘do you want to get on to the questions then↑'(283).
3.4 Introductions throughout the data

Providing a frame for research interviews can be done in two ways – either by explaining who you are and what your purpose is, or by getting on and doing it. I will now present some examples of the latter, from a trawl through the other visits.

Research Group members had set up these visits, and so a tacit rule was that they should frame and define what was happening. This is reminiscent of Schegloff's work on telephone calls, where it is the caller's job to indicate what the purpose of his call is (Schegloff 1968). Three main strategies for doing this work run through the data, and I will deal with these in order: doing business around recording equipment, establishing the right to define the agenda, and using framing remarks.

3.4.1 Setting up recording equipment

On five of the six visits, I was the person who did most of the technical work in setting up both video and audio recording. However, on all occasions it was Research Group members who made reference to it during their opening remarks. By definition, their request for permission to use audio recording was made before the recorder was switched on, and so those data are not available. However, explanations about video are on the audio tape on two occasions, one of which is given here:

Extract 3.3 (V 4)

1. Mark: the only reason that we er (0.5) would you mind if Val videos this↑(1)
2. the things we do we won't have people's names (.) on the video/ so
3. you (...) confidentiality (1)/ is that right↑ (→ Val)
4. Val: OK↑
5. Mark: what I mean to say we won't have people's names actually on the
6. report/ we won't mention anybody's names ( ) on the video/
7. Val: can I swap seats with you Harry↑ (setting up video)
8. Mark: does everybody understand what I am talking [about↑
9. Several: yeah/ yeah
10. Sue: I think so/
11. Val: is that alright↑

It is clearly Mark who leads, in terms of initiating turns and sequences (lines 1, 5, 8). He asks other members for a response. The recording equipment is socially produced
as under his control, and he establishes that he has the power to turn it on or off, through the medium of Val. Moreover, he provides a slot for other members to say yes or no to its use. They are given the rights to grant permission for recording to take place. What do they make of this right?

On no occasion was permission refused, or even questioned, yet Mark persists with some explanation or justification of his request. ‘We won’t have people’s names (.) on the video’ (2) can be heard as an attempt to pre-empt criticism from other members. He then self-corrects with the word ‘confidentiality’ (3) and checks with me to make sure it is the right word to use, but clearly still does not feel his justification is complete, as he self-repairs again at lines 5-6. What work does this talk do? At one level, it is part of a researcher’s scripted pre-amble, and Mark could be simply establishing himself as a researcher through using the correct verbal formulations of ‘confidentiality’ and ‘report’. Since this genre of talk is new to him, it is not surprising that he checks with me (3) to make sure he is doing it correctly. More fundamentally, however, we can see that what he says can only be understood against the background of many assumptions about research-type activities. For instance, why should members be concerned that their names are not mentioned? The use of the word ‘confidentiality’ derives from the unstated assumption that things might be written (or made public) that are based on the video tape being made. The talk that is produced will be in the public arena (Silverman 1973). There is also an assumption that the words of those who are being interviewed, who are referred to as ‘you’ (2) and ‘everybody’ (8), are of prime interest – it is those words that will be the subject of some future ‘report’ (6). Moreover, it is not their individual ownership of the words that is important: indeed, they have the right to remain anonymous. Clearly, this small piece of work does much to start establishing what is going on. There are some stock sequences here, some first intimations of what a research interview might be, and these were aired on all six occasions.
3.4.2 Establishing the rights to define the agenda

The power that Mark and other members assumed over defining these interactions as research interviews was arguably focused and emphasised by the defining icons of audio and video recorder. Moreover, they also had with them sheets of questions they wished to pose, copies of newsletters and leaflets. They had come with the goods, and they quite literally laid these out on the table at the beginning of each event. However, this in itself would not be sufficient for visiting members to establish themselves as interviewers. The reader will have had experiences of going to meetings with their own paperwork and agenda (and even with equipment), only to have to wait their turn on someone else's agenda.

The defining question seems to be: 'whose agenda is this?', and the definition of the event as an interview was closely connected with the interactional dominance of Research Group members, as is evident in the following example:

Extract 3:4 (V 6)

Mark: thank you for - for (. ) u::m inviting us this afternoon (1)/ can we just see what people's names are†

Alternative frames for the visits abounded, such as that of group activity. A common experience for members, in day centres, college courses and even in People First organisations, entails sitting in groups - either with the purpose of communicating about personal matters (most centres have base groups where people can share problems) or with the purpose of learning something. There might also be many reasons for two groups of people to come together, and so these events might have seemed quite familiar to many participants. However, such familiar group activities are led and established by the non-disabled group leader, and so the defining feature of this event was perhaps the set of actions undertaken, both by myself and by members of the Research Group, to establish who was in charge.
Chapter 3: Doing introductions

For instance, the opening moments of an encounter are very important for participants’ interpretation of what is going on. Each occasion included an arrival and introductions, which are not on tape. However, I was there and can testify to the fact that as far as possible, our physical entry was led by group members themselves. I always held back, encouraging members to go to the reception area, ask for the room, introduce themselves directly, and so on. Against the backdrop of expected behaviour with people with ‘learning difficulties’, this very action of holding back is a marked activity. By doing it, one is contributing strongly to the message that members are taking on new and unexpected identities. Through many such clues, there was no doubt much evidence of our separate identities as ‘supporter’ and ‘self-advocates’, especially to those who had experience of People First or other such groups.

It may well have been a combination of many factors that led to the situation where other participants held back, and literally looked towards Mark as initiator and definer of the situation they were in. However, in all six visits, his remarks formally open the event, and set up the proceeding talk as being for his and his colleagues’ purpose.

3.4.3 Framing remarks

Having taken the lead, how did members follow this up? Again, it was Mark who did this work on each occasion. Consider the following:

Extract 3:5 (V 1)

11. Mark: what we’ve got here are a list of questions from our group to
12. you lot about certain things/ I know Ian and Harry have got one and
13. Angela could say/ because we’re the people who made up these
14. questions to ask you lot/ →everyone(hand gestures) what’s the best

What Mark is doing here is a pre-amble, a reference to his intentions and a warning of what is going to come next. Instead of going straight in with the first question, he is framing it by an explanation of how to hear it. It is to be heard as part of a ‘list’ (11) (so members know that there will be more to come), and it comes from ‘our group’ (11) collectively, not just from the person who asks it. Furthermore, he explicitly sets
up the membership of two groups, and the two sets of expectations: ‘you lot’ (12, 14) are the group who are going to be asked, and everyone else is part of the ‘we’ group, the group that does the asking. Just in case this is not clear to everyone, Mark even finds a way of naming each individual who can claim to be part of the ‘we’ group, and to have a question. He then goes on to make explicit their authorship of the questions (13-14), and backs this up with his body language, indicating the whole group of ‘you lot’. This is a very finely crafted introduction, and could almost serve as a model for researchers. Further, it relies heavily on the setting up of two group identities. We will see in later chapters how successful alignment into interviewer and interviewee groups was both a goal of the research interview, but was also at times blurred and challenged. For the moment, however, in these opening encounters, it was a resource that Mark used to start to establish what was to happen next.

In all six visits, some such pre-amble happened before the opening question, and I would argue that it was essential for starting to define the event. Research Group members knew how important it was to establish ownership of the events, as is evidenced by a tape we made after the third research visit.

Extract 3:6 (S 4)

49. Mark: I was very very pleased with the way (. ) we all took it our [(.)
50. ourselves/ [seriously]
51. Angela: [seriously] 52. Mark: ourselves without turning to you/
53. yes yes you did more -
54. Mark: because we actually made it (1) our OWN =
55. research
56. Angela: = research visit/ although [Val – although Val Williams was there I
57. thought we took it [1 1]
58. Angela: [in turns to ask questions
59. Mark: [yes we didn’t ask you very much did we↑ (→ Val)

Clearly, being in charge and doing it themselves are essential ingredients of the type of event on which they are embarking.
3.5 Discussion

3.5.1 Who are we?

This chapter has started to identify strategies available to members for introducing both themselves and their purpose, and it has revealed the links between these two types of work. Towards the beginning of each visit, there had to be some kind of explanation of what was going on. The uncertain nature of the event that was occurring was matched by the uncertain nature of who the visitors were, and I have shown how tightly these two questions were intermeshed. In order to explain what type of event was happening, Research Group members had to foreground various aspects of their own identity. They could choose at any point to make one or other aspect salient, just as any participant in conversation can do (compare, for instance, Edwards 1998). To that extent, the tools that members used here were generally available ones that anyone would use – they are not specific to the self-advocacy or to the research context. As Antaki and Widdicombe (1998: 2) put it, people do not have 'this or that identity', but 'they work up and work to this or that identity, for themselves and others, there and then, either as an end in itself or towards some other end'. However, if they were to move into doing a research interview, then there were certain aspects of identity that definitely supported that purpose, namely group identities and professional researcher identities.

The two main extracts analysed in this chapter were from an occasion that was exceptionally mystifying to all participants. Research Group members were not normally called upon to account for themselves in such detail, but were able to produce the event by material actions such as the business around recording equipment, or by framing remarks that set up what was to follow as a research interview. However, the greater the doubt about the nature of the event, the more it was necessary for Research Group members to present the event in terms of their own identities. This appears to be why, in Visit 2, there was an extended discussion on the subject of group identity,
which led to the interesting situation of two slightly different group agendas rubbing up against each other, that of the self-advocacy group and that of the researchers.

Putting yourselves over as a team is, almost definitionally, joint work. One way for this to occur is for the whole team to defer to one spokesperson, and this is what appeared to happen in Extract 3:1. The few attempts by members other than Mark to do team talk did not cause trouble. Instead, they created the context for a demonstration of mutual support. Even in Extract 3:2, where individual identities were made salient, members still basically deferred to Mark; for instance, it was by Harry's reaction to Mark's implied criticism that he supported Mark's position as group leader.

What was happening here, though, was more than just one group doing a presentation to an audience. There were two groupings of speakers, and, as noted, they had two slightly different agendas. One of the features that emerged was how the organisation of the talk could contribute towards identity work. In other words, members all aligned either with one group or another, and they did this by virtue of the type of turns they took. Consider how it would have been if one of the Research Group members had turned to another to ask basic questions about the group's constitution. What happened at this point in the talk is that all members of the Research Group aligned themselves as respondents, while all members of the host group aligned themselves as questioners. By grouping themselves through talk, they identified their own groups. They could then use specific tools to build a self-advocacy group identity, such as use of locations for meetings, and times, and other tools to build the professional identity of researcher, such as the use of particular work-related vocabulary and the icon of the written leaflet. Both these sets of actions were devices to produce slightly different, but not incompatible, group identities.

Through all this, adherence to the meeting structure, and its formal turn allocation did help to maintain order, did seem to ease the communication between the different speakers, and the two slightly different repertoires. Doing a meeting involves participants in taking up very distinctive discourse identities, which feed into their transportable identities (that is, they re-create what they are talking about by their
present actions in talk). The orderliness of this particular stretch of meeting (Extracts 3:1 and 3:2) made it possible for two slightly different group agendas to come together and to co-exist. This finding is potentially important for self-advocacy groups: the process of the talk actually feeds into the product. I will summarise here some of the tools for identity work that have been revealed in this chapter.

Tools for identity work

1. **As a group**
   - group alignment in the talk: being one of the questioners or one of the respondents
   - referring to typical activities of the group (e.g.: meetings)
   - use of pronouns (‘we’/ ‘you lot’)
   - use of locations and place names
   - agreeing with, or complementing, each other’s contributions
   - deferring to one spokesperson.

2. **As individuals**
   - contradicting another group member
   - creating sub-conversations
   - invoking categories for one’s own status (e.g., committee member).

3. **As researchers**
   - professional vocabulary
   - use of a printed leaflet
   - construction and ownership of a body of knowledge (‘what is research’).
3.5.2 What are we doing here?

Although identity work is essential to establish an understanding of what is going on, interestingly the stretch of talk from which extracts 3:1 and 3:2 were taken did not flow smoothly into the further development of the group interview. The Research Group had an agenda, they had questions to ask. It was part of the definition of the event that questions were going to be asked and answered, and these questions belonged to the Research Group, not to the hosts. On Visit 2, their problem was to switch from being the respondents to being the questioners, while on other occasions this work was done perhaps more smoothly, without the preamble of a group presentation.

However, even when there was a degree of shared, prior understanding of the events as research interviews, some kind of formal introduction to what was about to happen still needed to be made. Research Group members clearly had a range of very potent actions open to them, which all contributed towards their definition of the event as a research interview:

- produce objects that would be used in the research interview, such as the tape recorder or the question sheet
- identify the agenda as their own, for instance by framing remarks
- ask for consent and mention confidentiality: thus producing the talk that is to follow as interview talk.

All of these actions are specifically research-like actions, especially when they occur in the context of doing a meeting, in which one chairperson takes control of turn allocation.

However, on their own they could not constitute, or set up, the event. In order for the talk to develop into a research interview, these actions had to be interpreted by
other members. This chapter has started to reveal how important membership categorisation is within this interpretative process. Indeed, the set of questions that the host group posed in Visit 2 were all premised on particular categories, which they were in effect testing out. They were interested to see how closely the visiting group fitted into a category with which they were familiar, that of self-advocacy group. In seeking to define the visiting members, the host group were also defining themselves. Their key assumptions, or membership categorisation devices, included very general ones, such as:

‘as you have all come together, we will assume that you are all a group that has regular meetings, unless you tell us otherwise’

Even when group presentation talk did not happen as explicitly as in Visit 2, it was still necessary for members to start assigning at least provisional categories to each other, in order for the event to get going.

In the end, it was by doing the actions of research that all members started to constitute the events as research interviews, and I explore in further chapters how this work happened. This analysis of introductions has started to underline how the various levels of identity are intertwined in these data. For instance, by behaving in a ‘researcher-like’ way, one can literally become a researcher; by asking questions (discourse identity of questioner), one can work to an identity of interviewer (situational identity), and this will in turn support a wider identity as a researcher (transportable identity).

It is interesting that one identity that was not made salient, so far, was that of person with a ‘learning difficulty’. However, it could be argued that the frame of self-advocacy group that was introduced in extracts 3:1 and 3:2 carried with it the presumed identity of people with ‘learning difficulties’, or self-advocates. In order to unpack that further, the following chapter focuses specifically on self-advocacy talk, a very salient context for the present project.
Chapter 4

Groundwork: self-advocacy talk

4.1 Chapter overview

This chapter sets out to explore what sort of a social activity self-advocacy is, and how this is played out in talk, as this is an essential issue for the characterisation of the research project described in this thesis. The Research Group met at a People First office, they called themselves a Self-Advocacy Research Group, and the project involved going to talk with other self-advocacy groups. In fact, their own seventh question (see Appendix E) was: ‘What do you think self-advocacy is?’

The central question in this chapter is the relationship between inclusive research and the self-advocacy context. Is that context essential or accidental to the nature of the research? Could inclusive research (see 1.7.2) take place outside the context of self-advocacy, or would it then be something different? This is a question that has great pragmatic significance, in view of the large number of different models of inclusion in the research process (Ward and Simons 1998).

The first problem was selection of extracts that could arguably be instances of self-advocacy talk, and so I discussed this with the Research Group. What follows is a summary of the themes that emerged from the sixth discussion session. There seemed to be a group of responses about self-advocacy as an individual quest, and another about collective action, as has also been noted by Goodley (2000) and Sutcliffe and Simons (1994). In our discussion members particularly focused on the type of talk that characterised self-advocacy.
### Table 2 Summary of Research Group members’ ideas about self-advocacy.

#### Self-advocacy as an individual quest

<table>
<thead>
<tr>
<th><strong>Saying what you want and hoping you’ll get it</strong></th>
<th>You can say what you like, and put the points of view to, and let them know what you want.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Learning independence skills</strong></td>
<td>It’s actually having people with skills and giving them a chance to develop. Skills are important I think.</td>
</tr>
<tr>
<td><strong>Individual assertiveness – sometimes seen as ‘therapy’</strong></td>
<td>I think it means speaking up for yourself, if you don’t speak up for yourself, you bottle things up for yourself.</td>
</tr>
<tr>
<td><strong>Behaving in a reasonable manner</strong></td>
<td>Being reasonable in your demands […] not shouting at others.</td>
</tr>
<tr>
<td><strong>Solving your own problems</strong></td>
<td>I see self-advocacy as a decision making – making decisions for yourself, rather than relying on other people.</td>
</tr>
</tbody>
</table>

#### Self-advocacy as constituted by a particular type of talk

<table>
<thead>
<tr>
<th><strong>Strong talk</strong></th>
<th>You’ve got to say bugger you, if I’m disabled so are you, so what the hell.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Using ‘self-advocacy’ vocabulary</strong></td>
<td>I wouldn’t use the word ‘caring’. I would use the word ‘support’ more than caring.</td>
</tr>
<tr>
<td><strong>Emotional talk</strong></td>
<td>We’ve got to feel – we’ve got to be personal in our lives as well, to speak out […] you’ve got to really pour it out.</td>
</tr>
<tr>
<td><strong>Social skills and understanding in a group</strong></td>
<td>It’s to do with their behaviour, isn’t it? Talking and listening, I would say - yes and listening.</td>
</tr>
</tbody>
</table>

#### Self-advocacy as collective work

<table>
<thead>
<tr>
<th><strong>Working hard together</strong></th>
<th>Everybody is working together like a team.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Advocating for each other</strong></td>
<td>We’re working hard for the people.</td>
</tr>
<tr>
<td><strong>Collective work over a network of groups</strong></td>
<td>It depends on the contacts you have with people in that group […] that is what self-advocacy is for me anyway.</td>
</tr>
<tr>
<td><strong>Taking ownership</strong></td>
<td>I’m thinking like it’s OUR meeting.</td>
</tr>
<tr>
<td><strong>Deciding what is right and wrong</strong></td>
<td>Saying […] what people should do and should not do.</td>
</tr>
<tr>
<td><strong>Campaigning talk</strong></td>
<td>It’s like going to Parliament, and going to an MP, and they think oh well, you don’t know anything about that. And we say, yes we do, we need access, we need rights.</td>
</tr>
</tbody>
</table>

When I took these themes to seek illustrative extracts, the picture was slightly more complex. For instance, the first extract, in section 4.2, illustrates the way members worked jointly to create several personal positions, and to explore political solutions together. The following section, 4.3, was chosen by group members as an example of
strong talk, and again explores the moves between the personal and the political in self-advocacy. In these extracts, particular types of talk and interational rights seem to be linked with the move from the personal to the political, and this theme is explored further in 4.4 by a trawl through the data, revealing how collective identity as 'people with learning difficulties' can be built up as a foundation for action. The discussion section, 4.5, will return to the question of the characterisation of self-advocacy talk, and the nature of the link between this research project and its self-advocacy context.

4.2 Moving between the personal and the political

This talk occurred some forty-five minutes into the first interview, and followed on from a question about transport. The extract given here occurs immediately following a discussion about the needs of wheelchair users for a minibus with a tail lift.

Extract 4.1  (V 1)

844. Darren: I like to say that we should be able - ab - not we - I or people like
845. me↑ (.) that are in wheelchairs↑(0.5) should be able to go out
846. anywhere/ (→ directly to camera)
847. Mark: yes/
848. Darren: if we got a life/ (0.5) no↑(1)
849. Mark: I see your point there/ (0.5)
850. Darren: but can you tell me why not↑/
851. Mark: uuhh (.)
852. Darren: no you can't↓/
853. Angela: hard question that to answer isn't it that one/
854. Ian: yeah/
855. Darren: aahhh (scowls)
856. William: Darren Darren have you tried to write to your MP about it↑/
857. Darren: if I try and write to my MP (. ) my mother does it (1) / I don't
858. bother (0.5)/ my mother does it (. ) all/
859. Val: you don't bother your - ↑/
860. Ian: MP/
861. June: his mother/
862. Val: your mum and dad would [do it]↑/
863. Darren: [yeah] yeah they look after me so I don't
864. mind/(1)
865. Angela: that's worth doing isn't it↑ (1)/
866. Darren: worth doing↑/
867. Angela: yes it is worth doing/ if you keep on – if you keep on then
868. they might do something about it for you/
869. Ian: yeah/
870. Darren: why – thank you (0.5) how do you mean though↑/
871. Angela: why don't you write to the – why don't you write to the prime
872. minister and ask him for some help and advice and see if you can get
873. some money for doing it right↑
4.2.1 Darren as a wheelchair user

In terms of turn structure, Darren remains the focus throughout this extract. He has alternate turns most of the way, and is most often selected by others, although he himself does not seem to select anyone in particular. He is addressing everyone, and commands everyone’s attention. There are no sub conversations here, very few overlaps or interruptions. It is true that Darren’s slow speech (and my clarification repeats at lines 859, 862) may contribute to the sense of order, since we all have to concentrate to understand him. However, the category that appears most relevant for Darren in this extract is that of wheelchair user, a category that he explicitly makes relevant in his opening lines (844-5). Darren appears to be the focus of attention because of his self-identification as a wheelchair user; he is taking the floor on behalf of others ‘people like me (.) that are in wheelchairs’, and he moves between ‘I’ and ‘we’, speaking as a representative. Since wheelchair users had already been under discussion, the relevance of his identity as sole wheelchair user present was important. It could be that members expected him to have something to say on this subject, and this is why the turn slot is left open for him, with everyone looking towards him. His first turn is delivered directly to camera.

In the first part of the extract (844-855), Darren fills the slots he is given with strong argumentation. His first turn is thus a statement of a general right (‘should be able to go out anywhere’), while his second turn at 848: ‘if we got a life (0.5) no’ carries the implication that this freedom of movement is essential to having a life. The
‘if’ raises the strong possibility that wheelchair users do not have a life, which is confirmed in his third turn: ‘But can you tell me why not?’ (850). This three-part argumentative structure is hearable as a kind of rhetoric to develop the unfairness of his situation. The implication is that there is no logical reason for him not having freedom of movement, and therefore not having a life. Therefore the fact that he does not have those rights must be due to other factors, other barriers. Together with his delivery to camera, these rhetorical strategies help Darren to come over as a political activist in these opening lines.

4.2.2 Keeping the talk going

The sequence structure reveals yet more of Darren’s strategies. There are eleven initiation/response sequences in this extract.

Table 3 Sequence structure of Extract 4:1.

<table>
<thead>
<tr>
<th>844-849</th>
<th>Darren (I)</th>
<th>Mark (R)</th>
<th>Darren (I)</th>
<th>Mark (R)</th>
</tr>
</thead>
<tbody>
<tr>
<td>850-852</td>
<td>Darren (I)</td>
<td>Mark (R)</td>
<td>Darren (third part)</td>
<td></td>
</tr>
<tr>
<td>853-855</td>
<td>Angela (I)</td>
<td>Ian (R)</td>
<td>Darren (third part)</td>
<td></td>
</tr>
<tr>
<td>856-858</td>
<td>William (I)</td>
<td>Darren (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>859-864</td>
<td>Val (I)</td>
<td>Ian (R1)</td>
<td>June (R2)</td>
<td>Val (I)</td>
</tr>
<tr>
<td>865-870</td>
<td>Angela (I)</td>
<td>Darren (R)</td>
<td>Angela (I 2)</td>
<td>Ian (third part)</td>
</tr>
<tr>
<td>870-873</td>
<td>→Darren(I)</td>
<td>Angela (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>874-875</td>
<td>Darren (I)</td>
<td>Angela (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>876-880</td>
<td>Darren (I)</td>
<td>Val (I)</td>
<td>Darren (R)</td>
<td></td>
</tr>
<tr>
<td>881-884</td>
<td>Mark (I)</td>
<td>Darren (R)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>885-888</td>
<td>Val (I)</td>
<td>Darren (R)</td>
<td>Val (I)</td>
<td>John (R)</td>
</tr>
</tbody>
</table>

As can be seen from this table, Darren only initiates four of the eleven sequences. At any end-of-sequence point, the whole extract and topic could have been terminated, yet he manages to keep it going. How does he do this? For instance, at line 870, he
responds to Angela with ‘why - thank you’, which could have been a final comment to round things off. However, he then keeps the argument going with another initiation ‘how do you mean though?’. At other points, he seems happy to allow others to initiate, and his responses can be heard not only as answers to their questions, but also as challenges to the force of what they are saying. When William, for instance, advises him in the fourth sequence to write to his MP, he responds that: ‘if I try and write to my MP (.) my mother does it (1)/ I don’t bother’. Each response he makes is a counter argument to a suggestion of another member, and this is what keeps the sequences flowing, since he provides slots for other members to come back with a fresh initiation. There seem to be some quite subtle judgements here on his part.

It is also interesting to consider the membership categorisation work that Darren does: ‘can you tell me why not?’ (850) would be more expected if addressed to someone who supposedly had the power to change the built environment. One could imagine it being said to a planning department official, or a local councillor. There is a definite sense of trouble in the replies. Mark hesitates at line 851, and Angela voices the trouble with: ‘hard question that to answer isn’t it that one’ (853). Mark and his colleagues clearly hear the question as challenging or perhaps unexpected. At this point, Darren is not including the other members in the same category as himself (people with a common cause), but is posing the arguments on behalf of the category to which he has assigned himself (people like me that are in wheelchairs). It is this act of splitting into two camps, wheelchair users and non-wheelchair users, that provides the real challenge. It also appears to keep the talk going, since no response entirely satisfies Darren’s challenges, and he moves to his final position ‘it’s a pain in the butt’.

4.2.3 Exploring action together

The initial three sequences in this extract (down to line 855) seem to leave Darren successful in convincing other members how difficult his position is. However, from that point onwards, there is a change in the turn content. First, at 856 it is William who introduces the solution of writing to an MP. This is an interesting suggestion, since it very concretely brings together personal action with a political force. It is about an
individual taking responsibility and doing something about the situation, but within a political framework.

It is interesting to see here how both Darren and his interlocutors position themselves in relation to significant others in their lives. Darren uses the following forms:

- I try and write (857)  
- my mother does it (857-8) – (twice)  
- I don’t bother (857-8)  
- they look after me (863)  
- I don’t mind (863-4)  
- if I write to the prime minister [... ] I’m just going to get my letter I send to him/ it’s going to be ripped up and thrown away (874-7)  
- I cannot explain what I want (882)

All the phrases in which he places himself as subject are negative disclaimers (‘I don’t mind’, ‘I don’t bother’) or are events in which he tries, but does not succeed, to do something. By contrast, his mother (and ‘they’ who might include his father?) are active and competent actors, who ‘do it all’, and even ‘look after me’. Darren almost wallows in working up his identity as a cared-for person. The actor who rips up and throws away his letter could be the prime minister, although the clause in which the ripping up occurs is a passive, subjectless format. Darren’s quick stepping down is remarkable. From the strength of his previous rhetoric, he now puts himself over as a passive, pathetic victim, dominated by his mother.

Angela and Mark, by contrast, use the following forms in their attempts to counter Darren’s defeatism:

- that’s worth doing isn’t it† (865)  
- it is worth doing (867)  
- if you keep on (867)  
- they might do something about it for you (868)  
- you write to the prime minister (871)  
- ask [...] and see if you can get some money for doing it right†(872)  
- you might get something out of it (875)  
- explain what you want (881)

Their advice to Darren places him consistently in the role of active agent – someone who could achieve something by his actions. In the main, these are verbal actions (in this case through the written medium), and so they are in a sense placing their trust in the power of words to change things. It is only a matter of ‘explaining what you want’.
Angela upgrades the target of this verbal requesting from 'your MP' to 'the prime minister', thus giving even greater force to the potential action which Darren could initiate. This portion of the discussion really seems to represent advocacy-in-action, with one or more self-advocates advising an individual about the best way of dealing with his (collective) problem. Solutions are being found from within the group, from the resources of the members themselves, and this very much illustrates the theme of advocating for each other (see Table 2). The work that Darren does in countering each suggestion of action has the effect of prolonging this flow of advocacy-in-action.

The sequence ends with Darren's recourse to emotion, and he is comforted by June, who holds his hand. His use of emotion, and the positioning of it within this extract, is interesting. It has the effect of terminating the flow of suggestions about what he could do. Emotions (Edwards 2001) do have purposes within conversations. Darren's remark at line 886 ('pain in the butt') changes the mood yet again, through invoking humour. His identity immediately becomes that of the comedian, rising above his current plight. What is so interesting about this example is the way in which several personal identities are created, all of which might lead to different forms of action. The identity of cared-for son leads to the action his parents might take in writing a letter for him. The identity of strong self-advocate leads to the action of the Prime Minister receiving his letter, but then tearing it up, while the identity of wheelchair user leads to the emotive suffering of inaction. Darren and the others are to some extent playing around with the concept of taking action, and exploring together what the possible consequences of certain actions might be.

4.3 A strong speaker

Having seen how members could work jointly to help one person move towards political solutions, I turn now to an extract that arguably has an equal claim to be considered self-advocacy talk, although it is largely an individual achievement. This extract was picked out by members when reviewing tapes, as an example of strong speaking.
Chapter 4: Groundwork: self-advocacy talk

Extract 4:2 (V 2)

297. Brian: well (.) hh I think it's very very bad when-when you - when you
298. LABEL people you know and I don't like the term er mental
299. handicap/ [I prefer the term
300. Mark: [no::
301. Brian: learning difficulty my-myself [or learning disability myself/ only I
302. don't like
303. Harry: [I quite agree
304. Brian: the term mental handicap/ cos I was -I was labelled myself some
305. years ago until my mother spoke up for me- as a mentally defective
306. but [we're not a
307. Angela: [what's that↑
308. Brian: mentally defective just because we're disabled you see/
309. disabled too/ and as I say (;) disability is not inability you see/
310. [just
311. Harry: [(...]]
312. Brian: because we're disabled we're not IMBECILES [you
313. Mark: [no::
314. Brian: see as some people/ so I think labels↓(.) labels can be pretty
315. awful you know/
316. Mark: no WH
317. Brian: very very awful/ this is why we phased out- phased out the
318. spastics society where I work and called it scope/ because it
319. doesn't er put so much of a stigma on it] you see/ and where I work
320. it's now called scope and it
321. Mark: [stigma↑ that's what we
322. Brian: talked about last week WH→ Val
323. Mark: [yeah
324. Brian: [ the spastics society is no more so it's now scope/ because
325. we found that (.) word s-spastics society put too much of a stigma
326. on- on it you know/ it had a stigma with it you know (0.5)
327. Mark: [unfortunately↑/

(throughout this extract, Brian addresses the whole group, glancing round the group from
time to time. Looks round towards camera and Angela, eyebrows slightly raised)

4.3.1 Keeping the floor

Starting with the turn structure, it is noticeable that Brian has one long overarching
turn throughout this extract. When I first listened to the tape, it appeared as if Brian
were the sole speaker, but on closer examination, many intervening or overlapping
remarks could be made out (lines 300, 303, 307). Brian is not simply performing a
monologue: his audience is very active and supportive. How does he manage, both to
hold onto his turn and develop his own meanings, but also to keep his audience with
him?
Brian gets the floor at line 297 with a ‘well’ and a throat-clearing noise. This follows quite a lot of confusion and false starts from other members, about appropriate answers to the Research Group’s question ‘What do you think about people being labelled?’ Brian’s turn is self-selected, and can be heard as an assertion of his right to clear up the confusion and give a definitive response. The first thing that can be noted about strong speakers is that they have assertive strategies for gaining the floor in the first place.

As I have remarked, Brian is not the sole speaker. There are many other speakers, who do short overlaps or interruptions. For instance, Angela’s interjection ‘what’s that’ (307) is seemingly ignored, or simply not heard. Other interjections are broadly supportive of Brian’s turn (‘I quite agree’ 303), and so are hearable as encouragement for him to continue. However, there are many potential turn allocation points, created by Brian appearing to have reached the conclusion of what he is saying (end of 308, end of 315). How, then, does Brian succeed in keeping his own speaking rights, and not ceding his turn? The most obvious strategy he employs is the manipulation of speed of delivery. The end of phrases, or units such as ‘mental handicap’ (298, 304) and ‘disabled too’ (309) are nearly all marked by a rapid move to the next phrase, without any pause whatsoever. This strategy removes the possibility that these points will be heard as turn allocation points. By contrast, when he is in mid phrase ‘when—when you – when you’ (297); ‘I think labels(. ) labels’ (314) he often repeats a word, or does slight hesitations, which slow down his speech slightly and have the effect of emphasising what he is saying. If he hesitated at the end of the phrase, this would run the risk of another speaker getting in.

There are alternative devices for keeping the floor, used by different speakers. Harry, for instance, often uses gaze direction very effectively. He glances round at his audience and engages individuals in short bursts of eye contact. All these are structural devices which enable a member to be in a position to deliver a long speech. They are prerequisites to such a delivery, but they could not of themselves constitute strong self-advocacy talk. For this, we must examine more closely the turn content and identity work being done.
4.3.2 Moving from ‘I’ to ‘we’

Brian (lines 297 – 304) introduces his speech by briefly, but strongly, stating his own opinion, both in general terms: ‘I think it’s very very bad when-when you - when you LABEL people’ (297) and then in specific terms: ‘and I don’t like the term er mental handicap’ (298). He then contrasts the label he is rejecting with those that he prefers, ‘learning difficulty’ or ‘learning disability’. This gives a tight, logical structure to what he is putting over. He subsequently repeats the phrase verbatim: ‘I don’t like […] the term mental handicap’ (302-4), giving it strength and emphasis. This opening section is all framed as personal opinion, with the ‘I’ pronoun, and verbal forms such as: ‘I think’ (297); ‘I don’t like’ (298); and ‘I prefer’ (299).

Following this strong opening, Brian then turns briefly to personal experience, which he uses very clearly as an example, a justification of his opinion relating to labels.

304. Brian: I was – I was labelled myself some
305. years ago until my mother spoke up for me↓ as a mentally defective

At line 309, he moves from the personal to the general, by quoting what sounds like a campaign slogan: disability is not inability. He introduces it as his own insight, however, and there is no reason to believe that any of the other members would know it as a slogan. In fact, Brian takes care to personalise the slogan, by the phrases ‘as I say […] you see’ (309). These could be heard as devices to draw the audience over to his point of view, and to put himself over as a good explainer. The final phase of his speech (314→ ) brings together the personal and the political, since he portrays himself as taking on a key role (along with others – ‘we’) in changing the very name of the Spastics Society to ‘Scope’.

The different phases of Brian’s speech, moving from personal opinion, then personal experience, to general adage and then political action, are marked by his use of personal pronouns (the ‘I’ of the personal passages is replaced by ‘we’ when he reaches the stage of generalities). His final use of ‘we’ in connection with SCOPE links up with the earlier ‘we’: ‘we’re not a mentally defective just because we’re
disabled' (306-8). In that first ‘we’ he had included himself in a group who could be called ‘disabled’, and it is this same group of people, including himself, who changed the name of the Spastics Society to SCOPE. Thus labelled people can be active workers, who can change things.

4.3.3 Portraying oneself as an active agent

In addition to his use of pronouns, it is interesting to note Brian’s portrayal of his own agency.

I think (297)
I don’t like (298)
I prefer (299)
I was labelled myself (304)
my mother spoke up for me (305)
we’re not (312)
we’re (disabled) (302)
we phased out (317)
where I work (318)
we said (323)
we found (328)

Brian consistently positions himself as a responsible agent rather than a passive recipient of others’ actions. The only subject in which he is not included is ‘my mother’, who has a very brief role during a subordinate clause. In particular, his own actions occur in the form of cognitive processes (opinions) which account for the first three processes mentioned, and also in the form of material actions ‘we phased out – where I work’. Of particular interest are the verbal forms ‘we said’, ‘we found’, which are statements of actions performed by the talk of himself and others (we). The only absent subject is in the phrase: ‘I was labelled myself’. The person or people who did the labelling are not present, and are not specified. By their very absence, they appear to pale into insignificance, by contrast with the firm action of Brian and those with whom he identifies. Through these precise strategies, Brian gives a view of himself as part of a political process, as actively able to change the view that society has of him. It is a masterful piece of rhetoric, and as we have seen, the audience responds very positively to him.
4.3.4 Doing social commentary

Having explored how one member can take and keep the floor, it is perhaps worth looking beyond Extract 4:2, to see how a strong speech such as Brian’s is dealt with. The following occurs directly after 4:2.

Extract 4:3 (V 2)

331. Angela: excuse me what’s that↑ I don’t know what [stigma means/  
332. Harry: [disabled people  
333. (. ) I THINK (. ) is-is usually based (0.5) I think (. ) the disabled people  
334. are the same people as are being labelled↑/  
335. Looks round → Angela, then back to whole group  
336. ? yes  
337. Harry: what I think what I think about this I think it is— I think it is wrong/  
338. anyone ANYONE in this group here could be dis- disabled (0.5)/  
339. anyone/  
340. ? mm  
341. Harry: they come from- it’s usually back there in Norton where I live  
342. you know/ (0.5) I think to myself I think Norton’s a very big city and I  
343. THINK (. ) there is people who label are usually- are usually in  
344. Norton( ) / an - and I said there again I think people who label people  
345. (. ) there is nothing to la- laugh about because they have (0.5)— they  
346. are the same people as learning difficulty or people who are  
347. disabled/ to me it is all the same/ (1)  

(throughout this speech, has addressed the whole group, glancing round the group from time to time. Looks round towards camera and Angela, eyebrows slightly raised.)

Harry self selects at line 332, ostensibly to respond to Angela’s clarification request, but in effect his turn then becomes an extension, or a further response, built on Brian’s previous turn. Brian left unsaid the issue of who does the labelling, but Harry picks up this point, and locates those who do the labelling as inhabitants of Norton: ‘there is people who label are usually- are usually in Norton’ (343-4). He also specifies who could be described as ‘disabled’ (‘anyone ANYONE in this group here could be disabled’: 338) and then makes a further attempt to clarify their identity and the identity of those who do the labelling: ‘they are the same people as learning difficulty or people who are disabled’ (346-7). Harry appears to be making the point that people are basically equal, that everyone is a person.

His turn does the work of fleshing out the generalities of Brian’s speech, and giving it yet greater authority. Where Brian’s strength was achieved through some technical language such as ‘stigma’, and the naming of national societies, Harry makes continued use of ‘I think’ (ten instances), and uses a slower pace of delivery than
Brian's. He uses short phrases, pauses and glances around the group, all of which lend weight to his discourse identity as a thoughtful social commentator.

His comment 'there is nothing to laugh about' (345) is especially interesting. It is not clear whether he is commenting on people's tendency to laugh at people with learning difficulties, or on the possibility that someone might laugh at his own speech right now. Whatever the case, it is clear how important it is for a self-advocate to be taken seriously. This is not something that is a given; it has to be worked up by strategies such as the ones I have outlined above. This finding is backed up by other self-advocates; the Swindon People First Research team suggested the following item on the research skills curriculum which was mentioned above (2.8.2): 'get other people to take you seriously'.

4.4 Strategies for constructing self-advocacy as a collective enterprise

The three extracts (4:1 – 4:3) that have been analysed so far in this chapter have revealed how self-advocacy talk can be about individual or joint achievements. It was characterised by strong, rhetorical arguments at times, but above all by the subtle interplay of the personal and the political. Often this was done jointly, as we saw in the first and the last extract, marking it out as a collective enterprise. In Chapter 3, we saw how this collectivity could be built up by talk about group adherence and ownership. There were also some occasions when members took this type of talk further, and linked their own group membership with possible action. The following section is based on a trawl through the data for examples of such group talk.

4.4.1 What does self-advocacy mean to members?

The obvious place to seek examples of group talk might appear to be in answers to the Research Group's question (Appendix E): 'What do you think self-advocacy is?' However, not all talk about self-advocacy is self-advocacy talk. This question led to some very different responses, and as always these are embedded in local contexts. For instance, the question was frequently heard as a test question, which admitted of correct or incorrect answers, as in the following extract:
Chapter 4: Groundwork: self-advocacy talk

Extract 4:4 (V 1)

914. Mark: what do you think self-advocacy is? (looks up and smiles at end of question)
915. John: speaking up for yourself (smiling → Mark)
916. Mark: yeah yeah/
917. John: saying what you want/ (.) what what you think and what people should should do and should not do/ (looks away during this speech, then with a smile back to Mark at end)
918. Mark: yeah that's right/

'Speaking up for yourself' (915) and 'saying what you want' (917) are familiar phrases to those who have talked about self-advocacy before, and feature in many definitions (Sutcliffe and Simons 1994: 2). Members here also seemed to hear them as correct, since they were reinforced by the evaluative comment 'that's right' (920).

The follow-up question which the group posed was 'how do you organise your group?' and this again often led to some trouble. In Visit 2, for instance, the group constitution was so confused that the self-advocate members could not explain it, and the paid supporter to the group took over. In Visit 1, as well, the supporter took over the explanation, and in Visit 4 the following exchange occurred:

Extract 4:5 (V 4)

1356. Mark: so - so have you - are you only just STARting (.) starting the group
1357. up↑
1358. Andrew: yeah
1359. Mark: not actually - you haven't really (.)
1360. Andrew: yes we are only just starting as this group yeah / this Thursday groups um (0.5) / but we are trying to extend what we are doing you know to other groups
1361. Mark: that's right/
1362. Sarah: = in this group at all/
1363. Angela: why's that then↑

A few turns later, the supporter to that group broke in, saying:

1387. Sarah: we have STRUGgled/ I'm sorry I know they should speak but we're talking about staff/ I'm not a member of staff in this group/ there is no support from anywhere =
1388. Mark: no support↑
1390. Mark: = in this group at all/
1391. Sarah: why's that then↑

There is interactional trouble here, amounting to an expressed dilemma, with Sarah feeling she has to apologise for taking a turn. Clearly, self-advocate members should have the right to tell of their own group process. In Chapter 7, I return to the issue of how identities of supporter and self-advocate are built up through their respective
interactional rights. However, there was one occasion (Visit 2) on which the depiction of group process had a feel of greater confidence, as will be seen in what follows.

4.4.2 Team work

Extract 4:6 (V 3)

Roger: self-advocacy (0.5) is (.) a special word/ (1) pointing gesture with index finger of left hand
because the special word is (.) everybody is working together like a team (1)/ because we do lots of advocacy/ we does a lot of things/ we go to self-advocacy groups/ (.) we run groups/ we does a lot of groups/ (finger gesture stops) but I'm finding is (folds arms) you work like a -we work hard/ I'm thinking (0.5) if I didn't have that/ we wouldn't (.) have (.) a word rounded gesture with both hands/

Roger's turn is very neatly constructed. He starts with the statement that self-advocacy is a special word, then he gives examples of what makes self-advocacy special in his experience, and finally comes back to a consideration of the word in line 506: 'if I didn't have that/ we wouldn't have (.) a word'. He uses three-part structures, or rhetorical lists, such as 'we go to self-advocacy groups/ we run groups/ we does a lot of groups' (504-5). He is an extremely effective rhetorical speaker, just as Brian was in the previous extract. However, a rhetorician is an individualist, and I would like to show here how Roger achieves his aim of working up collective ownership of the self-advocacy group.

Firstly, Roger's use of the pronouns 'I' and 'we' is interesting. In his first turn he uses the following forms:

everybody... we do... we does... we go... we run... we do... I'm finding... you work... we work hard... I'm thinking... if I didn't have that... we wouldn't have a word

The use of 'I' is contrasted with the 'we' of the group: 'I' is the person, himself, who is considering the issue and delivering his opinion, but self-advocacy is portrayed as a group, a 'we' activity. Roger builds up a group identity of effective social actors, by portraying the 'we' as a group who can achieve things:

we does a lot of things (503)
we go to self-advocacy groups (504)
we run groups (504)
4.4.3 The link between ownership and identity

As I have suggested, Roger effectively presents a group identity in which members are active, and the joint work he talks about is mirrored by the interaction they demonstrate. This is how that same extract continues some six lines later on:

Extract 4:7 (V 3)

At line 515, May self-selects with her question 'what IS self-advocacy?'. She gets in here very quickly, with no pause between this and the previous turn. This question can thus be heard as implying that his previous contribution may not have been quite on target. He immediately responds with ‘it’s for learning difficulties’ (516), choosing to define self-advocacy not as an activity, but by a particular membership categorisation of the people who take part in it.

Roger then goes on to give a storied example of what this identity can mean. He refers to a particular occasion, on which some other people came into their group, who were not welcome. This is a particularly effective way of making salient the identity of ‘learning difficulties’: it is a pre-requisite for ownership of the self-advocacy group. Instead of defining ‘learning difficulties’ as an impairment, Roger then contrasts it with ‘people from outside’ (519), the people who are not allowed to come into the group. May assists him with this contrast work, by specifying the outside people as ‘some big bosses’ (523) and even characterises their intention as trying to ‘hi-jack’ (523). Through this short piece of narrative, then, Roger and May together manage to give the strongest argument for foregrounding an identity as people
with learning difficulties. It is by virtue of this identity that members own the self-advocacy group, and it is this that gives them their strength.

May’s use of vocabulary could be drawing on various discourses. The ‘hi-jack’ is a metaphor from terrorism, but the words ‘big bosses’ sound very much more like a childish characterisation of adult, important people. In this context, however, it evokes laughter (518) and so it comes over more as a shared joke. By using these words to describe the people who shouldn’t have been in the meeting, May and Roger are effectively turning the tables on them. Whereas people with ‘learning difficulties’ are often treated as children, it is now the outsiders (the others) who are dealt with in childish language. Roger picks up the implication of May’s words, and carries on with the strong, bullish vocabulary ‘we kicked them out the door’ (524), thus adding to the strength and power inherent in the ‘learning difficulties’ identity.

4.4.4 Strength through interactional rights

Building a strong identity as people with ‘learning difficulties’ can lead to the possibility of ownership of self-advocacy. The salience and strength of this identity makes it possible for Roger to reach his climax with ‘it’s OUR meeting/ and we run it like what we run it as’ (526-7). This is the clearest statement yet of the importance of interactional rights. Being in control of the process of self-advocacy (i.e. being in charge of the meeting) is the key to moving on to collective action. This is the crux of the matter. Where the identity of ‘learning difficulty’ is linked with strong interactional rights, then this is the heart of self-advocacy, and can lead immediately to effective action.

Paradoxically, in our data, those in the role of supporter, like May, were quite often the people who moved the talk on to this plane, as will be explored further in Chapter 7.
4.5 Discussion

What has this chapter shown us about the characterisation of self-advocacy talk? In summarising the findings, I will also consider some issues about the link between the current research project and its self-advocacy context.

4.5.1 Individual rhetoric

Is self-advocacy about rhetoric? Brian and Harry in Extracts 4:2 and 4:3 demonstrated how important it is to have assertive strategies to gain a turn, keep the floor, and keep your audience with you. Both these speakers, as well as Darren and Roger (Extracts 4:1 and 4:4), used rhetorical devices such as three-part structures, lists and repetitions.

However, the term ‘rhetoric’ can be used pejoratively, as empty rhetoric, to mean that a speaker’s words have no substance, but are used simply to gain effect. All talk is tied to its local situation of interaction, and in these research visits, a certain amount of rhetoric was often considered to be appropriate. Members were being asked, in effect, to perform and to rehearse their arguments in public. Moreover, the public setting was a very particular one, in which interviewers and interviewees purported to share the identity of self-advocate. They were therefore able to draw on a shared interpretative repertoire about rights, labelling, and discrimination, which could be worked up into the verbal shorthand of a speech.

It could be claimed that the research project depended on the ability of members to work up a rhetorical speech. Collection of data would not have been possible if no one had felt able to talk, and strong individual speakers were much appreciated by the researchers. Their own analysis made much use of those parts of the data containing strong rhetoric. In Chapter 3, it could be appreciated how the research project fed on the structure of meeting talk, which enabled turn allocation to proceed in an orderly fashion. In a similar vein, individual speech-making in self-advocacy is also a resource that this research project, and other similar research projects, can use.
4.5.2 The personal and the political

Much of the analysis in this chapter was about the mechanisms that self-advocates used, in order to move from individual self-advocacy into political or collective action. However, the route from the personal to the collective was found to be a two-way street; members were interweaving the personal and the collective. Brian, for instance moved between ‘I’ and ‘we’, and portrayed the changing of the name of the Spastics Society as part of his own personal action. Darren, even more clearly, in Extract 4:1, actually used his own personal problem as a wheelchair user to trigger discussion of possible individual and collective action.

In order to ‘do self-advocacy talk’, members need to bring with them their own personal issues, and to be prepared to use these in the talk. This is the self in the self-advocacy, and it is this element which one of the Research Group members referred to when he commented:

And we've got to feel – we've got to be personal in our lives as well, to speak out. And you've got to say, I've spent my time in an institution, that sort of thing. You've got to really pour it out. You've got to be more open. (D 6)

Again, one can see how the research project also needed and used this move between the personal and the political. Personal stories of discrimination and of achievement were the meat of the data. Most of the Research Group's questions were asking members to reflect on their own experience and to contribute aspects of it to the discussion of more general issues. The aspects of self-advocacy talk described thus far have very general significance. They are not just a product of the current research project. Any research, or consultation, exercise would find these features very useful:

- An orderly meeting structure, where people take turns to speak.
- A few members who are prepared to deliver strong rhetoric.
- An expectation that personal stories of members' experience can be used within political talk.
4.5.3 Finding your own solutions

Moving further into what self-advocacy actually means also moves us further towards the essential connections between this research project and its context. It will be recalled that many of the characterisations of self-advocacy talk were to do with individuals portraying themselves as decisive social actors, rather than as passive recipients of others’ actions. In Extract 4:2, we saw how active agency could be achieved through the precise use of verbal forms. In Extract 4:1, members explored possible routes for action through the talk itself. Other members were feeding Darren with possible active roles, while he countered these with the passive, cared for identity that he created for himself.

It is the resourcefulness of the self-advocates themselves that marked these passages out as self-advocacy talk, and these three extracts would certainly not have been selected as strong self-advocacy talk if, for instance, supporters had been responding to members’ complaints with suggestions of what they should do. Goodley (2000) also found that resilience was an important characteristic of self-advocacy. It should be noted that resourcefulness is a marked feature of the talk precisely because of the background of discourses in which people with learning difficulties are placed in passive, helpless roles, just as Darren indicated. It is this contrast that makes the talk challenging, and make it important for self-advocates to ‘do resourcefulness’.

It could be argued that the present research project was equally constituted by resourcefulness at the level of talk. Instead of waiting for others to solve one’s problems, the research was conceived in a spirit of do-it-yourself. By taking up the reins to be researchers, members were demonstrating that they could indeed solve their own problems. It could be argued, then, that resourcefulness provided a very strong connection between their project and its context of self-advocacy. Could the research have happened outside this context? On one visit (Visit 6), as will be explored in Chapter 6, the usual resourcefulness of self-advocacy talk was not apparent, and in fact, the construction of the event as a research interview did become severely threatened.
4.5.4 Collective work

A final theme to emerge from this chapter is about self-advocacy as team work. In Extracts 4.5 and 4.6, the team work Roger talked about was reflected in the smooth team approach to producing the talk. Doing team work, as demonstrated in this example, was dependent on a background of shared knowledge (this was how May was able to support Roger in putting over his story about ‘kicking out the bosses’). Extract 4.1 also demonstrated how self-advocates could produce and construct political action together, through interaction. Instead of dominating with one long turn, Darren demonstrated his interaction skills in bringing in other members, and keeping the talk going by re-initiating sequences and producing verbal challenges. This led to interaction in which members were pushing Darren into considering possible actions, taking his own issues beyond the personal and well into the political. As Roger described, and Darren and others demonstrated, self-advocacy is actually about a ‘we’: the process of self-advocacy is about collective talk, and it is through talk that positions can be explored and change can be brought about.

It seems then that the key to understanding self-advocacy as a mechanism is the group, the collective. Inherent in this concept is an idea of belonging, and Roger expressed this very eloquently in his description of his self-advocacy group. It is precisely the membership categorisation of ‘learning difficulties’ which enables self-advocates to be strong in taking ownership of the interaction within their own group. However, the final trawl through the data revealed how essentially fragile the interactional rights of members to describe their own processes could sometimes be. This fragility appeared to be linked to factors quite outside the talk, factors relating to the funding for their groups, the regularity of meetings, their own status and the possibility of setting up proper structures with support.

It was the posing of the group’s penultimate question that revealed some of this trouble, but in the very posing of that question, Research Group members salvaged their own interactional rights to pose their own questions. Research talk is thus a form of self-advocacy talk – it could almost be characterised here as the leading edge of self-advocacy talk. This chapter has demonstrated the potential of talk itself. Sel-
advocates have rights within their own organisation to deal with their own talk, to find their own solutions, and to take ownership as a collective. It is these features (which are features of the talk-in-interaction) which distinguish self-advocacy talk as a genre, ‘a socially ratified way of using language in connection with a particular type of social activity’ (Fairclough 1995: 14). It is by embracing this genre of self-advocacy talk that self-advocates are creating a strong challenge to the dominant orders of discourse relating to Learning Difficulty.

This chapter has started to unravel some of the essential connections between that enterprise and that which the Research Group undertook. Not only was the self-advocacy context a bedrock for the present project, but by doing research members contributed to and strengthened that context. The following chapter will take a closer look at how they did this work through being interviewers.
Chapter 5
Doing interviewing

Mark: I don’t think you’re going to get as much information from an MP than you are from a researcher [...] Val: who has got the most power then†/ Mark: people with learning disabilities/ (S 5)

5.1 Chapter overview

This chapter and the following one are about how Research Group members became researchers, through the work they did in the interviews. It is argued that they not only worked up research and their own researcher status through talk, but they contributed towards defining a new type of research. A central aim of this chapter is to consider how and to what extent they created something new, and how far they drew on existing repertoires of research interviewing.

The data that will be analysed in these two chapters are from the research visits (see Preface: third stage). These are very much occasions which were constituted by talk (as argued in Chapter 3), but I am mindful of the fact that interviewing is only one activity in the wider social activity of research. For instance, it could be argued that being a researcher also took place in the group sessions we held to plan and write up our research, and this material is analysed in more depth in Chapters 8 and 9. Interviewing, however, could be considered the first public face of a research project, and as such it was important in constituting what we were doing.

Section 5.2 is about the views of Research Group members concerning research. The data come from one of their discussion sessions, and a thematic summary of their views is included here, in order to ground the selection of extracts. The themes they suggested led me to an extensive trawl through the data, to find both examples and counter-examples, before selecting extracts for analysis.

Section 5.3 presents an analysis of an extract from the third visit (see Appendix E), which I argue is demonstrably research like. It has the feel of a successful interaction, in which collaboration is achieved jointly by all participants’ contributions to the talk.
Such collaboration may be essential for in-depth interviewing, as Holstein and Gubrium (1997: 114) claim, but it has to be worked up in local interaction. I wanted to highlight extracts where one can witness this process at work, and to see how members achieved this. Some features emerge of the kind of research they were doing, including, for example, the joint construction of meanings. In the following section (5.4) further strategies for successful interviewing are explored through some examples from the wider data, concluding with a brief discussion (5.5).

5.2 Views of group members about research

As was mentioned in Chapter 1, it is often considered that people with ‘learning difficulties’ cannot do their own research. In depicting the visits we made as research interviews, and the four members of the Research Group as researchers, we were thus challenging many assumptions by professionals and academics about the identities of people with the label of learning difficulties. Questions about the status of the events were part of the reflexive process for group members themselves. One member commented after a research visit we had conducted:

Member: It's not actually a very easy job, people think oh it's easy, but it's not. You come home in the night time, and you're knackered. And people think you go to a meeting and you sit on your backside all the day, and that is crap. (S 4)

Although they had reflected on their research activities all along, we decided to draw together their insights in one of our discussion sessions (see Preface: Stage 6). This took place on 7th April 2000, and was held specifically in order to guide my own thinking and choices in analysing what it means to be a researcher.

The first point they made was about campaigning. There is often a considerable blurring around the boundaries of campaigning and research activity, as one member commented:

Member: I think I am more on the line of campaigning – taking action and getting things changed. That is what research is for. (D 7)
People wanted to do research because of strong feelings about some issue or other. Research is an activity relating to something that affects their own lives, or the lives of people with whom they identify.

The process of doing research is perceived by all group members as something that has given them autonomy and independence. Therefore, another of the themes on which they focused was their own sense of power:

Member: People with learning difficulties have been unempowered for a very long time, and it's about time that people with learning difficulties have power to themselves.

(D 7)

The power within the interviews is chiefly to do with taking control of the interaction, which is seen as similar to chairing a meeting, and they mention things like listening and being in charge. However, members also realise the implications that their work could have in a wider context:

Member: It's the only way that you're going to have a chance to express your opinion on things. One of the things I feel very strongly about is disability, because the book deals with disability. Not only in the book, but actually in a conference. If a researcher goes to a conference, and they see the book, they can see the sort of thing that I've done.

(D 7)

It is worth emphasising that the process of doing the research is not the end result, nor is it seen as such by the self-advocates. They perceive that it can have power to change things in the world, and that is why they are doing it. Another member characterised research as being about communication, in the widest sense – about groups of people getting better at listening to each other (Palmer and Turner 1998). The doing of the research is an instrument, a route between the present endeavour and the wider world.

I was particularly interested in finding some examples of talk which related to strong feelings, especially about wider issues, and which showed members relating present experience to broader themes. This seemed to all of us characteristic of what we meant by research. However, at the same time, I was mindful of their view of research interviewing as an (individual) skilled activity, which involves posing and explaining questions, listening to responses and encouraging people to talk. The process of
conducting a research interview does involve taking on these conversational rights and obligations, and it is by doing this that members achieve the status of researchers. Therefore, my goal was also to focus the analysis on extracts which revealed this process at work.

5.3 Success in doing research interviewing

The first extract that I wish to examine in depth in this chapter is from the fourth visit. It follows the question about jobs, but as will be seen, there is still some unfinished business from the previous question about discrimination.

Extract 5.1 (V 4)

646. Mark: I want to go back to [Andrew/] on that – on that thing → Andrew
647. Frances: [and Mrs Potter wasn’t [it]LF
648. Jenny: [yeah
649. Mark: were you pressured↑(0.5) =
650. Keith: that was years ago wasn’t it↑ (sits back in seat, smiles)
651. Mark: did you feel that you were pressured against doing the job↑(1)
   (leans forward → Andrew)
652. Andrew: e: r yeah I did feel pressured in – in one way yeah/ because =
653. Mark: mm
654. Andrew: um they never give me the opportunity to prove what I could
655. and couldn’t do you see/= giving them tasks to do↑=/
656. Mark: oh right right/
657. Andrew: = you know I was quite capable of looking after a group and
658. Mark: so /
659. Andrew: it was left to one of the students there/ and I felt I felt (. ) very
demoralised about it you know/ er very (. ) hurt about it/
   → Mark, but at ‘hurt’ → Sarah: hand gestures ‘tasks’ ‘demoralised’
660. Mark: so that was (. ) you tu- (. ) er ju- (. ) / this going back to question
661. two again
662. Frances and others: LF
663. Mark: really going back to question [two again because you are
664. Andrew: yes
665. Mark: saying that you were PRESSured by not (. ) showing a person what
666. you were doing/ but you were also discriminated against it/
667. Andrew: (is that right)↑/
668. Mark: yeah
5.3.1 Taking control of the interview

The first feature to notice about this extract is the way in which Mark controls the turn allocation. His rights in this respect are made more obvious by the fact that a sub-conversation is continuing at the opening of the extract, but despite this, Mark does a very deliberate selection of Andrew for next turn: ‘I want to go back to Andrew’ (646). He establishes this going back to Andrew as the main business, despite the fact that he has technically interrupted another sequence. The video transcript (p. 1) indicates that he was leaning forwards, with his gaze directly on Andrew at this point, slightly smiling, and with both hands outstretched in front of him. In this context the continued talk between Frances, Jenny and Keith actually comes over as an interruption of Mark.

Mark’s questions to Andrew (649 and 651) continue, and he successfully hands the floor to Andrew, to establish a dialogue. From that point on, Andrew and Mark have alternate turns, although Mark’s own turns are minimal (‘oh right right’ 656; ‘mm’ 653). Andrew is effectively showcased as a respondent, with a right to tell his story, and overlaps and interruptions in the remainder of the extract do not cause trouble for members. On the contrary, they seem to lend a flow to the whole sequence (Mark’s ‘so’ at line 659), since they indicate that members are engaged and listening to each other.

In terms of sequence structure, this extract can be seen as a very orderly exchange between Mark and Andrew, overlapping at the beginning with the tail end of a conversation between Jenny, Frances and Keith. The former consists of an initiation by Mark, which is continued over three turns (646, 649 and 651), followed by a response from Andrew (652, 654, 657 and 660), and then Mark’s third part which starts at line 662. This turn is important, since Mark comes in at this point, in order to offer his own interpretation and evaluation of Andrew’s response. Looking back to the start of this extract, his initiating remarks (649 and 651) were not neutral invitations to speak. They were strongly suggestive of the way in which Andrew should frame his response: ‘were you pressured↑’. The laughter at line 667 is perhaps an indication
that members too feel that Mark has framed the whole sequence, almost to the point of setting it up.

When I considered the wider context of the talk, I realised that Mark is referring back to something which Andrew has contributed much earlier in the discussion (some 50 lines earlier):

Extract 5:2 (V 4)

599. Andrew: well I was um I was a volunteer care worker for about (...) um for about 600. 3 years up there (...) and um they never give me the opportunity to 601. look after the group or help them out properly† you know/ the ones 602. who wasn't able to do anything for themselves/ and um after about 2 603. years I got fed up with it – fed up with it/ because er it was a childish 604. – the staff were treating me like a child to start off with/ (hand gesture on 'properly', then on 'childish' and from then on) 605. Frances: that's true/

The job that Mark refers to in Extract 5:1 is that of ‘volunteer care worker’ which Andrew had mentioned here; Mark recalls a piece of earlier talk, produces it from Andrew, and then takes on the rights to problematise it. In order to do this, he poses a question to Andrew that is not part of the pre-set agenda of interview questions. He makes up his own question ‘did you feel that you were pressured against doing the job†’ (651) which is locally tailored to Andrew’s earlier story, and which is going to link in with the work he wishes to do in his own elaboration.

Mark is taking on here the classic functions of the interviewer, as described by Silverman (1973) (see 1.7.1), such as controller of relevance. He effectively sidelines a conversation which is not at that point part of the research, he allocates turns, and he establishes that this display of Andrew’s experience is the business of the occasion. The ordinary resources of conversation are used in a very particular way, to lend this event (at this point) definition as a research interview.

5.3.2 Achieving collaboration

As observed above, the remarks made by Frances, Jenny and Keith (647-50) are the tail end of another sequence; it related to college courses, and at this point, what these members say is based on their own shared knowledge (for instance, the name of a particular tutor they knew) which is not explained for the visitors. However, after line
650, this conversation ceases, and all attention turns to Mark and Andrew’s dialogue. What are participants doing in making this move? The group supporter can be seen on video just after line 650, putting her right index finger to her lips to silence Keith, and so there seems to be a realisation that the proper thing is now for Andrew and Mark to talk. It seems that members are demonstrating their sensitivity to the fact that they are doing a research interview, and that, as Silverman (1973) observed, talk should be ‘on-the-record’. Although personal stories are called for in an interview setting, they must orient to the interviewer’s needs. The collaboration that Andrew and Mark work towards is dependent on all other participants displaying sensitivity in this way.

The video evidence also indicates that all members present are, from then on, attending to the one conversation, which is going on between Mark and Andrew. The laughter at line 664 is a good indicator of how closely other members are following the import of what is going on, since it can be heard as a kind of surprised applause for Mark’s ‘going back to question two again’. At that point, the video camera sweeps back from Andrew to Mark, and every member can be seen smiling or laughing, including Andrew himself, who is leaning forward attentively.

In terms of sequence structure, Mark’s short remarks at lines 653, 656 and 659, as well as Andrew’s ‘yes’ at line 666, are all responses to the immediately preceding remark. However, they serve the purpose of encouraging the speaker to continue, since they acknowledge that the talk is acceptable and praiseworthy. These short remarks do the work of encouraging Andrew to say more, and to fill in the detail about what happened in his story. Line 655, for instance, could have formed the end of Andrew’s contribution, but Mark continues with a ‘right right’ in the following line, and Andrew then goes on with: ‘you know I was quite capable of looking after a group’ (657). His initial hesitancy at line 652 (e::r) is overcome, and he not only fits his example in to Mark’s frame of ‘feeling pressured’, but he also details what he was capable of doing, and who was actually given the tasks he should have done.

Appeals for a collaborative attitude can be done through quite small details, and they include here Andrew’s own use of ‘you see’ (655) and ‘you know’ (657). These appeals for agreement are part of the stock of generally available conversational devices for helping conversations to flow smoothly, and are matched by use of gesture,
both by Mark and by Andrew. An example of this is contained in the following fragment, when the camera was on Andrew:

Page 6 of video transcript of Extract 5:1

I felt (. ) very demoralised about it you know/er very (. ) hurt about it/ M: so that

Andrew:  
Gaze→ Mark ............................................................. /→Sarah/→Mark........
Hand forward........../hand down ................................................ /... * l.h. gesture, then drops hand.......... (gestures towards own chest)

The gestures towards the chest seem to work as a way of illustrating and emphasising his feelings. Thus Andrew is giving Mark precisely what was asked for, namely an example of being pressured. The sharing of feelings is what is called for here, and both players collaborate on this project.

5.3.3 Competent identities

The identity work done in this extract is very much about competence. Andrew’s whole case rests on the contrast between himself as someone who could do things, if given the chance, and the group whom he wanted to look after, who in fact needed to be given tasks to do (657-8).

In line 654, he makes his first appeal to a competent identity: ‘what I could and couldn’t do’, and he then portrays himself as someone who was ‘quite capable’ (657) and someone who can give out tasks to others. In the particular setting of the day centre, about which he was talking, this would give him the status of a member of staff, rather than a client. It is interesting to see how he introduces the other social actors in this short narrative. The identity of the student is contrasted with his own, but he is referred to as ‘one of the students there’, not even worth bothering about as an individual. Our shared understanding of a student (in the context of a day centre) was someone who is only there for a few months (on a practical placement), someone who is temporary. The fact that such an unimportant person could be chosen for a job, over Andrew himself, is further argumentative justification of his hurt feelings.
Moreover, those who have the power to allocate jobs in this setting are backgrounded as subjects. At line 654, Andrew uses the impersonal ‘they never give me the opportunity’, and at 660, he uses the passive, which deletes the subject: ‘it was left’. The methods Andrew uses to achieve a competent identity for himself (or a capable identity which had not been sufficiently recognised) are dependent on positioning other social actors in less-than-favourable places. Those who had the power in the day centre were seen as non-supportive of the very people (himself) that they were supposed to be helping. The student in some ways is seen as unimportant and neutral, and the ‘group’ consists of unnamed, unidentified others, who are constructed as incapable by contrast with Andrew himself.

When Mark evaluates this narrative (lines 665–), his logic is that people should be allowed to prove their capabilities. The point of Andrew’s narrative depends on portrayal of a situation in which his competence has to be proved to powerful others, and Mark shares this frame of reference. The pressure consists of not ‘showing a person what you were doing’ (671-2) and that, as Mark says, is a type of discrimination. This whole example of discrimination that Andrew and Mark have worked up between them is about the question of competence. The work that they both do to create Andrew’s experience as ‘discrimination’ depends on the assumption that they have similar identities, similar experiences.

If the final evaluation were offered by someone who did not share identity with Andrew (such as myself, or the other supporter), it would not have the same meaning or force. Mark’s argumentative structure is as follows:

- Andrew has a similar identity to his own.
- People like them can get pressured.
- One way of being pressured is that people don’t let you show what you can do.
- Andrew is able to achieve things.
- People should be given a chance to ‘prove themselves’.
- If they are not given this chance, that amounts to discrimination.
- This example will help you understand what we were trying to talk about with the word ‘discrimination’.
It can be noted that the discursive work that Mark does (i.e. his discourse identity as interviewer, and evaluator of experience) is in itself a demonstration of his competence. The tight interconnections between discourse and transportable identities can again be observed, as the local situation feeds into the wider issue of competence and incompetence.

5.3.4 Making sense of experience

Extract 5:1 was chosen originally for the fact that it demonstrates how the work of research is, at least partly, about making meanings from individual experiences. This is precisely what Mark does throughout this extract, first by framing the response as something that might have made Andrew feel ‘压了ured’ (a word which is repeated four times in this extract), then by encouraging Andrew to continue to elaborate his narrative (653, 656), and finally by problematising the response (putting it in a wider context of meanings). Interestingly, Mark chooses to link Andrew’s story specifically with the pre-set agenda belonging to the Research Group, by referring back to a previous interview question, ‘going back to question two again’. This question was part of the original agenda of the Research Group: ‘Have you ever been in any tricky situations where you’ve been discriminated against?’

Mark’s move reinforces what Silverman (1973) calls ‘the scheduled nature’ of the interaction, and the status of the Research Group members as having the right to determine that schedule. It is also interesting to note that the video transcript shows Mark engaging in some quite tightly co-ordinated work with hand gesture and gaze:
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Page 8 of video transcript of Extract 5:1

Mark:
Gaze→A ... /*glance/→A .................................. /*glance/→A .................................................. /down/
down at paper
Hands ........................................... /both hands/ r. h. on paper ............................................................... downward *l. h. gesture

because you are saying that you were PRESSED by not (.) showing a person what you were doing / but you

When Mark raises the issue of ‘going back to question two’, he is physically referring to the printed questions in front of him on the table, and he emphasises this with his glances down at the paperwork. After his two-handed gesture on ‘pressured’, he then actually puts his right hand on the paper, and leaves it there for the rest of his turn and Andrew’s subsequent one, freeing only his left hand for remaining punctuation. This is a very authoritative expression of ownership of the question, with all that its printed status implies.

The word ‘discrimination’ had in fact caused some trouble earlier on, and some candidate responses had been hesitantly offered, such as the following one:

Extract 5:3 (V 4)

431. Jenny: I was going to say what a bit like um Lee was saying (.) last night that er (.) she said that er (.) what about what Lee was saying last night†/ she said that I [ whispered overlapping talk going on throughout from here on ] I haven’t to do too much for other people/ other people are to do more for themselves/ she said er let everybody do for themselves/ in the group - they make out they can’t do anything and they can do lots of things/ she said Rob can do lots of things/ Molly can do lots of things/ Beth can do lots of things and I haven’t got to do so much for them↓

The similarity between this story and Andrew’s is quite striking. Jenny is talking here about a situation in the group home where she lives, and in which she has already said she is more capable than others. Clearly, her efforts to prove her capability by helping the others are not always appreciated, as this tends to disempower them (in the eyes of Lee, who is presumably a staff member at the home). However, this story of Jenny’s is not immediately accepted as a relevant response to the discrimination question. Jenny
herself questions its relevance, and the supporter refers it back to Mark, who then
himself hesitates about what discrimination might mean:

Extract 5:4 (V 4)

471. Mark: discrimination means (.) er when when you go into a job↓ (. ) or an
472. interview↓ it's your (. ) na (0.5) nationality or colour/
473. Sarah : age↑
474. Mark: or yeah anything like that/ and that - discrimination means/ (. )
475. racial discrimination (. ) is a big word/ I know (. ) because I have done a
476. lot of work at college/

Following this, there had been some more talk about examples of being picked out
because of the label learning difficulty, and Mark had also associated discrimination
with the idea of being denied an equal opportunity. Thus the extract relating to
Andrew being pressured has a particular place within the development of meanings in
that particular interview. The significance it has can only be appreciated in the context
of that local situation.

Mark and Andrew are taking a particular example of personal experience, and then
Mark uses this example to help everyone present construct the category of
discrimination. This not only links back with the original group agenda (the pre-
written questions), but takes these meanings now into a new context and re-considers
what they could comprise. In many senses, this whole extract does correspond quite
closely to Silverman’s concept of ‘interview talk’:

In hearing interview-talk, then, surface appearances (the words used by the subject) are only
important for the glimpses which they give of the patterns which purportedly underlie them.
(Silverman 1973: 33)

What is perhaps slightly unusual, however, is the way in which this pattern is
actively attended to in the talk. Although led by Mark-as-researcher, this task is
performed out loud, and is done, as it were, jointly with the audience. As we have
seen, he is perhaps concerned to work out the congruence between Andrew’s and
Jenny’s previous story, as examples of discrimination. The researchers are not simply
recording subjects’ views and taking them away for analysis. The analysis is
collaboratively worked up, in situ, and the category of discrimination is actively taking
on a new and fuller shape during the course of the talk together. Some of the
distinctiveness of research done by self-advocates is starting to emerge.
Chapter 5: Doing interviewing

5.4 Other features of research interviewing

5.4.1 Joint ownership of relevance

From the analysis so far, one essential feature of doing interview talk seems to be the adoption of asymmetric conversational rights, whereby interviewer(s) are distinguished from interviewees. To the extent that this structure is observed by all participants, the event becomes an interview. I was therefore interested to search the data for evidence of further strategies which were to do with asymmetries of conversational rights.

One of the obvious ways to gain acceptance as the chair of the occasion is by physical placement, so that everyone present can make eye contact with the chairperson. For instance, in Extract 5:1, video evidence reveals many occasions on which all participants direct their gaze towards Mark, as interviewer. In this example, as he often does, he refers to a sheet of paper on which the questions are printed. In his case, since he reads the questions quite fluently, the printed paper seems to add to the incontrovertible authority of the questions themselves, and acts as an icon of his own status. On other occasions, where members may have difficulty reading out the words, this activity distances them from the written word (as if the printed sheet had an existence and a meaning that had nothing to do with the talk). Authority of the written word can cut both ways.

Given this, it might be considered even more important for these researchers to demonstrate ownership of the questions during the talk, as this ownership was not completely conferred by the documentation. This is done in different ways. For instance, researchers could demonstrate their right to decide what is relevant to their questions, and what is not relevant. Simply by acknowledging a response, by expanding on it, or by providing follow-up questions, members can build the relevance of whatever has been said. In the following example, this work is done by Angela, who thus sanctions what was being said as an appropriate response:
Although it might appear trivial, this extract is typical of ones in which members use ordinary conversational resources to take control of the direction of the interviews.

In line 426 ('what doing↑') Angela encourages Thomas to say more – to give more detail, thus indicating that his response was relevant to the purpose. Although a casual comment, ‘that’s interesting’ (428) is important here in giving positive feedback to Thomas that he is on the right lines, and that his experience is worth recounting in this context.

Another way to demonstrate ownership is by explaining a question – to make it one’s own. During the course of one interview, for instance, Angela expands on the question about jobs, by asking members the following:

This question has a lovely apparent logic, as a two-part, alternative structure. However, it is clear on closer examination that it is not an open question, since the two alternatives given are essentially the same (1. going to the same place every day = getting fed up; 2. preferring to go and do something different). By posing the question, Angela is telling people quite clearly what her own view is, and what sort of answer would be acceptable to her.

An extract to be analysed in Chapter 9 contains another interesting example of relevance work. It will be seen there how a response to the labelling question was at first met with some collective doubt about its relevance, which Mark is given the authority to decide on.
Interestingly, although Mark is acknowledged as the final arbiter of relevance, the work done to establish that they have 'gone off the wrong track' is joint work, and includes a major contribution from Darren (who is one of the interviewee group). Therefore, the split between identities of interviewer and interviewee is not completely solid at all times.

At most points where there was trouble about the meaning or intention of particular words or phrases, it was Research Group members who were called upon to discuss exactly what they meant by a question. The only times that this rule was not observed was when a member of staff (supporter) from the interviewee group decided to try and help, and this was then heard and acknowledged as a usurping of the rights of the researchers. In the following extract, Jenny has just questioned what discrimination means. It will be seen how Mark is given first option of explaining, but when he appears to stumble, the supporter (Sarah) offers her help. However, the fact that she has to ask permission to do this work invokes Mark's privileged researcher status:

The key point in all this seems to be the conversational right to own and define what counts as knowledge in this context. Although the Research Group members primarily hold this right, the work is often done jointly. Thus the absolute distinction between researcher and researched becomes slightly blurred; this is arguably another key feature of this kind of research.
5.4.2 The blurring of boundaries between researcher and researched

Unlike many traditional interviewers, researchers in these events presented themselves as a team. They brought off this team work, for instance, by supporting each other in either posing or explaining a question. There were certainly plenty of instances where they jointly followed up a response. The following example is one of many similar ones.

Extract 5:9 (V 3)

216. Angela: what do you do/
217. Jess: yeah what you doing↑/
218. Mark: what is your job↑/
219. Jess: I goes to work/ (→ Harry)
220. Angela: what do you do when you get there↑/= 
221. Harry: = do you work in a factory or to a day centre↑
222. Angela: a shop↑/
223. Jess: no I work in a canteen/ [washing up -
224. Angela: [washing up↑/
225. Jess: yeah (2)/ not washing up um cleaning tables and taking meals out/

Each time one of the Research Team (Angela, then Mark at 218, then Angela and finally Harry at 221) intervene with a question, they produce a more explicit choice to guide Jess's answer. There are many other instances where some complicated negotiations have to go on between team members about which question should be asked next, who was going to ask it, and whether particular questions had already been answered. What is notable about all these extracts is that they take place exclusively between members of the Research Group. In this context, being a researcher means being demonstrably a member of the Research Group. The alignment into Research Group members and interviewee group is mostly adhered to when it comes to business about questions.

However, team alignment is not always maintained, and it is interesting to note examples of occasions where the split between interviewer and interviewee breaks down entirely. For instance, members of the Research Group sometimes gave examples from their own experience, to clarify a question, thus breaking Silverman's (1973: 41) observation that 'the interviewer's questions imply that nothing need to be made available about his own views and experiences'.
Take, for instance, the following exchange:

**Extract 5:10 (V 5)**

96. Harry: no no one should be never on the streets at night/ because someone
97. some people (.) as I said/ because this is what Jack Straw
98. announced/ no one should be never on the streets after midnight/
99. (1) nor even after 10 o'clock at night/ because I tell you this (.) some
100. people can get attacked at night/ (0.5)
101. Steve: do you- right/
102. Harry: yeah because- (1)
103. Steve: do you get like (3) do you think (1)
104. Harry: well sometimes one or (.) or supposing let's put it round this way/
105. supposing you went to work like I do by Wallcroft which is in Norton
106. right†/ where I've got to go on the bus every day†/ like the 77 from
107. Foster Road right over to Wallcroft/
108. Angela: do you catch that one Harry †
109. Harry: yeah/ Wallcroft you know/

Prompted by the previous speaker's story about being attacked at night, Harry starts with a general proposition, backed up by the authority of the home secretary's words (96-100). If he had left it at this, one could say that he was doing the same kind of work as Mark in Extract 5:1, in exploring the general significance of an interviewee's contribution. Steve then self-selects, to get a turn (101, 103), perhaps to further explore this significance, but he is hesitant; Harry comes back in with a personal story of his own journey to work, linking his experience and the interviewees' by the phrase: 'supposing you went to work like I do' (105). However, he does not reach the point where he might link his story with the business of being safe on the streets at night, because Angela, another interviewer, interrupts him with the comment 'do you catch that one Harry' (108), signalling her interest in the detail of bus routes. Note that these details would not be particularly relevant to the interviewee group. Has the point of the interview been lost at this juncture?

Rather than count this as inexperience, or bad interview practice, I would consider such examples to be a central feature of the methods employed by this team. It is when all members share their experiences openly that the talk becomes richer and more conversation-like. Providing this texture of ordinary conversation could be heard as a means to slow down the interview, to allow for repair and adjustment, and give interviewees time to reflect and to make their own responses richer. In addition, it is by making salient aspects of their own personal (outside-the-context) identities that
interviewers enable interviewees to make a judgement about their membership, and the relationship between aspects of interviewers’ identity, as compared with their own. For instance, Harry’s status as an independent bus user would have been of interest to interviewees, as they might then want to make salient aspects of their own independence. The blurring of boundaries can be seen to be an important resource, as the very activity does depend on a sharing of experience and identity between all parties.

5:5 Discussion

5:5:1 Tools of qualitative research

Research group members have consistently referred to the skills they developed in interviewing. They have even analysed those skills in order to present workshops at conferences and other events. The central skills referred to are:

- listening
- following up what people say
- using body language appropriately
- getting the questions right
- relaxing the interviewee.

All these skills are central aspects of producing good, rich qualitative interview data, for any researcher. They are not specific to research done by people with ‘learning difficulties’.

Despite my fears, from the very first interview, Research Group members embraced their discourse identities as respectful listeners with great enthusiasm, as is seen in Extract 5:1. Interviewees’ contributions were taken seriously and respectfully, as members elaborated together on the meaning of what had been said. Interviewees, as Silverman (1973) observed, are accorded the status of experts in qualitative research interviews, and this is exactly what Mark and his fellow researchers achieved by the quality of their attention.
In a traditional research interview, one might expect the nature of the occasion to be dictated by the interviewer-cum-researcher. It is he or she who has set up the event, and who has a purpose in mind. It is the interviewee’s task to determine that purpose, and to produce talk that fits. As we have seen in this chapter, members of the Research Group did exercise considerable control over relevance, by:

- choosing a next speaker
- orchestrating the talk (with a loaded question)
- determining the sequence of knowledge that will be explored (‘going back to question two’).

In an extract such as 5:1, research group members appeared very similar to the powerful, controlling interviewer in Suchman and Jordan’s (1993) description of the survey interviewer, who is trained not to allow deviations from the script (see 1.7.1).

Being an interviewer might therefore seem unremarkable, since it is drawing very heavily on models of traditional, qualitative interviewing. However, when one considers people with ‘learning difficulties’ taking control of an interview in this way, it is both challenging and surprising. Indeed, controlling what will count as relevant knowledge is perhaps the most powerful act that members performed, since they were challenging the interactional rights they had been assigned (as incompetent, less-than-full members of society), and also the very discourses about them, formulated by powerful others. Just like the children in Ochs and Taylor (1992), and the older, confused speakers in Shakespeare’s (1998) study, they are often in conversations that are controlled by others. Therefore the importance of being in charge of the agenda, and of making their own rules for talk, cannot be overestimated.

It is hard to consider this kind of activity as simply ‘copying’ traditional, academic research practice. It seems to me that members were taking tools which had been made available to them, and truly making them their own. The tools of a research interviewer were transformed in their hands, and they used them as a lever to overturn traditional assumptions about the incompetence and lack-of-rights of people with the label of learning difficulties.
5.5.2 Hallmarks of inclusive research

I will turn now to a summary of the distinctive features of research, as they emerged in this project and have been observed in this chapter.

5.5.2.1 Sharing of a labelled identity

In most social research, the interviewer stands apart from the interviewee. The purpose of the occasion is to tap the views of the interviewee, and the interviewer's own identity is managed as irrelevant. In the present project, however, not only were the interviewees expected to be experts on their own experience, but also they were expected to share that experience, and to identify with, the interviewers. This assumption of talking to your peers was part of the Research Group's purpose in setting up the interviews, and is explored further in Chapter 9. A constant task for all members was to address the questions:

- 'Who am I?' – what aspects of my identity should I be making relevant here?
- 'Who are you in relation to me?' – what aspects of identity do we have in common?

We have seen in this chapter some quite elaborate and detailed strategies for doing this identity work, through the fine details of eye contact, hand gestures and body posture. Sharing of experiences was a two-way event, and there were conversational strategies for matching up the two sets of experiences: Mark often acknowledged a contribution by saying something like: 'we found that in our group too'. In addition, Research Group members did not keep their own personal experiences out of the discussion. They also had relevance, as was shown briefly in 5:10, and interviewees showed interest and involvement in the accounts given by interviewers of their own lives. Talking with peers was very different from talking with an objective, outside interviewer, and this quality of sharing was what marked out inclusive research as different. The common experience of being labelled became a positive force for change.
5.5.2.2 The interactional rights of interviewer and interviewee

In the traditional research interview, the rights to determine content and structure lie with the interviewer, whereas in the current project, these rights were often shared by both teams. We have seen how, on occasions, interviewees could take charge of the agenda, and how on other occasions interviewers stepped outside their discourse identity as interviewers to contribute their own views and experiences. A distinctive feature of this kind of research was its collaborative team work, and this joint approach extended across the boundaries of group adherence. In the main, it was the task of Research Group members to pose questions, and not to answer them. However, on occasions they did answer as well as ask. Similarly, it was not unheard of for interviewees to pose a question to the researchers (see also Chapter 3). Thus these interviews moved more towards the model favoured by some feminist researchers, (Gluck and Patai 1991) who seek to break down the traditional barriers between interviewer and interviewee.

When I returned to the participating groups, some two years after the original interviews, to explain to them the current PhD project (Appendix D), I was surprised by the fact that they all described their participation in those events as doing research. For them, there was no absolute distinction between researcher and researched, although by then the Research Group had published the Finding Out book. Because they were included in that book, they felt their contribution had been recognised. This assumption of collaborative enterprise was a revelation to me, and it continued into the mini conferences which Research Group members held in March 2001. Interviewees were as proud of the outcomes of the project as the Research Group members themselves, and talked in terms of the research they would do next.

5.5.2.3 Working things out openly

Interviewers are not only distinct in their talk within the interview situation, but their rights to the talk extend beyond that situation (Silverman 1973). All talk in an interview is considered to be on-the-record, and the interviewer has the rights to take
away the data (usually quite literally, on tapes), and to mull over them – to listen, to transcribe, to analyse and to make meanings.

In a sense the interviewing team did have those rights. They were making both audio and video recordings, with my assistance, during the events, and they did go back over much of this material in order to write up their own articles and booklet. However, inclusive research was also somewhat distinctive in this respect. As observed in this chapter, a hallmark of the process was the way in which members openly explored interpretations together (see Extract 5:1). The interviewees were also prepared to enter into that discussion, and seemed to be genuinely engaged with the questions pursued.

5.5.2.4 A research agenda of challenge and change

Inclusive research can be characterised as research which involves strong feelings. Members choose to do research about issues that concern them and their lives, not about something abstract and objective. It is highly 'subjective' research, and can best be understood in the context of self-advocacy, where personal stories (the subjective) are used to develop solutions and support for each other.

Self-advocates do research about matters which concern their own lives. For them, the issues that they choose to pursue are both important and practical. They want action, and they see research as part of that action. Interestingly, what we have seen in this chapter is how the actual process of doing the research can be as much a part of the action as any product of the research findings. Indeed, there was little distinction in the current project between findings and process. It was by becoming researchers that members could change societal attitudes, in that they became more powerful and challenged others' expectations. By examining these research interviews, this challenge is witnessed at its source, actively forming itself through interaction.
Chapter 6
Threats to being researchers

6.1 Chapter overview

Having explored in the last chapter some features of the research interviewing done by Research Group members, I aim in this chapter to throw further light on the characterisation of their research project, by deviant case analysis (see 2.8.1). By examining occasions where the research frame appeared to break down, even momentarily, one can become clearer about what exactly is involved in the achievement of doing interviewing, and becoming researchers. In terms of discourse analysis, deviant case analysis can help to shed light on the discursive practice under investigation, in this case inclusive research. From the perspective of inclusive research itself, however, this analysis has vital practical value, since it reveals some of the issues that can threaten its success.

Section 6.2 considers an extract in the sixth visit where the interaction was quite troubled, and it was very hard for the members to establish that they were doing interviewing at all. The analysis shows what may happen when researcher identities are not successfully worked up. There are multiple threats to self-advocates trying to do research, and the following section (6.3) elaborates the idea of threats by presenting the results of a trawl through the data. I will also start to consider how threats may be countered. Finally, the discussion section, 6.4, reflects on the notion of threats and considers how they can be conceptualised in terms of competing discourses.

6.2 A deviant case

The following extract is from a visit where it was very hard to establish what was going on. Earlier on in the transcript, there had been several hitches – silences in response to questions, fill-ins by Research Group members, and supporters being called in to rescue the talk. This extract occurred after the question about jobs (Appendix E: third question) had produced, at last, a response from one member of the
host group, Kathy, who had mentioned her job at a pet shop. Jack was a paid member of staff in the host group and Brendan was one of the members who had not spoken at all at this stage.

Extract 6:1 (V 6)

208. Kathy: I like er — I like to work there/ (.) I don’t mind working there/ because
209. they’re very — they’re very good for me and that you know↑ / and I
don’t get paid or nothing/ (.) [I just] go there and help out/ (0.5)
210. Angela [ voluntary↓]  
211. Jack: what about YOUR animals Brendan↑/ (0.5)
212. Brendan: mm↑/
213. Jack: [your ANIMALS at your house↑]/
214. Harry: [(WHO………………. )]
215. Brendan: yeah mm/
216. Jack: you ought to tell people what — what you’ve got at your house↓/(0.5)
217. Brendan: shoes and socks/
218. Kathy: shoes and [socks]↑/ LF
219. Jack: [animals] yeah/ animals/ you’ve got an interesting animal
220. Brendan: haven’t you↑/ well not an animal↓/ [what is it↑/]
221. Mark: Wednesday……………….) (1)
222. Jack: your PETS↑↓/
223. Kathy: [like YOUR name↓ begin with F]
224. Brendan: [yeah I know WH ] (3)
225. Kathy: with F isn’t it↑ (2)
226. Val: LF
227. Jack: what do you have that’s interesting at [home↑/
228. Angela: [what a dog↑/ LF
229. Jack: maybe you don’t think it’s interesting↓ LF/
230. Kathy: he don’t like his name be called/ [don’t like his NAME]
231. Jack: [what is it↑ ]
232. Kathy: HE DON’T LIKE THE NAME OF IT/
233. Angela: what is it↑/
234. Kathy: fish↑↓/
235. Jack: what is it you’re called↑/
236. Kathy: FISH - HE DON’T [LIKE NAME CALLED FISH↑↓]
237. Brendan: [(……………….)]
238. Jack: what kind of fish is it↑/
239. Kathy: HE’ S a fish↑↓ /LF (3)
240. Jack: it’s because Brendan’s second name is fish/
241. Kathy: HE DON’T LIKE IT/
242. Jack: but he’s got an interest — you’ve got an interesting—
243. Brendan: I’m a fish/ I’m a fish/
244. Jack: yeah/
245. Brendan: (name………….)
246. Val: yeah↑ LF brilliant/ (3)
247. Mark: right (.) anybody else↑/
248. Kathy: it can be boring/ LF
249. Melissa: he take it to bed later on Kathy/
6.2.1 Topic control and forcing a response

The first thing to note about this extract is the distribution of turn-taking. Brendan is most frequently selected by other speakers (14 times), most often by Jack (11 times), though also by Kathy twice and Angela once. However, he very rarely self-selects (perhaps only at 245: 'I'm a fish/ I'm a fish'), while all the other speakers self-select during this extract. Jack has more turns than anyone else (13 out of 40), and appears to dominate, certainly towards the beginning, in terms of self selecting, and selecting Brendan for next turn. Angela’s and Kathy’s turns seem to be supportive of the work that Jack is doing in selecting Brendan:

229. Jack: what do you have that's interesting at [home↑]
230. Angela: [what a dog↑ LF

What Kathy does is quite interesting, since she is supportive of Jack’s purpose at the outset, in selecting Brendan for next turn (225, 227) but later on she appears to be taking Brendan’s assigned turns (232, 234, 236, 241) and answers for him:

232. Kathy: he don't like his name be called/ [don't like his NAME]

As for Brendan, his turns are noticeably shorter than others, and often consist of response tokens (see 3.2.2) that simply fill the slot, like: ‘mm ↑’(213). There is also a considerable degree of overlapping, hesitation and pausing, indicating that the interaction is not running smoothly, and it is not always clear who is selecting whom – one turn does not necessarily lead to the next. This is very different from the orderly, research-oriented structure in Extract 5:1.

Turning to the sequence organisation, the underlying pattern and focus become much clearer. Nearly all of the turns selecting Brendan are in the form of initiations, requiring a response from him. The whole purpose of the sequence seems to be to elicit from Brendan a particular response, and each of the other participants has a go at doing this work in a slightly different manner. For instance, Jack’s initiations are nearly all display questions, such as a teacher in a classroom would use (Stubbs 1983) which can be heard as invitations to Brendan to speak:
what about YOUR animals Brendan↑ (212)
your ANIMALS at your house↑ (214)
you ought to tell people what – what you’ve got at your house↓ (217)
aminals/ yeah animals/ you’ve got an interesting animal haven’t you↑ well not an animal↓ what is it↑ (220-1)
what do you have that’s interesting at home↑ (229)
maybe you don’t think it’s interesting ↓ LF (231)

No two of his initiations are identical. Each time he adds on another bit of information, and a picture is gradually built up. He starts (212) with an open invitation, but to talk about a specific topic, which relates to a previous turn of Kathy’s about her work placement in a pet shop. At 214, he adds the prompt ‘at your house’, then the purpose of getting Brendan to talk is made more explicit (‘you ought to tell people’: 217), and in 229 he focuses Brendan on the word ‘interesting’. Finally, line 231, ‘maybe you don’t think it’s interesting ↓ LF’, can be heard as a laughing admission of defeat – or a meta-comment on how this conversation is going, intended for the company at large and to save his own face.

However, Brendan does not give the desired response. When he does respond, ‘shoes and socks’ (218), he does a literal response to the immediately preceding initiation, but ignoring the topic of animals proposed by Jack. Doing literal answers can be heard as a kind of joke, and it certainly occasions laughter here, which then persists throughout the extract. The other speakers then progressively combine their forces to elicit the sought-for response, which appears to come at line 245: ‘I’m a fish/ I’m a fish’.

Jack’s sole purpose is evidently to bring Brendan into the conversation in what he perceives is a relevant way – by mentioning his pets at home. His question at 212, although it links topically with what Kathy had been saying, is not part of the Research Group’s agenda, and it is clear that he cuts across a potential line of talk that Angela was pursuing at line 211, relating to the paid or voluntary status of Kathy’s work. This control of topic in itself can be construed as a threat to the researchers’ task. He seems determined to keep giving as open an initiation as possible, to lead Brendan to give a response that could mark him as a contributor to the conversation. Although he knows the answer that he is searching for, he does not give him that answer and ask him to confirm it, for instance by asking: ‘You have fish at home don’t you Brendan?’
So what happens when Kathy (and Angela) join in with initiations? These are their attempts to get Brendan to respond:

Kathy: like YOUR name begins with F (225)
Kathy: with F isn’t it (227)
Angela: what a dog LF (230)
Angela: what is it (235)

Kathy’s techniques, it will be noticed, are far more direct than Jack’s. At line 225, her introduction of the letter F sounds like the start of a riddle. By providing this frame, she is acknowledging the game that Jack has been playing: it is as if she is giving a clue to Brendan about what is going on here, which is something like: ‘Jack is trying to get you to say a particular word. I will give you a clue, then you might get the right answer’. It is through this riddle-making, though, that the talk becomes even more openly child-appropriate, rather than adult-appropriate.

The riddle strategy does not work either, in terms of getting Brendan to respond, and it is only when Angela joins in with specific questions, presumably directed towards Kathy: ‘what is it’, that Kathy herself gives a direct response, and brings in the word ‘fish’ (236). She then starts using her turns to provide responses for Brendan. She goes even further than this, because by her response: ‘HE DON’T LIKE THE NAME OF IT’ (234) she is not only answering for Brendan, but moving to a different order of talk. This is a type of plane change, in the sense that Sinclair and Brazil (1982) use that term. They describe how teachers in classroom talk often use such a move to shift the relevance of a pupil’s contribution, and relate it to something outside the present context. In this case, however, Kathy appears to be doing this in order to explain to Jack, and to the visitors, why the talk is going as it is. It is a meta-linguistic comment, that does the work of explaining why Brendan is so reticent about saying this word.

It is interesting that, of the two lines of attack on Brendan, it is Kathy’s strategy that actually produces a response finally in line 245: ‘I’m a fish/ I’m a fish’. Although this looks structurally like a response to Jack’s renewed opener at line 244, the content clearly relates more to Kathy’s comments about Brendan’s name. He does not answer about what he has got, but about what he is. In the sequencing of initiations and responses, one can see some intricate joint work going on here, and these two main
initiators (Jack and Kathy) providing different strategies for bringing Brendan into the talk. Jack, although looking for a very specific response, uses questions that have a maximum degree of openness. Kathy's strategy is partly aimed at giving Brendan a clue as to what is going on here, (repairing the conversation from his point of view) and also at giving Jack and the others a clue about Brendan: this is why he is not talking about the word 'fish'. She performs the role of go-between in facilitating this talk.

6.2.2 Creating an incompetent identity

In this extract, despite his failures to reply, Brendan is still expected to display his experience, and to contribute something to the talk. He is expected to say something appropriate, and is pursued by other speakers until he does. He appears to have interactional rights similar to those of a child. Kathy, however, as has been noted above, takes on the role of go-between, by doing meta-linguistic comments, or plane-changes, explaining to Brendan what is going on here, and explaining to others (in particular to Jack) the reason for Brendan's reticence.

It should also be noted that the exchange between Jack/Brendan/ Kathy can only take place because they all share knowledge of the personal details of Brendan's life: that he does have fish at home, and that his name is Fish. They pursue him with a question to which they already know the answer, again reminiscent of teacher talk. These three players all have a group identity by virtue of this common knowledge, which is the topic of the present exchange. In some places, this group membership is mirrored in joint work within the talk – Kathy with Brendan (answering for/with him) and Jack with Kathy (when they are both pursuing Brendan with questions).

The few occurrences of talk outside this frame are by Angela and Val (248) and then Mark at line 249, who again becomes chairperson by taking back the right to assign the next turn. These players do not share the knowledge that Brendan has fish at home, nor that his name is Fish. We are the genuine audience for the performance that is conducted by the Kathy/Jack/Brendan trio. It is being done, in a way, for our benefit; if we had not been there, then this bit of talk would not have happened.
I noted earlier that Jack dictates the relevance of the topic of animals, basing it on a previous response of Kathy's, while effectively ignoring the Research Group's agenda. It could well be that he seizes on this topic since he knows it is something that Brendan can talk about, and will understand. Jack’s own situational identity becomes one of all-knowing facilitator, implying that Mark and the other visitors cannot possibly draw Brendan into the talk without his assistance. In many ways, then he usurps the identity of researcher. He persists in framing questions in ways that he knows, or hopes, will produce a response from a particular individual. This strategy is based on common, shared experience and is echoed in the data from other visits. For example in Visit 1, the staff member filled a pause, after Research Group members had been discussing attendance at day centres, and effectively took up the link between work and day centres:

**Extract 6:2 (V 1)**

474. June: would somebody like to tell them about what happens in the work unit
475. here?
476. John: yes [yes
477. William: [they] do furniture/
478. Sheila: furniture - and kind of sell it/

In the above example, just as in Extract 6:1, the supporter/staff member of the host group is taking up a theme that has been suggested by previous talk, and is trying to engage host group members in answering more fully. The difference between this example and the previous one, however, is that here the question is an open one, directed towards anyone in the group (474: ‘somebody’), whereas Jack is trying to elicit a response from one particular member. The boundary between providing a sensitive support or a threat to the research agenda is very narrow, and will be taken up again in Chapter 7, when I will consider some of the strategies that are typically open to supporters. For the moment, it is the difficulty of the task created by Jack (asking for a specific response from one specific person) which is of interest, since it is this that leads to Kathy partially taking over the situational identity of facilitator.

All this provides a good example of how an identity of incompetence can be achieved, in this context. It is a joint accomplishment, to which Brendan also contributes, by answering minimally and giving dispreferred responses (see 2.4.2). His identity is constructed as someone who can only respond minimally, will have a
difficulty in remaining relevant, and moreover has seemingly idiosyncratic reasons for not wanting to say certain words. It is instructive to see how quickly this identity, which is rooted in the unfolding discourse, can then be transferred into assumptions about his transportable identity, the kind of person Brendan is outside this situation. However, in the measure that Brendan takes on this incompetent identity, Kathy correspondingly grows into the competent, all-knowing, conversationally skilled friend. This is quite a leap for her, since she herself has only responded minimally earlier on.

So what is going on here? Talk continually constructs the situation. It would not be apparent at this point that this was a research interview conducted by Research Group members. At some points, it appears to be more like a slightly teasing interrogation, in which certain participants pursue one person until he responds. Certainly, the most common construction of a closed-question exchange would be that it is a classroom-like test, where the respondent is expected to display competence; in this case, he has great difficulty doing so. In line 248 I also treat the occasion as a test, since I supply the positive evaluation (‘brilliant’) which could also echo classroom talk, although Antaki et al. (2000) have pointed out that this type of ‘high grade assessment’ is often used in an interview to close down one unit of talk, and go on to the next. That seems to be how the remark is heard by others, since after a two-second pause, Mark moves to the next question.

The occasion seems to be hinging on whether or not Brendan can contribute to the talk, on whether he can display himself as a speaker for the benefit of the visitors. In the course of this, as we have seen, Brendan acquires the interactional rights of a child, reminiscent of Ochs and Taylor’s (1992) adult-child interchanges, discussed in 2.7.1, which are set up in order to encourage a child to perform. The various interpretative frameworks here become quite muddled, and I would argue that the resulting muddle is very threatening to the construction of the situation as a research interview. This deviant case can thus throw light on what it means to do research. Interviewees, as well as interviewers, are expected to be competent. Indeed, in some respects, they are expected to be experts, as Holstein and Gubrium (1997) pointed out. Not only does ‘doing interviewing’ depend on competent identities for the interviewers, as we
witnessed Mark working up in the last chapter, but equally the interviewees have to be accorded discourse rights as autonomous respondents.

It is Kathy, in the above example, who to some extent salvages the situation, by moving the talk on to a different plane and explaining why Brendan does not want to say the word ‘fish’. In doing this, she is according Brendan the rights, not only to say what he wants, but also to be silent. His silence is not only evidence of his incompetence as a social actor, but is re-construed as evidence of a justifiable personal preference. This is a competent response, and once established it seems that the research agenda is able to continue. This extract reveals how research interviewing has to be a joint accomplishment of both interviewers and interviewees.

6.2.3 Failure to establish identity alignment

In considering the above extract, as it stands, I have tried to analyse the local work done by each member. However, it is also part of a wider social occasion formed by the events that have happened already during that encounter, which I will now briefly summarise. On this particular visit, there had been considerable trouble in establishing what the Research Group members had planned, which was for people to talk and to answer their questions. The following short example illustrates this trouble:

**Extract 6:3 (V 6)**

15. Mark: and um the first question is ( . ) what do you think about people being labelled↑ ( ........... ) ( 12)
16. Clarissa: don't know/ (10)

These pauses are very long, and it is probably only because of the researchers’ greater experience and confidence by this sixth visit that they could allow them without interventions or without turning to me for help. One can speculate on many reasons for this interactional trouble. For instance, the interviewees may have had little experience of self-advocacy, and in addition, as their staff member points out later:

94. Jack: perhaps- perhaps our members don't FEEL labelled in this way/
They may not identify as people with 'learning difficulties' at all, and they are certainly unused to discussing this identity explicitly.

How they viewed the identities of the visitors is another compounding factor. These interviewees were young people who attended college, and so would be unused to being with older people with 'learning difficulties'. Their experience of older people is likely to be with their parents or staff members. Therefore, they may have found the status of the visitors very confusing, including my own status. I carried in and set up the video camera, and so may have been seen as a technical person, but I was largely a non-contributor to the conversation. Membership categorisation may be necessary, in order to define the event, as I illustrated in Chapter 3, but it is not always easy to achieve. Devices for assigning membership to other people are conceived within one's own repertoires, and are based on one's own life experience. It will be recalled that in Chapter 3 the host group used their own repertoire of self-advocacy group, which served as a springboard for questions to the visitors. However, the group in Visit 6 did not have at their disposal such a repertoire.

The first 200 or so lines of Visit 6 were filled with interactional trouble for all members, similar to the example above. However, considerable efforts were made to repair the talk, by Research Group members. The transcript opened with a small amount of process talk amongst the Research Group members, about how they were going to conduct the event, followed by some introductions by name. The interviewees gave their names, claiming individual identity tokens for themselves, whereas Mark introduced all the other members in his group, including myself, establishing the fact that we were a group (see 3.4.2) and that we were in charge of the agenda. He then posed his first question, about labelling. However, as observed above, this question (and the subsequent one) did not meet with the expected response, and instead occasioned long silences. How did the Research Group members deal with this? Harry immediately offered to fill the silence, by answering the question. The sequence that followed was a group attempt by all Research Group members to salvage the situation, by describing what they meant by labelling. Harry, for instance, tried to allude to 'people with learning disabilities' by describing where they might be found:
Extract 6:4 (V 6)

40. Harry: what I think about people with learning disabilities is (.) the question/ some of them might go to day centres/ some of them works in different places↑/

He then took a long turn to describe his activities at his day centre, which led into some talk about tea and coffee making. Mark then took over, and at my suggestion, described how it is ‘unfair to have labels’ and put this in the context of the research they were doing:

68. Mark: to get out like people's views on labelling↓ discrimination↓/ those sorts of things which could relate to anybody point of view/ when you get a job or something/

69. 70.

This is as explicit an introduction as they had done on any visit, and yet the host group members still did not start to speak at this point. Instead, the question was deflected by Mark to one of the staff members present, who declined to answer, as she said, ‘because I am not in that position’. In the ensuing section, also, Research Group members did long demonstration answers to their own questions, and it was at that point that one of the interviewees (Kathy) had a substantial turn, which was the talk about her voluntary work in a pet shop.

What then was the cause of all this trouble? One of the fundamental problems seems to be that the host group members did not know basic rules about being interviewees, for instance that they were meant to talk. It is impossible to tell from the data whether the problem was their lack of experience of being interviewees, but one can assume that this particular type of interview situation was quite new to them. In particular, it seemed that a problem was the failure to establish alignment of identity between the interviewers and themselves. Even when Harry talked about his experiences in a day centre, they had no particular reason to relate this to themselves. The two groups of people were drawing on different interpretative repertoires, while the questions (certainly the first two questions) relied rather strongly on assumptions of mutual understandings of the terms ‘labelling’ and ‘discrimination’. Thus the ground was prepared for the staff member to try and save things, using the tools that he could bring to the situation – shared knowledge of Brendan’s background, and strategies to elicit talk. Unfortunately, both these factors, as we have seen, were very unproductive of research-like talk.
Chapter 6: Threats to being researchers

The final run-down into Brendan’s ‘I’m a fish’ can therefore be attributed to a whole range of interlocking factors, both local to the interactional context, and more widely relating to the transportable identity choices of participants, and the way they used these to account for each other. Membership categorisation is again a key to understanding what is going on. Successful research interviewing, in this context, was based on a foundation of shared identity between researcher and researched.

6.3 Other threats to being researchers

In order to extend and deepen the findings from the extract analysed in this chapter, I trawled through the data for all places where identity as researchers appeared to have an effect on what was going on, without necessarily being a topic for conversation. The business of ‘what we are doing here’ was continually being re-constructed, and it was only when there was some tension between varying accounts of this that it became explicit. In all, I found 31 extracts from just three of the visits, which gives a large corpus of data.

6.3.1 Shifts in discourse identities

Many occasions on which tensions came to the surface could be traced back to one member or other shifting their discourse identity, as appeared to happen in Extract 6:1 above. This could be either one of the Research Group members, or another participant. For instance, on one occasion, a research group member takes such a long turn in problematising a narrative, that it appears he is no longer being an interviewer:

Extract 6:5 (V 1)

266. Harry: the thing about shoplifting is (1) well some people I heard in the news the other day/ well if you went in the shop and bought something they think you haven't paid for it/ they think oh this person hasn't paid for this↓ this person haven't paid for that/ or if you go into any kind of shop↓ it don't make any difference if it was a greengrocer's shop or a paper shop/ or a -
268. Darren: what are you on about↑/
The challenge from Darren here is scarcely something one would expect from a member of the interviewee group. In this case, I as research supporter did quite a deliberate move a couple of turns after this, to deflect Harry back into the interviewer role:

290. Val: I wonder how Thomas dealt with that/ do you want to ask him how he dealt—

It seems then that Harry's move into a discourse that one would not expect from an interviewer occasions a shift in situational identity. By doing this, he literally changes the situation from being a research interview into being something else. The effect is that other members also immediately shift their situational identities. Darren, in the above example, is freed up from being a respondent/interviewee, and feels free to question what is going on.

There are other ways in which members can shift their discourse identities, with potentially significant consequences for the definition of the event. Consider Extract 4:4, which I looked at in Chapter 4:

Extract 4:4 (V 1)

914. Mark: what do you think self-advocacy is?
(looks up and smiles at end of question)
915. John: speaking up for yourself/ (smiling → Mark)
916. Mark: yeah yeah/
917. John: saying what you want/ ( ) what what you think and what people should should do and should not do/ (looks away during this speech, then with a smile back to Mark at end)
918. .
919. Mark: yeah that's right/

The question posed by Mark at 914 was in fact one of their planned research questions. He gets two responses, at 915 and 917, both of which he accepts. His first response, 'yeah yeah' (916) is a fairly non-committal acceptance, but his second response at 919 very much suggests that the speaker has got the right answer, the answer that he, Mark, had in mind. This is a third part move which is very typical of teacher talk (see 6.2.1); teachers often pose questions to which they already know the answer, in order to test pupils' learning. Through this small piece of talk, there is a shift from the genre of research interviewing, where all responses should be equally valid, and indeed construed as part of the interviewee's expertise, towards the genre of teaching, where the pupil is proving that he has learnt something correctly. One can imagine how
destructive this genre would be for the construction of collaborative knowledge in this type of research interview.

In the above case, the interactional trouble did not persist, but it is evident that quite subtle shifts in discourse identity could cause considerable trouble. A research interview sometimes appeared to be quite fragile, perhaps because it was so new and unknown for all of us.

### 6.3.2 Taking over the agenda

In Extract 6:1 I have shown how Jack, who was a staff member, interpreted both the topic and the purpose of the talk in his own way. This kind of usurping of the agenda is occasionally done throughout the data, not only by those designated as supporters, but also by other members. On some occasions, these re-definitions of the events could be construed as threats. In particular, supporters are often, quite naturally, torn between the urge to enable their own members to speak up and the urge to support the visiting researchers in their roles. For instance, in Visit 4, Mark was about to move on to a new question, when the supporter stopped him:

**Extract 6:6 (V 4)**

<table>
<thead>
<tr>
<th>Mark</th>
<th>um / (2) right (1) question three we've covered haven't we with jobs↑/</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>um I want to ask Angela (0.5) I want to ask Angela to answer (1)</td>
</tr>
<tr>
<td></td>
<td>four↑</td>
</tr>
<tr>
<td>Val</td>
<td>this is about courses this one WH/(→ Angela)</td>
</tr>
<tr>
<td>Sarah</td>
<td>some some of them have done quite interesting jobs actually and</td>
</tr>
<tr>
<td></td>
<td>haven't mentioned them yet/ which you may want to do/ sorry about</td>
</tr>
<tr>
<td></td>
<td>that (→ Mark)</td>
</tr>
<tr>
<td>Mark</td>
<td>that's OK that's alright/</td>
</tr>
</tbody>
</table>

It is interesting here that the supporter says ‘sorry’ (671) to Mark for her intervention. It is not clear from the text whether she is apologizing for the fact that these ‘interesting jobs’ have not been mentioned, or whether she is aware that she has flouted the unwritten rules of what is going on. In all these cases the line between supporting and threatening is very fine.

Where these tensions happened, it was interesting to observe how members performed rescue work, as Kathy did in 6:1. By contrast with Visit 6, on most
occasions, the research frame was established early on, and accordingly it was quite possible for Research Group members to make successful bids to reclaim their rights as researchers. In the following extract, for instance, interviewees had started to discuss their problems in going to London People First meetings, and the following talk ensued:

**Extract 6:7 (V 1)**

961. June: it's very hard/ it means that we've got to have somebody to drive the minibus who's got to be prepared to work for a long day when you live in this area/
962. Thomas: yes/
963. June: so -
964. Others: right/
965. June: does anybody belong to any groups (.) connected with People First↑/
966. Others: right/
967. Mark: yes I do/
968. Thomas: yes I do/

Identifying as self-advocates was what was at stake in the talk at that point. London People First, it ought to be explained, is one of the original, largest and most powerful People First organisations in the country. Therefore the possibility of having met up with them gave a certain status and coherence to the status of the host group as a self-advocacy group. However, June’s explanation of the difficulties in lines 961-2 focuses on the problems of getting to London. Further, her argument implies that members can only go to London if there is ‘somebody’ (961) who is ‘prepared to work for a long day’ (962). The autonomy of members to be independent self-advocates is undermined; they are dependent on people who are paid to support them, but who are not paid to work the long hours that a trip to London would entail.

However, it is interesting to observe how confidently Mark takes back the agenda into his own hands:

967. Mark: does anybody belong to any groups (.) connected with People First↑

Instead of accepting the problems of transport to London as the defining feature of self-advocacy membership, he refers to ‘any groups’, emphasising that self-advocacy can take place in many groups, some of which could be outside London. He also refers to the possibility that members may already ‘belong to’ such groups, and that they may therefore have relevant identities that lie outside the efforts of this particular group to get to London. He is successful in his bid to re-claim the agenda, as Thomas’
response shows (968), and Thomas then goes on to mention his membership of the local MENCAP group. It seems at this point in the talk, once the fundamental purpose of the event has been established, and the identities of all parties explored, then it is far easier for slight threats to the research interview to be confidently deflected.

6.4 Discussion

What has this chapter added to the characterisation of inclusive research given at the end of the last chapter? In certain important respects, it has confirmed and sharpened up some of the features mentioned before, and in other respects it has added new perspectives. For instance, at the end of Chapter 5, I concluded that this research project was marked by a sharing of identity, where assumptions of being peers in some sense were a key to working up the kind of talk necessary for research interviewing. From the analysis of the deviant case in Visit 6, in particular, one can appreciate how essential this identity work was. Where it failed, then the interview itself was under threat. Members could not use the tool of a shared identity to build collaboration, as Mark and Andrew had done in 5:1. In Visit 6, for instance, Harry tried to encourage host members to talk by giving them a demonstration of how to answer one of Mark’s questions. However, this failed because host members did not have any reason to assign Harry to the same membership category as themselves. Therefore, the way in which he answered the question did not lead them to talk of their own experience in a similar vein. A failure to establish common membership led inevitably to a failure to appreciate the force of the questions, and to go on to jointly explore meanings.

In this chapter, I have also concluded that a common feature that caused trouble was when one member shifted their discourse, and thus their situational, identity. For instance, when the host supporter became interviewer/facilitator, when one of the interviewers started to answer a question at length, and when the main interviewer took on teacher-like functions, then it was comparatively easy for the event to slip away from being a research interview. However, at the end of Chapter 5, I also suggested that a hallmark of inclusive research, as revealed in this project, was the frequent blurring of distinctions between researcher and researched. Those who took part as host group members felt a high degree of ownership of the research, and a
characteristic of the talk was the joint and open making of meaning. The current chapter has revealed how fragile these boundaries are.

Perhaps the key to success in these interviews was the assumption of competence for all members, both interviewers and interviewees. Extract 6:1 was such a strong counter-example because of the assumptions of incompetence made for one particular member. At the same time, however, Kathy’s role as go-between must not be forgotten. It proved to be vital, in allowing her to account for Brendan’s reluctance to speak, and in mitigating the account of him given by Jack. In other visits, there were frequently such lead members in the host group, who played a role in shaping the event, and who acted as links between their own friends and the visitors. This is part of their shared agenda, where they were all taking joint responsibility for the talk, and for doing research together. It was not always necessary for the agenda to be solely in the hands of the interviewers. A degree of openness and sharing characterised these events.

Perhaps the strongest theme in this chapter has been that of interactional rights. The analysis of Extract 6:1 revealed how easy it is for members to be placed into the interactional situation of children. By pursuing one person for a response, by using shared knowledge to elicit an answer, and by using display questions, Jack effectively put Brendan into the position of a child who had to perform in talk – to make his own experience public. The fact that he was reluctant to do this contributed even more to his childlike status. These events could only become part of a shared agenda of challenge and change in so far as members had the interactional rights to ask and respond in any way they saw fit, including the right of silence. As soon as one member was pushed into speaking, the joint work of all members was undermined.

By considering the ways in which a research interview can break down, or fail to establish itself, this chapter has sharpened up the characterisation of ideal, or paradigmatic interview talk in the context of inclusive research.

- It was shared, and jointly constructed.
- It depended on an assumption of common membership between the interviewers and interviewees.
Both parties (interviewers and interviewees) had to have their interactional rights respected.

There was a necessary assumption of competence on both sides.

It was based on an agenda that, by and large, belonged to the interviewers.

It could be threatened by many factors:

- Forcing one member to speak: asymmetrical interactional rights.
- People other than the research group members taking over control of topic.
- Creating incompetent identities for one or more members.
- Lack of assumption of common membership.
- Shifts in discourse identities by any party.

Is the concept of threats a productive one? I would argue that it is a useful and practical idea, since the task of the research group was to challenge and take on a very potent array of discourses that was ranged against them. It is perhaps even more important to pick out and describe these threats, since they might in many circumstances go unnoticed.

An extract such as 6:1 would seem odd in most stretches of adult talk. But within the Learning Difficulty world, it would appear quite ordinary. Those of us who have long worked within this world would be quite used to situations in which one person has a word or two elicited from them, in the cause of participation or communication of intention or experience. There is a sense, then, in which this type of talk is naturalised within the discourse world of Learning Difficulty. It can be heard as the dominant discourse, in which people with ‘learning difficulties’ are perceived and treated as children. As such, the types of threats delineated in Extract 6.1 might on many occasions go unquestioned. The line between providing support through talk and undermining the interactional rights of researchers, is a very difficult and delicate matter. Support talk is part of the picture of self-advocacy and of inclusive research, and we need to examine and detail its strategies, to see how it can be successful. This will be the task of the next chapter.
Chapter 7
Doing support talk

7.1 Chapter overview

The previous chapter highlighted some of the ways in which research talk can become troubled. In Extract 6:1 a supporter, or staff member, became involved in eliciting talk from one member, and I showed how problematic this became. This was however but one example of the wider phenomenon of support talk in these data. Support for self-advocacy, as well as research, is a contentious area of debate (see 1.6.2), fraught with doubts about control and ownership. However, self-advocates themselves do not in general dispute the fact that they need support in many ways. Supporting talk within a group is but one social activity in the much wider job of the supporter; this chapter simply attempts to look further at support talk within the setting of the group interviews, to give a more balanced picture of some strategies that were generally available.

In transcribing these data, I have consistently referred to each member simply with an assumed first name, so that the reader can have no prior assumptions as to their status, their group adherence or their institutional identities. These all have to be worked up through the talk, or, as Heritage (1997: 161) puts it: 'evoked and made actionable in and through talk'. Further, although I will be particularly interested in how talk gets supported, no assumption should be made that supporters are the only members to pay attention to process work. As will be shown here and elsewhere, self-advocate members also supported each other's talk. However, my primary interest in this chapter is to investigate the work of officially designated supporters, and so it might be useful to sketch in who was present. I was there during all the visits, apart from two short absences during two interviews, and I also participated in all the group working sessions. I will examine my own role separately in the next chapter; these were the other people who were present in a support capacity:
Table 4: Support staff present during visits.

<table>
<thead>
<tr>
<th>Visit</th>
<th>Support staff present</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Day centre staff member</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Supporters employed by group</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>Supporters employed by social services for the group</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>Volunteer supporter</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>Day centre staff members</td>
<td>2</td>
</tr>
<tr>
<td>6</td>
<td>Staff employed by housing project</td>
<td>2</td>
</tr>
</tbody>
</table>

In addition, there was another non-disabled researcher present during Visit 2, who had been talking with the group in the morning. Although she made no verbal contributions to the data, members did occasionally address their comments to her. Therefore there are plenty of occasions to witness supporters at work with self-advocates. Sections 7.2 and 7.3 aim to reveal some of the more common strategies available to support the talk of self-advocates, and use extracts taken from work done by two supporters of interviewee groups. Section 7.4 reflects briefly on the extent to which this activity is category-bound (see 2.7.1), and concludes that support strategies can be and are used by all members. The discussion section (7.5) then reflects on how support talk can fit into a self-advocacy framework, particularly considering identity work, prompt strategies and the problematic issue of interactional rights (7.5.4).

### 7.2 Supporting self-advocacy talk during visits

I should first draw attention to the limited number of turns supporters took overall. My contributions seemed to remain fairly constant, at about 7.9% of total turns, while supporters of interviewee groups took between 7% and 17%. This is summarised in the table below.
Chapter 7: Doing support talk

Table 5: Turns taken by supporters in two interviews.

<table>
<thead>
<tr>
<th>Visit</th>
<th>Total number of turns</th>
<th>Val’s turns</th>
<th>Val’s % of total</th>
<th>Other supporters’ turns</th>
<th>Other supporters’ % of total</th>
<th>All supporters’ turns as % of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>V 1</td>
<td>786</td>
<td>62</td>
<td>7.9%</td>
<td>134</td>
<td>17%</td>
<td>24.9%</td>
</tr>
<tr>
<td>V 2</td>
<td>621</td>
<td>49</td>
<td>7.9%</td>
<td>48</td>
<td>7.7%</td>
<td>15.6%</td>
</tr>
</tbody>
</table>

A large number of these turns were clarifications, to enable one member to understand what another was saying, or general repair work. For instance, the first four turns of the supporter in Visit 2, spread over 400 lines, are all requests for clarifications, such as:

12. Fiona: could you speak up a little bit↑

In selecting extracts for analysis in this chapter, I was deliberately seeking places where supporters did work that went further than simple clarifications. I started by a trawl through the data, in order to note all places where designated supporters intervened. A core activity seemed to be that of helping group members display their experience through talk. Following ten Have’s (1999: 109) proposal, I then sought extracts that illustrated as many of the features I had noticed as possible. For instance, I looked for extracts where one member was intervening to enable another to display something through talk, where a supporter had several subsequent turns, and where they did some work about relevance of the other member’s contribution, and about interpretation. Therefore, both the main extracts analysed in this chapter are specifically chosen to illustrate supporters at their most active, like May in the following example:
Extract 7:1 (V 3)

26. Mark:  the first question is (.) what do you think about people being labelled↑/ (5) 
27. May: you go (...) first yeah↑/ 
28. Tracy: mm/ 
29. May: tell them what you think about being labelled↑/ 
30. Tracy: um (3)/ we’re not allowed to use (.) those um um um (.) labels/ 
31. May: which are the labels you don’t want people to use↑/ which are the 
32. names you don’t want people to use↑/ 
33. Tracy: well I mean like um (.) um don’t know exactly/ 
34. May: OK/ do you know what labels are↑/ 
35. Tracy: no I don’t/ 
36. May: [ OK/ 
37. Mark: [ do you want me to explain↑/ 
38. May: yeah/ 

7.2.1 Keeping the conversation going

The first thing I noticed in Extract 7:1 was that Mark and May are the only two speakers to self-select, and they both take turns where they have not been deliberately selected as next speaker, for instance at lines 31 and 37. They both have greater turn-taking rights than other speakers, as was the case for Jackie and Kathy in Chapter 6, Extract 6:1, the ‘fish riddle’ episode.

In terms of sequence structure, Mark does an initiation at 26. This is the first of the planned questions, and an invitation to someone to speak. However, the reply is delayed, with a five-second pause after 26, and so the adjacency pair structure is almost violated. May’s first turn, ‘you go (...) first yeah↑’, can thus be heard as a kind of repair of this violation, in which she aids members towards an understanding of their role in the conversation. What she is putting over is: ‘someone ought to speak, and it ought to be one of the four members from the interviewee group who says something here, so would someone like to have a go first?’ The following section (28-35) constitutes the response to Mark’s original initiation, in which there are eight turns comprising four adjacency pairs. As far as the evidence of the tape goes, these are all initiated by May.

In some ways, May’s whole involvement in this sequence has a kind of repair function, helping members to achieve an appropriate second part for Mark’s initiation. For instance, line 29 can be heard as an attempt to reinforce or repeat the sense of 26,
due to Tracy’s failure to do more than a minimal response in line 28. When Tracy does do a fuller response (30), it is judged as inadequate in some way, as I will explore below. Following this, Tracy hesitates and pauses in line 33, and then admits that she does not understand (35). May’s turn (34) and Mark’s (37) are like a diagnosis of the cause of the hesitation. These two members together are trying to find out what the problem is for Tracy, and to repair the misunderstanding by a further attempt at an explanation. It is due to this joint work that the conversation proceeds in an orderly way.

The first support strategy, then, is simply that of self selecting at points of trouble in the talk, and selecting other members for next turn. It should be noted that this strategy is not the sole preserve of designated supporters, like May. The work is done jointly by Mark and May, self-advocate and supporter working together.

7.2.2 Supporting understanding

One of the most interesting turns in Extract 7:1 is Tracy’s: ‘we’re not allowed to use (.) those um um um (.) labels’ (30). Instead of the preferred turn design, which would make reference to ‘I think’ or ‘we think’ (the question had been what do you think...) she formulates her answer with the passive construction, as ‘we’re not allowed to’. She puts herself, together with others in the ‘we’ category, in a passive position as recipients of instructions from an unnamed other source. The grammatical choices she makes are significant, but also the vocabulary item ‘allowed’, implying that she and others are subject to rules set by others.

In the following turn, however, May ignores this formulation, and reacts as though Tracy had used the preferred option of ‘we/I don’t want...’, since she asks Tracy ‘which are the labels you don’t want people to use↑’. Either she had misheard, or she finds Tracy’s answer unacceptable in the present context, implying as it does that someone had laid down a rule. Tracy after all has some face to keep up, as a self-advocate, a representative of a People First group, and as an interviewee. Her question to Tracy, and indeed my analysis of it, reflects our shared understanding of an
important aspect of self-advocacy, as a context in which members can and do decide things and speak for themselves.

May rephrases twice (31-2), using exactly the same frame but inserting first the word ‘labels’ and then the word ‘names’. This is an enabling move, giving Tracy a double chance of understanding, and checking at the same time that her misunderstanding was not due simply to an unfamiliarity with that particular vocabulary item: ‘labels’. May supports Tracy to re-formulate what she is saying.

However, Tracy’s response at 33 is even more confused, as we have seen, and fraught with hesitation. May’s subsequent turn (34), ‘do you know what labels are†’, for the first time acknowledges the fact that Tracy’s answers are based on a failure to understand. Instead of responding to Tracy’s contribution at face value, May moves back one level to enquire about the concepts on which Tracy’s original answer was based. Tracy appears to find this much easier to answer, and acknowledges that she does not understand. At 34 May implicitly recognises that the earlier attempts at answering Mark’s question were based on misconceptions, and were as such inadequate. May can advise Tracy on what counts as an adequate response, and what constitutes a misunderstanding, and her right to do this is ratified by Tracy’s acquiescent responses.

However, it is Mark (37), who takes back the right to explain his original question, and thus the work May has been doing supports his ownership of the interview. The self-advocate researchers are nearly always given the primary rights to explain their own questions explicitly, as was seen for instance in Extract 5:8. Supporters intervene and assume interactional rights on the part of the Research Group, only if a sequence appears to have run into trouble. In the present extract, May defers to Mark, and the work she is doing supports his rights as researcher, as well as supporting Tracy in her understandings of what is going on.

The supporter of the interviewee group is often the one who spots the need for such repair work, and in doing so determines what might or might not count as adequate. This notion of adequacy is closely linked, as we have seen in this example, to common.
understandings of what the self-advocacy organisation is, and in what membership category Tracy should be responding. These issues will be further explored after a brief look at another example of supporter talk.

### 7.3 Use of shared knowledge

I now turn to an extract where the supporter, Fiona, again takes on the task of allocating a turn, but where the talk turns out quite differently.

**Extract 7: 2 (V 2)**

568. Fiona: I don't know whether you want to (…) I mean Alex James/ do you want to talk about it Alex?

569. Chris: [puts out her arm, finger pointing → Fiona during F’s turn]

570. [I tell you who talked about it Fiona] Jane Jones used to be there/

571. Fiona: yeah/ yeah /

572. Chris: (…..)/

573. Fiona: go on then Alex/ → Alex

574. Alex: all these years I’ve been in Bay Hospital/(1) er (1) the food wasn’t very use to people/ because people were eating the same food/ and I I went and seen about it/ and I went I went to the (advocacy) meeting and I said this is not the right food for the residents to eat/ and I said – I asked them (0.5) er can we have different (1) er food to eat/ and they said – he said – they said they can’t change it they couldn’t change to er (.) you know the the same sort of food/

575. Fiona: you got it changed in the end though didn’t you Alex?/ (.) it did change in the end/

576. Alex: yes they did in the end/ (Alex speaks quite quietly, everyone else is quiet. Stares ahead of him, sad expression.)

577. Fiona: because you were in fact one of the founder members of Bay – of Bay’s People First weren’t you?

578. Alex: yes/ yes well um the last time I – I didn’t like it (…..) because I didn’t like the staff the way they were/ you know what they were doing/ (2)

579. Fiona: yeah yeah/ (2)

580. Angela: [from this point to end of extract, an overlapping whispered conversation takes place between Angela, Mark, Ian and Val]]

581. Alex: which wasn’t very nice for people to do you know / mucking you about and (………..off) and all such as that/

582. Fiona: you talk about discrimination but discrimination takes place within services doesn’t it?/
7.3.1 Assigning a relevant and important membership category

This extract occurs after the second question: 'have you been in any tricky situations, when you’ve been discriminated against?'. There has already been some talk in answer to that question when Fiona starts to allocate a turn at the start of this extract. Contrary to Fiona’s turn allocation, Christine then self-selects, not in order to respond, but to select a speaker called Jane Jones. Fiona simply acknowledges this, while persisting with her own speaker selection (Alex) at line 574, framing Christine’s contribution as an interruption. It could well be that Jane Jones is not present: this I do not know. However, that exchange with Christine gives Fiona’s selection a force it might not otherwise have had, as a deliberate opener for Alex’s extended turn, which starts at 575. Following Alex’s long turn, the structure is slightly more complex, consisting as it does of a number of question-answer pairs (adjacency pairs) between Fiona and Alex, in which as I will argue, Fiona is prompting Alex to mention other aspects of his time in Bay Hospital. Throughout this sequence, Fiona consistently self-selects (574, 582, 585, 589) and then selects Alex for next turn.

The sequence from 585 is worth looking at in more detail, with respect to turn allocation. This is Fiona’s first attempt to make explicit Alex’s membership category, as one of the founder members of ‘Bay’s People First’. This is met with a simple ‘yes’, and then Fiona tries again with another turn that is formulated as a question (591-3): ‘am I right in thinking […]’. One possible answer to this question would be another simple ‘yes’. However, on this occasion, Fiona’s reference to a past event is heard not as a simple yes/no question, but as an invitation to speak more about the circumstances that led up to it, and Alex therefore mentions the reason why he changed ward, and the conditions in the hospital. Similar invitations to talk are to be found elsewhere in the data. For instance, in Visit 6 Mark brings Harry in to the talk through shared knowledge of a problem he had experienced over a taxi journey.

What Fiona is building on here, both in selecting Alex and encouraging him to continue, is shared knowledge of the fact that he would have something very relevant to say about discrimination. Just as May’s work in Extract 7:1 could be traced back to understandings about self-advocacy, so Fiona’s here is firmly grounded in her understanding of Alex as ex-hospital resident, and as ‘one of the founder members of
Bay’s People First’ (585-6). It is because of this shared knowledge that she is able to bring him in as a suitable respondent and support his rights to have a turn. Alex also builds on this shared knowledge, by referring to circumstances that he knows Fiona understands (‘I didn’t like the staff the way they were/ you know what they were doing’ 596-7). At 598 Fiona reflects that she understands what Alex is saying, and that he has a point. This use of shared knowledge, and reference to other conversations, is very common in the data. Not only is a member prompted to speak, but he is also assured that what he will have to say is important and relevant at this moment.

7.3.2 Engineering a sustained turn

Alex is the main speaker in this extract, having the longest turn at 575-81, and then continuing with three other turns. As pointed out, Fiona had chosen him as a relevant respondent. However, he does not have the floor to himself. From 594 onwards there are at least two conversations going on. Val, Ian, Mark and Harry are carrying on a whispered conversation, overlapping with the Fiona/Alex exchange. There is also a total interruption at line 590 with the loudspeaker announcement. It will be recalled that this visit took place in the leisure area of a swimming pool complex, and there were at least 25-30 people present. In this context, the achievement of one person having a say, and being heard, is considerable. How is this achieved?

Alex is brought in by Fiona, and so obtaining a turn is unproblematic for him. However, he then does several things to hold the floor. Video evidence from 568-587 reveals that Alex leans forward slightly, using his hands and arms in symmetrical gestures to emphasise his points. He also looks away from any particular person during much of his longer turns, and especially during pauses. This has the effect of helping him to own the pauses; no-one interrupts during his long turn from 575, even though there are several short pauses and self repairs, ‘I said – I asked’, and a number of hesitations ‘er’. His quiet tone of voice, noted in the transcription after 584, and his sad expression, also appear to contribute to the dramatic effect of his talk, and to his rights to speak.

From the evidence of the text, this achievement can partly be attributed to the overall structure that Fiona has set up. Having nominated Alex as speaker, she gives
him her full attention (although unfortunately there is not video evidence of this), and gives him feedback noises like ‘yeah’ (598). This is followed by a two-second pause, and so the expectation is raised that Alex has some more to say. Fiona orchestrates the waiting. Her acknowledgement operates not only as a confirmation of what he has said, but also as an encourager to continue. It is the quality of her attention that underpins Alex’s contribution.

In many ways, this strategy is a kind of identity work. Fiona is attributing to Alex a significant identity, as survivor of the system (ex-hospital resident) and as important self-advocate (founder member of People First). It is because of these attributes that Alex has a right to speak, and to be accorded respect, and Fiona both supports and demonstrates this respect in the way she attends to what he has to say. Again, however, it should be noted that support strategies such as this are only possible through joint work. If Alex himself did not work at keeping the floor, Fiona’s work would not be successful. Theirs is a joint accomplishment.

7.3.3 Attributing expert status and linking with wider meanings

As I have shown, much of the work done by Fiona depends on shared knowledge. She does not claim to have been in the hospital (and because of our shared cultural assumptions, we know that she would not have been a resident), but she does claim to know in some detail what happened within the hospital, and to share that knowledge with Alex. However, she does some quite careful work to play down her own expertise and simultaneously to attribute expert status to Alex.

The first way in which she does this is by achieving a tentative impression, with phrases like ‘if I recall’ (589) and ‘am I right in thinking’ (591). She maintains Alex’s role as expert, due to his personal experience of the situation. Again, this is echoed elsewhere in the data, for instance in my own reluctance to respond in Extract 9:1, and in the following neat example from the third visit:

Extract 7:3 (V 3)

561. Harry: how is your group here organised/ number seven/
562. May: you’re the chairperson/ do you want to say how we do it↑/ (→Roger)
This strategy of downplaying your own expertise, and simultaneously boosting someone else’s rights as expert witness, seems to be a central support strategy. It is reminiscent of the work that family members may do, in using forgetfulness of detail to signal each other’s respective rights to tell particular stories (Goodwin 1984).

The second way Fiona attributes expert status is by the aspects of the Bay Hospital story that she chooses as worthy of mention. Each time she intervenes, she picks out an event that puts Alex in an active role:

- you got it changed in the end (582)
- you were in fact one of the founder members of Bay – of Bay’s People First (585-6)
- you were the first resident of Bay Hospital ever [...] to get a change of ward at your own request (591-3)

Fiona constructs the situation as one of institutional change. She takes aspects of what is being said by Alex, and links them up with a wider argument. In her final turn (601) she shifts to an evaluative framework, to bring out the point and the relevance of Alex’s story:

601. Fiona: you talk about discrimination but discrimination takes place within services doesn’t it?

This is perhaps occasioned by the immediately preceding turn, and Alex’s mention of the bad, indeed criminal, aspects of hospital life: ‘mucking you about [...] and all such as that’. However, it is equally possible to see this comment about discrimination as relating to the whole purpose of Alex’s story. Throughout this extract, Fiona has been designing her turns to enhance and add to Alex’s turns. In this last attempt, she succeeds in making Alex’s story relevant to the overall purpose of the conversation, which was roughly ‘to produce examples and further thinking about discrimination’, in exactly the same way that Mark did in Chapter 5 (Extract 5:1), when he used Andrew’s story of ‘being pressured’ as an example of discrimination.

In the present example, Fiona’s remark is based on a whole package of shared assumptions. For instance, this is the first time that anyone has used the word ‘services’ in Visit 2, and so there is an (unexplained) assumption here that:
a) *a hospital is an example of a service.*

The very fact that ‘discrimination within services’ is worthy of mention rests on the assumption that:

b) *services are intended to help people, not discriminate against them.*

Fiona then builds on Alex’s talk, and makes the third assumption that:

c) *this is an example of discrimination.*

She is thus able to draw the conclusion that ‘discrimination can take place within services’, and because of assumption b) this is a shocking thing, and worthy of mention. Her use of ‘doesn’t it’ has the effect of drawing in her listeners to this argument, with its implied answer ‘yes’.

This knitting together of examples and wider meanings is clearly a powerful move, whether it is performed by a self-advocate or by a supporter, and has some resonance with what we know about classroom or teaching talk, which I examine further in Chapter 8.

### 7.4 Working up the identity of supporter

My quest for support strategies was not limited to the contributions made by those who were officially designated supporter; as I indicated at the start of this chapter, essentially the same strategies can be used by any member. For instance, the following extract is a very clear example of self-advocates themselves using the shared knowledge technique of prompting each other:

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**Extract 7: 4 (V 5)**

126. Steve: that happened to you didn’t it Gary once↑/
127. Gary leans slightly forward, looks → Steve, smiling, nods
128. who me↑/
129. Steve: yes remember↑/
130. Gary: one - one problem I used to ha::ve↓/ Sue knows this and -
131. everyone here↓/ was getting myself out (Smiles, nodding ) that’s the problem/ that’s what I find
132. Steve: yes - yes you did↑↓
133. Gary: [sorry Sue] LF slaps hand down on leg, looks down at floor
134. [what he’s on] - what he’s on about if - Gary/ he’s on about people
135. Mike: who’s got problems got to solve it themselves/ but they need help with
136. that problem↓
Gary is explicitly orienting to the fact that he shares knowledge with other participants ('Sue knows this and everyone here': 130-1) and uses this as a way in, or a warrant for what he is going to say. What Steve and Mike then do is very reminiscent of Fiona’s talk in Extract 7:2. Not only does Steve bring Gary in to the talk, by indicating what he should talk about, but Mike then explains why Gary’s contribution can be heard as relevant to the question about discrimination (135). Both Mike’s and Steve’s support can be heard as responsive to Gary’s evident embarrassment and confusion, shown in his many hesitations, repeats and smiles (130 onwards).

Supporting each other is a part of self-advocacy, and part of that support is to do with achieving a common identity, as argued in Chapters 5 and 6. In the following fragment Mark’s summing up is done on the basis of this shared experience, and would not have been possible if done by a non-disabled supporter:

**Extract 7:5 (V 2)**

371. Mark: I don’t know how many people it affects in this group/ (.) but it certainly affects us in the Norton group/ because we feel very strongly about discrimination/

372. 

373. 

Conversely, those designated supporter can on occasions speak as group members, aligning themselves with the self-advocates. For instance, in Chapter 4 (Extract 4:5), the voluntary supporter to the group expressed some trouble about her own institutional identity. How could she be a member of staff when there is ‘no support from anywhere’? Although she feels in the present context that she needs to apologize for speaking up in this way (i.e. she knows that she is not a self-advocate member), she nevertheless wants to express her solidarity with the whole group struggle. The supporter’s position is not always easy.
7.5 Discussion

7.5.1 What is support talk and who does it?

In ordinary conversation, support talk is something that goes on all the time. All talk needs the support of a listener, as will be evident to anyone who has started on an account of something, only to realise that the potential listener is not attending. As Duranti (1986) observed, the audience is co-author. The strategies used to support self-advocacy talk can simply be seen as an extension of these ordinary listening devices, and as such they are no different in principle from the listening work done by researchers (see Chapter 5). By enabling someone to have a turn and by giving sustained attention, supporters are indicating to a member that their contribution does matter. This is a kind of identity support, premised on the fact that self-advocacy is defined by and depends on the respect given to members’ contributions.

The power vested in a supporter’s attention draws heavily on their own membership categorisation, and the way in which this is recognised by all members. Walmsley (2001) for instance, has described this role as ‘non-disabled ally’ and this seems to capture nicely the position the supporters in this chapter take; they are both allied to the group members, but distinct from them. One of their distinctive features is the dependence that other group members often demonstrate towards them. There are times in every visit when all talk appears to be directed towards the supporter, and they may have to deliberately avoid eye contact in order to re-direct the talk to the members.

However, this chapter has revealed that strategies for support talk do not just belong to one type of member or another. Instead, membership of the supporter category had to be worked up, and these strategies were open to all members. In the measure to which any member supported someone else in their talk, they too became a supporter for that instant. Their situational identity grew out of their discourse identity (what they were doing in the discourse). These findings could have great practical value for self-advocates and their groups, since they give them ways of ensuring that the support
work is shared between all members. Part of the meaning of organised self-advocacy, as was seen in Chapter 4, was to do with mutual, peer support.

7.5.2 Strategies for identity support

In the two main extracts analysed in this chapter, supporters were instructing members on which aspects of identity should be salient, in this context. It is worth reflecting briefly on the contrast between what happened in the two cases.

In Extract 7: 1, Tracy faced a very difficult conversational situation, in which all she could be sure about was her discourse identity: she knew she had to make some kind of response. However, her situated identity as interviewee had not been explained, and her ability to perform in that identity was put in question during this extract. Her responses were questioned for their relevance and adequacy, paradoxically because she did not speak as a self-advocate. However, ‘doing self-advocacy’ is about speaking for oneself – having opinions, being in charge of stating one’s own identity, and forming judgements about others. This business of being a self-advocate is therefore bound up with the conversational rights one has, and anyone who is afforded less-than-full rights is constructed as being a less-than-full member, as Tracy appeared to be. In other words, through the very process of trying to help her clarify her view, May showed up her incapacities, and Tracy came over as someone who was confused and could not manage to speak adequately for herself, to some extent as Brendan did in Chapter 6.

In Extract 7: 2, Alex, unlike Tracy, embraced the role that was suggested for him, that of interviewee and expert witness, which on the whole resulted in a successful interaction. In terms of transportable identities, the most relevant and central one seemed to be ‘former resident of Bay Hospital’, since that was the basis on which Alex was asked to speak. It was also an identity that he himself had introduced as relevant: ‘all these years I’ve been in Bay Hospital’ (576). Furthermore, he went on to set himself up as a representative, a spokesperson for others living in the hospital: ‘people were eating […] I went and seen about it […] for the residents to eat’ (576-8).

He referred to others who lived at Bay as ‘residents’, and thereby set himself apart as a special sort of resident, one who could speak up for the others. An agreement over the relevance of an aspect of transportable identity led to Alex successfully embracing his
Chapter 7: Doing support talk

situational identity – that of interviewee. It is interesting to compare this with Tracy, where precisely this connection failed. Just as Alex had been a spokesperson for others in the past, he was now performing in that role during the current interview, as an accomplished speech-maker. These two levels of identity, the situated and the transportable, feed off each other.

Building on this solid foundation, Fiona was then able to do further identity work on Alex's behalf, by her prompt questions, to portray him as someone who was a founder member, a changer and a mover. Fiona and Alex also jointly built up another matrix of identities, namely the third parties mentioned during their talk:

- 'people': the people who had to eat the same food – residents (577)
- 'them': people at the meeting, who have power to change the food (579)
- 'Alex': as founder member of Bay People 1st – which has other members (586/7)
- 'the staff': on his ward, who were mucking you about (599 and 605).

The identities oriented to, both by Fiona and by Alex, were to do with power relations within the hospital. They built up a picture that was part of their shared knowledge about hospitals, the abusive power wielded by grassroots staff on wards, and the even more powerful hospital management, who held meetings and ultimately had the power to change things such as food or wards. The powerlessness of the residents was contrasted with the fact that things could be changed, either by an individual or by group action. This is a very strong message, and one that was reinforced by Fiona's final statement, with its background of assumptions about 'services that discriminate'. The strength of this final message, and of Fiona's final summary, was only possible because of the success Alex and Fiona had achieved in making the connection between Alex's situational identity as interviewee and his transportable identity as a founder member of a People First group.

7.5.3 How to do a successful prompt

In both extracts analysed here, as well as the 'fish riddle' episode in Chapter 6, one member was prompting another to speak. Arguably, the most successful outcome (at
least as far as these extracts go) was seen in Extract 7:2. Why was this? It may be at least partly that it relied on a story about personal experience, while Extract 7:1 hinged on, and got stuck on, a word – ‘labelling’, and the ‘fish riddle’ episode was searching for one particular vocabulary item. For instance, if Fiona had started in Extract 7:2 by saying ‘what do you think about discrimination?’, Alex too might have got stuck. Instead, she encouraged Alex simply to talk about his experience, in any way that he wanted, and she then picked out aspects of that experience to focus on, once he had had his say. Her prompts were not about words, but about the precise identity in which Alex was required to speak – as a former resident and founder People First member.

However, in doing this, it has to be said that Fiona usurped Mark’s identity as chairperson and questioner (which is possibly why Research Group members were plotting another whispered question towards the end of this extract). May on the contrary supported and respected that identity by a) letting his original question stand and b) deferring to him for an explanation when it was needed. It is hard for the supporter in self-advocacy to tread this fine line between supporting one party, and undermining another. This may be why some self-advocates simply set the rule that: ‘supporters should not speak’.

7.5.4 Strategies to support talk

Within People First, there is an expectation that members should talk, that they should display their own experience and explore their thoughts together. This chapter has picked out some of the ways that this process can be supported, and typical support strategies are summarised below:

- keeping the conversation going in terms of turn selection
- clearing up trouble with understandings (and determining such troubles)
- using shared knowledge or experience to ‘prompt’ a speaker
- engineering and supporting a sustained turn from one member
- attributing expert status to one (or more) members
- taking what is said to link it with wider meanings.
Although all this can be done by any member, and it was always done in the name of supporting and strengthening aspects of identity among the self-advocates, it was nonetheless true that officially designated supporters were very often to be heard doing this kind of work. In creating support talk together, all participants were drawing on an ideology in which people with 'learning difficulties' needed support to operate as full members. As was observed in Chapter 1 (1.6.2), the very existence of supporters within self-advocacy groups is problematic, because of the concern about whose voice is being heard.

This chapter has pinpointed exactly how interactional rights can both be undermined, and shared. For instance, I have described a very common strategy to prompt someone to speak by referring to common, shared knowledge about that person's experience. Shakespeare (1998: 133) similarly found that carers of older, confused speakers were 'required to know both the biography and the capabilities of the respondent in order for a narrative to be developed'. The supporter was assuming a potentially powerful position, in claiming knowledge of someone else's life, while keeping his/her own life apart from the talk. Were self-advocates put into the position of Ochs and Taylor's (1992) children, who are expected to perform as narrators, but take on only a limited range of narrative roles?

A practical outcome of this analysis could be that supporters could learn how to analyse their own contributions, to ensure that the interaction does not become skewed, with self-advocate members simply doing talk performances. If self-advocacy, and self-advocacy research, are to have any significance at all, then members with 'learning difficulties' must clearly be in control of the proceedings. A recurring theme throughout this thesis has been the range of novel discourse identities that members themselves achieve (questioner, arbiter of relevance) through research. However, control of talk is a joint accomplishment. It is possible to have control with support, and this very ownership of the process of self-advocacy is something that is jointly worked up. This chapter has illustrated some of the efforts made by all parties to ensure that self-advocates do take control.
Chapter 8
Shared work: supporting research

8.1 Chapter overview

This chapter deals with the crucial question of my own role in the research project. Were the strategies available to me anything like those that the supporters in Chapter 7 used, or is research support essentially a different social activity? These issues are important, since the project’s rationale was for self-advocates to be in charge. The central question of the chapter is how feasible it is for a research supporter to simultaneously:

- foster skills for research
  and
- support the empowerment of self-advocate researchers?

Data that include my contributions exist both from the six visits and the 14 tape recordings of sessions (see Preface, Table 1). Section 8.2 briefly compares the volume and type of my contributions in each of these settings, and explains why I have chosen to focus this chapter on the data from the sessions. It is hard to be truly reflexive, and to avoid the dangers of excessive arrogance or self-criticism, I have included as much as possible of the actual transcripts I analyse. This will enable the reader to get a feel for what went on in the Research Group, and indeed to challenge my own interpretations.

Sections 8.3-8.6 are analytic sections, each focusing on a different extract from the sessions, in which I played a role. They are chosen to illustrate the various types of talk in which I engaged, ranging from the most front-seat to the most back-seat. Section 8.3 takes a passage which illustrates me at my most agenda-driven and teacher like, while 8.4 is a passage in which the members are most definitely in control of the agenda. Section 8.5 was chosen to illustrate the crucial work I often did to support researcher identities, by taking up themes from a member’s talk. It also includes an illustration of how conflicting repertoires sometimes intrude on this work. Finally,
section 8.6 links with the previous chapter, giving a brief example of the common supporter function of maintaining a conversation.

In the discussion, 8.7, I reflect on some of the themes that have emerged from these analyses, namely the repertoires of teaching and learning, and the tension between these and supporting ownership. The final part returns to the question of comparison between the strategies available to the research supporter and the general self-advocacy supporter.

8.2 Comparison of the work done by the research supporter in interviews and sessions

This is the first time an extensive piece of data from the sessions has been introduced in this thesis, and so some contextual information may be useful. These sessions are the ones that took place between Stages 2-4 (see preface). They all took place at the offices of Norton People First, and I thought of them as times when the group could talk about what they were doing, plan for future actions, learn skills to do with research, and reflect. We generally had an agenda, with items contributed by all members, or occasionally planned in advance by Mark. One of the members chaired the meeting, but this was done usually in a very informal manner, with all of us contributing as we saw fit.

Although these sessions started before the fieldwork, they continued throughout the project, and afterwards, providing comparative data for my own contributions during backstage and public work with the group. It is interesting to compare the volume of talk that I did in each of these contexts, as shown in the following table:

Table 6: Comparison of research supporter’s turns in one interview compared with one session

<table>
<thead>
<tr>
<th>Context</th>
<th>Length of recording</th>
<th>Total no. of Turns</th>
<th>Val’s turns</th>
<th>Val’s turns as % of total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview (V1)</td>
<td>11947 words</td>
<td>786</td>
<td>62</td>
<td>7.9%</td>
</tr>
<tr>
<td>Session (S5)</td>
<td>4428 words</td>
<td>242</td>
<td>74</td>
<td>30.5%</td>
</tr>
</tbody>
</table>
It is clear that I was speaking far more during sessions than during interviews. In the interviews I deliberately tried to take a back seat, and so I will focus here on the sessions, largely because I am more involved in that talk. However, I will first give a brief indication of work I did in the interviews.

During interviews, although I was a silent witness for much of the time, there were many occasions on which one of the group members turned to look towards me, particularly at the end of a turn, or when they were having trouble with a question or explanation. Because I was nearly always the person holding (or near) the video camera, I often functioned quite literally as an audience, as members occasionally addressed their comments to camera. Therefore, I do not discount the power I might have had in that respect.

The actual interventions I made in the interviews were often to do with ensuring that people had understood each other. Over 30% of my turns in Visit 1, for instance, were at question transition points, where I had to help sort out what question we were on, who was going to ask it, and sometimes help with the reading. When my turns amounted to more than this, they were nearly always to do with supporting the Research Group members to do what I perceived as research. For instance, I occasionally intervened to get people back on track; a typical example would be during the second visit, after a lengthy exposition by Harry of his activities in the day centre.

Extract 8:1 (V 2)

666. Val: Harry do you want to find out if other people here go to similar places like you?/ 667. anyone here go to a day centre?/

I make a suggestion, and Harry follows it. What I appear to be doing is to turn a commentary into a question, thereby moving Harry over into becoming an interviewer. Interestingly, this concern to support researcher identities turns out to be a major theme in the sessions as well.
8.3 Being a teacher

In this section I will be particularly concerned with features of teacher talk, as they have been described by Sinclair and Brazil (1982), Stubbs (1983), and Payne and Cuff (1982). For instance, the teacher in a classroom situation nearly always takes on rights to dictate what is relevant to an overall plan, and indeed owns that agenda. Stubbs (1983) has observed framing remarks, where the teacher marks boundaries with words such as ‘OK’, ‘right’, ‘look’, ‘now’. I was also interested in Sinclair and Brazil’s concept of ‘plane change’ (see 6.2.1).

In selecting the following extract, then, I was particularly searching for examples where I appeared to own the agenda.

Extract 8:2 (S 10)

1. Val: right so come on then Ian do you want to come and join us?
2. Angela: come on Mr Bolton/
3. Ian: yeah/
4. Val: Mr Bolton IPC Ian walks over to join other members round table IPC
5. Ian: oh I'll leave the letter with you/
6. Val: thank you/ well done doing that/
7. Mark: he shouldn't (........) WH
8. Angela: yeah cos he might - he might forget to post it/(1)
9. Ian: I'll post it/ but I can't find (........)
10. Angela: give it to Val and she'll post it/ it'll never - never get posted/(1)
11. Val: right so last time () if you remember() if we talked a bit about() what things you wanted to do in the group and what things you wanted to
12. go on to/
13. Ian: yeah/
14. Angela: (giving minutes out of last meeting) it's only Mark who's taken these
15. minutes so far/ but just to look at that together() we talked about() plans() (0.5) / we talked
16. about () plans() (0.5)
17. Ian: yeah/
18. Mark: what page is this on/
19. Val: on page three/
20. Angela: page three/
21. Mark: oh yeah (2) (I want to tell you something about that...)
22. Val: right (1) / and (2) one of the things that you said on there was um ()
23. Mark: that you wanted to: () do su- - well Mark said he wanted to do his
24. OWN book
25. Val: he did/
26. Ian: yeah/
27. Mark: on research() and some of you said you'd like to actually learn more
28. Val: about research and perhaps write something as well/ (0.5) I mean
29. there was lots of other things you said/
30. Ian: yeah/
31. Val: like () you'd like to travel/ (0.5) some of you would()/
32. Mark: LF
33. Val: and you would like to get paid/
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35. Harry: yeah /
36. Others: LF
37. Angela: LF [that's a (ga)/ that's a boy's ↓ /
38. Harry: [(....................)]
39. Mark: well this thing about Ruth/
40. Val: yes↑/
41. Mark: mm I did tell her/
42. Val: oh thank you/
43. Mark: but I don't think (0.5) -- she may (.) I was going to get back to you actually( ) about Ruth/ she said she would like to come (.) on
44. Val: yesT/
45. Mark: mm I did tell her /
46. Val: perhaps [ do you think I need to get in touch with her as well↑/
47. Harry: [(... how many ...................)]
48. Mark: maybe
49. Val: because to be honest I did mean to (...) 50. Mark: because I think she [gets confused] -- I think she gets confused with
51. Val: [we know that yeah]
52. Mark: the newsletter group and the research group/
53. Val: well I don't blame her it is confusing isn't itT/
54. Angela: not really=
55. Mark: = well anyway/
56. Angela: I'm not confused/ =
57. Val: = OK what I've done is -- I had a think about (.)
58. Angela: don't think too much/
59. Val: LF all the things you might like to learn more ABOUT/

8.3.1 Directing relevance

The first thing the reader may notice is that I talk more than anyone else. Down to line 38, I have 11 out of 28 turns, and all other speakers address their turns exclusively to me, either as a response to what I have said, or as a way to get a response from me.

My first two turns (lines 1 and 4) are an instruction to Ian to come and join the group. Thus I am taking some responsibility for the design of the session, as well as the talk. I deem it necessary for Ian to leave the task he had been doing (printing out a letter) and to join the others. The implication is that we have something important to do, which warrants the full attention of all members. In coming to join the group, however, Ian decides to relinquish ownership of the letter he has just printed: 'oh I'll leave the letter with you↓' (5). This act is tantamount to saying he is not going to follow through his task, and post the letter, but is entrusting it to me. Why does this become an issue? Both Mark and Angela immediately disagree over who should post the letter:

7. Mark: he shouldn't (.........) WH
8. Angela: yeah cos he might -- he might forget to post it/ (1)
This exchange draws on shared understandings about the process in which we are engaged. Ian’s repertoire, as interpreted by Angela, is that he is an incompetent person, who cannot even be trusted to post a letter. There is a sense in which he relinquishes his ownership of the letter, not just literally but also figuratively, by giving it to me, thus casting me as the competent organiser. The alternative repertoire, on which Mark draws, is that of group ownership. If members are really in charge of this group, then they ought to be responsible enough to do their own process work. It is their business and not the supporter’s. This brief exchange therefore signals an important issue in the group’s progressive ownership of the business of research, which as it turns out will also be the main topic for the discussion.

However, following Angela’s decision to give the letter to me (10), I then self-select again, to override the exchange about the post, and take a dominant initiating turn at line 11. Each time I attempt to draw back the attention of group members, I use some marker such as:

right so (1)
right so (11)
right (24)

These are typical framing remarks (see above) for signalling change of topic, and I follow up (15) by producing and distributing written minutes of the last meeting to which I refer (11: ‘you remember’). The minutes are being used here as a tool to direct them towards aspects of the previous session that I deem relevant and reportable. The rest of this section (up to line 38) is in my hands. I do all the initiations, they do all the responses, and mostly these are straightforward confirmations of what I am saying.

My strategies in this first section are all to do with designating appropriate topics and relevance. I am in control, and I twice slip in a ‘thank you’ as a response to something which a group member has done or said (lines 6 and 42), implying that their action was done for my benefit, rather than for their own. As has been observed in classroom talk (Sinclair and Brazil 1982: 44), it is the exclusive right of the teacher to evaluate students’ contributions.
From what I have observed so far, then, it seems that I am the owner of the process – the dominant person in the talk. However, paradoxically, the very purpose and topic of the talk is all to do with *their* ownership. For instance, my comment ‘it’s only Mark who’s taken these minutes so far’ (15) refers to the fact that the minutes, though produced by me, were intended as a way for group members to keep control of what was said at each of their meetings. Therefore by picking out Mark as the person who had taken his minutes, I am modelling relevant aspects of a researcher’s activity to the group. It is they who need to be active, and take control.

I go on with formal strategies for looking back at what group members themselves had said, thus placing the agency of all actions with members, rather than with me. The formulations in the next few lines are:

- you remember (11)
- we talked (11)
- you wanted to do (12)
- you wanted to go on (12)
- we talked about (16)
- you said (24)
- you wanted to (25)
- some of you said (28)

There is a persistent use here of the second person plural (you) together with a verbal action (‘you said’). I am literally quoting back to them their words, by using the authority of the written minutes, and re-storying this as a research paradigm that comes from them. This strategy seems to be slightly stronger than a memory jogger. It is also about encouraging members to take ownership of what they had previously said, and what they intend to do in the group:

- well Mark said he wanted to do his OWN book (25-6)
- some of you said you’d like to actually learn more about research (28-0)
- you’d like to travel (32)
- you would like to get paid ↑ (34)

The implication of all these planned actions is that the research group is *theirs*: it belongs to them and exists only because of their plans.
8.3.2 Members taking ownership of the process

I want now to contrast what has gone on in Section 1, up to line 38, with the ensuing section. At 39, Mark self selects and initiates a new topic, without any clear conversational link with what had gone previously. During this entire section (up to line 56) Mark self-selects for each of his turns, and selects me as his respondent. This is a one-to-one conversation with Mark as the singular ‘I’. My use of ‘you’ refers just to him, rather than the plural ‘you’ of the previous section.

Mark starts with a preface (ten Have 1999: 114) to prepare or instruct his hearers about what he is going to say: ‘Well this thing about Ruth’ (39). He then goes on to describe what he has done to sort out the matter: ‘I did tell her’ (41) and ‘I don’t think [...] I was going to get back to you’ (43).

He also offers his own account of the muddle:

I don’t know what has happened to her today (45)
I think she gets confused (50)

He not only portrays his active agency in chasing up a missing group member, but assumes the right to judge both of her motives and the reasons for her absence. Mark takes on this role so effectively that I ask his permission to share responsibility for group attendance: ‘perhaps do you think I need to get in touch with her as well?’ (46), and at 49 I effectively apologise for my non-action in this matter. The conversation at this point is in Mark’s hands as initiator, and I am simply responding to him, as far as the Ruth-topic goes, although I do a short bit of multi-tasking at line 51 to deal with what Harry is saying, after which I go straight back to Mark.

From 50-3, Mark and I jointly explain away Ruth’s absence as a natural confusion, which is a way of making her absence appear justifiable. We are saving her face at a distance. Interestingly, Angela in one of her typical sardonic moves undermines this position with: ‘not really’ (54) and ‘I’m not confused’ (56). As a colleague has pointed out, this intervention could also be heard as team building, and as implicit valuing of group membership. As a member of the Research Group, how could anyone possibly get it mixed up with another group? It also points out how delicate
ownership can be: it is easy for established members to exclude new members, like Ruth.

It is noteworthy that this conversation about who does what occurs immediately after my attempts to re-direct the group to ownership of their own previous aspirations. Mark now portrays himself as being active outside the group context, and he parallels this by his conversational activity – doing initiations (39, 41, 43) and giving explanations (50-2). He is effectively building his identity as active owner of the whole process, having the right to deal with attendance of other group members. This is a powerful move, and in an oblique way, it answers my implied concerns earlier about group members taking ownership.

8.3.3 Agenda-driven talk

The final word on teacher-student balance has to be left to Angela, whose challenge at 58 is worth spotlighting.

57. Val: = OK what I've done is – I had a think about (.)
58. Angela: don't think too much/

My ‘OK’ here is an attempt to bring the group back from the issue about Ruth, to what I perceived as the matter in hand, and I do this by the device of alerting my listeners that what is to come has been thought through.

Angela’s ‘don’t think too much’ may well have sprung directly from my use of the word ‘think’, and she often appears to operate on the basis of responding directly to a word that has just been said. While her comment comes over as a joke, it does have, like all good jokes, a deal of truthfulness about it. The more that someone thinks, the more control they have over the process. If research work (and being a researcher) is fundamentally about thinking, then I am detracting from their status as researchers by doing the thinking work myself. The issue of who does the thinking and the preparation in between sessions is an important one, since preparing a session gives one control. In my subsequent work with other self-advocates, I continue to be very concerned about this issue, and I would now argue that there is a developmental
process which such teams undergo, where team members incrementally learn to do the thinking.

For the moment, however, I simply wish to highlight the strategies at work here. During this extract, I continue to do the majority of the conversational work, since I had prepared an agenda from the written minutes of the last session, and it is that agenda which overrides other considerations. I had also prepared a worksheet about research strategies for group members to consider in planning their own future work. However, the very fact that Angela can say, and get away with, a joke at my expense is a feature of our relationship. Jokes may be a way of dealing with tensions around ownership, but they also indicate a relationship of trust and friendship (Swain 1995) which is a pre-requisite to power sharing.

8.4 Collaborative learning

There are many different teaching styles, and as I indicated earlier, Extract 8:2 was chosen to illustrate an occasion on which I was attempting to guide and steer the discussion. In so doing, I dictated which of the members’ contributions were relevant, and kept to my own agenda. On other occasions, my strategies for teaching were more firmly rooted in what was already going on within the talk. I will give an example to illustrate this:

Extract 8:3 (S 4)

58. Angela: what do you achieve out of life Valerie↑(3)/
59. Val: ummm/
60. Angela: I asked that question at the Shrubbery today/ research/ it's finding out what people - uu you know me and [Stephanie going out/ [what I like doing a lot of things - [what do you like doing a lot of things - there are so many questions we come up with↑/
61. 62. Harry: I don’t think I want to answer that [now/ I'd - I'd rather - I think you're getting some good ideas going/ =
63. Angela: = go on/= = and I shall spoil it if I start answering them/ no go on/ I want to know your opinion]/ I asked you/
64. Val: I think you - what do you think of the question what is your ambition in People First↑=
65. Angela: = yeah it's a good [question/ [Norton People First↑/
66. Mark: yeah go on/ yes what is your big ambition/ [what do you want to achieve =
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8.4.1 Group members’ agenda

By contrast with the previous extract, in Extract 8:3 the agenda is firmly in the hands of group members. I will briefly describe how this emerged. We had been talking about the most recent group interview, and were trying to reflect on the phrasing of the questions, some of which we had altered slightly. Angela, however, had already introduced her own agenda, by suggesting rather forcibly that we think of some new questions. She had phrased her suggestion thus: ‘these questions are getting a bit boring’ (23). I had aired some worries about the group completely changing their research questions at this point, half way through their fieldwork. However, Angela had persisted, and engaged directly with other members in the group about this.

Thus a pattern of group talk had been established in which I was not the central pivot. It was Mark who had suggested the question: ‘what is your ambition in People First’ and Angela had jokingly challenged him on his use of the word ‘ambition’: ‘that’s a big word for this time of day [...] have you swallowed a dictionary’

Angela was in an authoritative position, and the collaborative work that she and Mark had done reflected both their understanding of research and their own identities as researchers.
The present extract starts at line 58 with Angela actually using the question, which she had adapted from Mark's original question, in order to get me to answer directly. From this point on, I am drawn back into the talk, but mainly in a responsive mode. All my turns are responses, apart from 71 (where I turn a response slot into a question) and 79, which is a request for clarification. During this extract I have 13 out of 33 turns, and Angela has an exactly equal number. However, it is Angela who dominates in terms of sequence structure, since she initiates and selects me on every turn.

8.4.2. Withholding personal identity

Through most of this extract I refuse to give Angela a straight answer to her question. It appears that I am not willing to make salient any personal aspects of my identity, despite the fact that outside the sessions members knew me as an individual, and we were developing friendships that included visits to each other's homes, meeting other family members, pub visits, and so on. Why am I so reluctant to answer?

What the members had been doing in the immediately preceding extract was meta-talk about talk: they had been planning questions, which they might subsequently use in their interviews. At line 58, Angela is therefore doing a plane change by asking a direct question, and so my resistance to answering could be a resistance to this move. This becomes clear at line 71, where I again shift back to meta-talk: 'what do you think of the question [...]'.

Composing interview questions was an important, but also an intellectually demanding, task. Members had to recognise that they were composing questions that they would ask on a future occasion of other people. These were not simply questions that they wanted to ask each other. I am here drawing on a characterisation of interviews (see 1.7.1) in which questions are for a wider purpose than just the current interaction. In earlier sessions, there had always been some confusion about this, since their first set of questions sprang entirely from things they wanted to talk about themselves, and they always spent time discussing their own answers. The success that Angela and Mark have just achieved, therefore, is considerable. Not only have
they performed independent, collaborative conversational work, but they have also managed to formulate a question that could be asked in future interviews. This is the reasoning that lies behind lines 66-8. I do not want to 'spoil it' by answering the question, and encouraging direct personal talk, which Angela has re-commenced at 58. In particular, answering about my own personal ambition might detract them entirely from their goal. My refusal to answer is a kind of identity move, downplaying the relevance of my personal motives and views.

8.4.3 Learning the importance of language

At line 79, however, I change my tactic of resistance, and this has to do with the continually shifting wording of the question being formulated:

a) what is your ambition in People First (47)
b) what do you achieve out of life (53, 56)
c) what do you achieve out of life Valerie (58)
and finally:
d) what is your big ambition what do you want to achieve out of the rest of your life (75-8)

In that final formulation, Angela puts the two questions side by side, and links them together with the future tense of 'want to achieve'. This is emphasised further by the 'rest of your life', and Angela thus links 'achieve' with 'ambition'. This lays bare the basis for her interpretation of Mark's original question.

The work that I am doing during the final part of this extract is all geared towards focusing members on the importance of this wording. That is why I request clarification at line 79 about the exact intention of the question, and then explain that: 'I actually thought of that question in a slightly different way' (82-3). The question that I finally answer at lines 85-92 is question (c), 'what do you achieve out of life?' and not the question about my ambitions for the future. Throughout this passage, there are many volume alterations on individual syllables (89) and contrastive work with the words 'ambition' and 'achieve'. I emphasise the latter by parsing it as 'achieve' (85), 'achieving' (90) and 'achievement' (94). My somewhat self-righteous answer therefore does the work of drawing attention to the difference between these two
formulations, and Angela notices this: 'no what – what is your ambition for the rest of your life↑' (95). That had been what she really wanted to know all along!

By engaging in a question-answer session, what we are exploring together is the precise effect that wording can have within a research context. By my initial refusal to answer, and then by deliberately answering the wrong question, I am attempting to support members in sorting out what their intention is. It is interesting that the original question ‘what is your ambition in People First?’ would not have been answerable by me at all, since I am not a self-advocate. It also makes this original question a particularly good one for the context, and this could also be why I was trying to re-instate this original question, rather than Angela’s achievement formulations.

In Extract 8:3, members are actively leading their own learning about research; this process is occasioned by the precise local context of the talk and its unfolding meanings. Not only am I opportunistic in seizing this chance for some learning about research, but we are literally creating the learning context together.

8.5 Supporting researcher identities

Here is another extract in which identity work is very clearly on the agenda. It is from a session held after the main set of group interview visits, when our aim was to produce material that we could use in writing about members’ experience of doing research. We were engaged in recalling the interviews, to find out what we wanted to say about them and how members felt about their experiences. In order to do this, however, it was necessary first to establish a common object of scrutiny.

Extract 8:4 (S 5)

1. Val: so: (1) really you-you’ve -you can look back and see all the different places you’ve been [to –
2. Ian: [oh yeah↑↓/)
3. Angela: [you know I- I’ve got all the photographs in my 4. photograph album at [home/ 5. Val: [yeah/
6. Angela: and I take it up the Shrubbery and show it to people↓/ (.)
7. Val: mm 8. Angela: and I’m quite proud of what I did (.)/ 9. Val: mm hm 10. Angela: and I take it home at – at Christmas↑ and I went up and show it to Uncle Rob and Jenny↑ (.)
13. Val: mm hm↑.
14. Angela: don't you↑ and his girlfriend↑/
15. Val: yeah/
16. Angela: and it's quite - it's quite - you feel quite really important/ I spoke to - I
17. it's in my (family)/ I showed it to Tony today↑/ he's my boss↑'oh
18. you do a lot then Angela↓ (.) and he's quite you know - and (I
19. was) telling Tony right↑ and he was quite - he was quite - he was
20. quite impressed with what I do↑/ (.)
21. Val: right/ cos um (1) you know you you've (.) you can now say –
22. Angela: [achieved a lot/
23. Val: [when you say something↓ carry on
24. Angela: I have achieved a lot(.)
25. Val: mm hm
26. Angela: too much/
27. Val: LF and you've got a view of what other people think [outside of
28. Norton now/]
29. Ian: [yeah
30. Harry: yeah
31. Val: which (.) makes it much [more important/
32. Ian: [we could beat – we could beat (...) people
33. outside
34. Val: well it's not a matter of beating people is it↑=
35. Angela: =it's not=
36. Val: =it's just - it's just (.) finding out really/ what life is like for [other -]
37. Angela: [ when you
38. think] about it (.) we have seen a few places haven't we↑
39. Val: uh – huh(,) u-huh yes you [certainly have/
40. Ian: [Valerie (...) you know next Friday↑ / do we
41. have to bring sandwiches with us or we going to have -↑
42. Val: can we discuss that in a minute↑[yeah↑
43. Ian: [ oh↓ yeah
44. Val: right so Mark(.
45. Angela: or we'll get side tracked
46. Val: what do you think it's like actually chairing the meetings/ because
47. you've been [very active with that haven't you↑

8.5.1 Building on tools offered by group members

Turns in this extract are fairly evenly distributed, with Angela having the longest
turn at lines 16-20. There is a fair amount of overlapping and interruption going on,
and members all jump in at turn allocation points. Everyone seems to be self-
selecting.

In terms of sequence organisation, apart from the very first pair (I initiate at line 1,
and Ian responds at line 3), the rest of the extract appears to be one overarching
initiation/response/evaluation sequence. Angela’s turns (from 4 - 20) form one
extended turn, in the form of a response to my initial suggestion (1). She describes
how she has shown her photo album to various friends and relations. She pauses for
confirmations and acknowledgements from her audience until she builds up to her main contribution at 16-20, in which she describes how she showed her photo album to her ‘boss’, and reports his reaction to it.

From line 21 onwards, we all elaborate on and evaluate Angela’s response. Embedded in that section is another sequence (21-31), which is started by my suggestion of what she can ‘now say’ (21). This is linked closely with the scenario Angela has just set up, about speaking to her ‘boss’, and my turn is designed to fit into that scene. Angela, Ian and Harry all join in with responses to my initiations (21,23,27, 31). This carries on until line 32, when Ian’s response ‘we could beat (...) people’ is seized on by me and challenged as being an inappropriate way of thinking about research. Angela then initiates again with something very similar to where we started: ‘when you think about it (...) we have seen a few places haven’t we’ (37-8).

Down to line 39, then, the sequences have a symmetrical structure. The first part (lines 4–20) is a sequence led by Angela’s initiations, and the second part (21–39) is led by myself. In a way, the second part is like a mirror image of the first, and what I would like to draw attention to here is the way in which the support work done in the second part builds on the picture Angela has painted in the first part.

In my very opening turn I do a self repair, to change my formulation of ‘you’ve [...] (presumably, ‘done lots of visits’) to: ‘you can look back and see all the different places you’ve been to’ (1-2). This formulation makes the issue more concrete. Instead of simply referring to the research interviews or visits, I direct their attention to the locations, ‘the places you’ve been to’, rather than the content of what they were doing there. The theme of locations is taken up by Angela (4-5) who then introduces the photographs in three different locations: at home, the Shrubbery (a day centre) and at Uncle Rob’s. The photographs perform a link role between the places we have visited and the places where they are shown to other people. Angela has picked up the purpose I had introduced, and provides an extremely potent tool for focusing both herself and other members.
Angela starts her long turn (16-20) with a kind of preface about how she feels: ‘it’s quite – you feel quite really important’ (16): it is those feelings which provide the point of her narration. Then she moves into a short narrative about her ‘boss’ and herself, using direct reported speech to bring to life what her boss had said: ‘you do do a lot then Angela’ (18). The vocabulary she uses, ‘impressed’, ‘proud’, ‘important’, together with the institutional identity given to Tony the boss, all help to reveal what the story is about, which is identity work. It is through making salient the identity of researcher that Angela is enabled to feel proud, especially in a context where she would normally be the client at the day centre, someone who is not expected to do something important like research.

The initial aim to focus on the research visits has been slightly diverted towards the effect of research on one’s own life. I then build on the scenario Angela has painted, by suggesting that she can ‘say something’ about her work. I take up the idea of a conversation between Angela and her boss, and literally fill in a script. This script-writing enables the talk to move very neatly back to the whole idea of what research is, the nature of their achievement. Not only do they have something to say in their own right, but as researchers they can report on what other people say:

and you’ve got a view of what other people think outside of Norton now [...] (27) which (.) makes it much more important/ (31)

Members are being supported to build ideas about the importance of what they have done. This work is about joint identity building, and the actual support strategies used are entirely dependent on this joint work, using the contingencies of group members’ own talk.

8.5.2 Dealing with conflicting repertoires

Sometimes, however, what is presented by a group member clashes rather fundamentally with the repertoire of research we had jointly been building up, revealing its essential fragility. In Extract 8:4 this happens when Ian introduces the idea of beating people (32-6).
Ian's remark (32) follows on from Angela's self-congratulation, but draws on the repertoire of competition ('beat people'). Interestingly, he also uses the word 'outside', reflecting perhaps the inside/outside repertoire, notable in many of their stories about discrimination. Their achievement in doing research, then, is framed by him as something which takes them out of the inside category of 'learning difficulty', in which they are only ever judged against each other's standards. Instead, this research activity has the capacity to move them outside these bounds, and to enable them to score higher even than 'people outside'.

Whatever the case, I immediately pick up the word 'beat', and challenge his interpretation. My turn at line 34 is very much a dispreferred option, since Ian's turn at 32 was placed at the end of a series of formulations by myself and Angela of what they have done in research: 'achieved a lot' (22); 'got a view of what other people think' (27); 'makes it much more important' (31). Ian's turn is occasioned by these turns, and was clearly part of this list, none of which had been challenged by anyone. The previous pattern of collaboration is neatly broken by my: 'well it's not a matter of beating people is it?' (34).

Our joint work in defining what we have done in research clearly has boundaries. Not every comment will count as valid, and by challenging Ian's use of 'beat', I am implying that I know and have access to these boundaries. Members appear to accept my rights in that regard, since Angela immediately backs me up with: 'it's not' (35) and no-one else brings in a counter-argument. In terms of my own situational identity, this is clearly an authoritative move, again reminiscent of teacher talk, although I soften the effect slightly with 'well' (34) and with the tag question 'is it?' (34). Essentially I am instructing group members how to view their own work, and also how to talk about it to outsiders. I use the occasion to contrast Ian's 'beating people' with a reformulation of what we are doing 'finding out really/ what life is like for other' (36), which echoes what I had been saying previously (27). I direct them to a view of research as an activity that enables them to have access to the views and experiences of others.
Just three turns later, Ian however comes up with another remark which again leads to controversy (40-3): 'do we have to bring sandwiches'. It should be noted here that he self-selects (40) to interrupt my turn, and also moves from the abstract to the particular. It immediately follows on from Angela’s talk in lines 37-8 about the ‘places’ we have seen, and it is presumably this which leads Ian to consider the practical aspects of the forthcoming visit.

At 42, however, I do not answer his question, but choose to make a meta-linguistic comment about the ordering of the talk, postponing Ian’s concerns to a later point. This is hearable as a strong instruction about relevance. Why is the business of bringing sandwiches not to be discussed at this point? Clearly, it does not fit in with my own agenda of relevance, and the fact that I can postpone it suggests that I do indeed have an agenda. Not only am I attempting to focus the group members on their experiences of interview visits, but I am also suggesting to them that they view these in a certain way – not as trips on which they are told whether or not to take sandwiches. Ian’s remark about sandwiches, therefore, while it may appear a quite innocent remark to an outsider, is heard by me as part of the interpretative repertoire of the world of people with ‘learning difficulty’. Through my own experience, I know that Ian will frequently have been a part of group trips, organised by someone else, and in which he was a relatively passive recipient. His articulation of this in ‘do we have to bring sandwiches’ raises the whole scenario of the group trip, and the consequent lack of control by people with ‘learning difficulties’ over their individual lives. By challenging it, I am also making relevant my own identity as someone who believes in full membership and autonomy for people with a ‘learning difficulty’. While she might or might not share these concerns, Angela also hears Ian’s remark as irrelevant, and comments at 45: ‘or we’ll get side-tracked’.

My rejection of his remark, then, can be heard as part of my attempt to enable the group members to appreciate the status of doing research. Much of the work I do in this extract can be characterised as identity work, in which I am supporting their own perceptions of their identities as researchers, by building on their contributions, and moving them towards collaborative talk about research.

The agenda that I am pursuing, then, could be summarised as:
Let’s re-visit our shared experiences (1).

You need to learn to value these and value yourselves (21).

This is what research actually is: finding out what others think (27, 36).

We need to stick to the point (42).

Now can you focus on the process of doing interviews, and your role in it (46).

8.6 Giving supports to the conversation

The talk in any session is continually fluid and evolving, and later in this same recording, there is an interesting extract, part of which I have already cited at the start of Chapter 5. Group members here are very much in control of the agenda, and my own role is about supporting their contributions, by contrast with aspects of ‘teacher talk’ which I have picked out above.

Extract 8:5 (S 5)

201. Mark: you've got yeah – but/ I don’t think you’re going to get as much
202. information from an MP than you are from a researcher↑/ (1)
203. Val: hh hh
204. Harry: [what we should do is write a letter to Tony Blair
205. Mark: see what I mean↑[the person who’s got the most] – sorry Harry I
206. interrupted you/
207. Mark: see what I mean↑[the person who’s got the most] – go on finish that sentence/
208. Val: the person who's got the most – go on finish that sentence/
209. Angela: power/
210. Mark: LF
211. Angela: power/
212. Mark: LF the person who's got the most
213. Ian: power/
214. Angela: that's a good word isn't it↑/  
215. Val: LF
216. Mark: no the person who's got the most - (1) inevitability about the er (.)
217. about the: (1) information we want the research/ has got the
218. most RIGHT to interview other people/ to find out more research/ and
219. how it affects people/
220. Val: who has got the most power then↑/
221. Mark: people with learning disabilities/

The preceding discussion had been to do with politics, the Government’s back to work policy and the much publicised cuts in disability benefits that had been in the news. These topics had been introduced by Harry, and all four of the group members were engaged in the conversation at this point. Mark then introduced his own visit to
an MEP, and he moved on from this to contrast the two identities of MP and researcher.

I want to highlight my own contribution in this extract, since it is very typical of other places in which supporters, including myself, intervene in discussions to do prompt work, as was seen in Chapter 7. At lines 204-206, there is an overlap between Harry and Mark, in which Mark cedes to Harry as next speaker. However, at 208, I then invoke my turn-allocation prerogative to give precedence to Mark, thereby setting off the sequence which leads to his formulation at 221: 'people with learning disabilities'. By encouraging Mark to continue, I imply that what he has to say might be important. Mark then takes over, and builds up a fill-the-gap structure: he keeps his audience waiting for his key word. Angela makes a guess, and then Ian; they both supply the word ‘power’ in Mark’s frame. Throughout this sequence, it is evident that I am still supporting the closure of his sentence by my continued attention. A large part of the role of the supporter is to supply this attention, and it is evident in my joining in the laughter at 215.

Mark chooses to reject the term ‘power’, although his turn at 216 is actually powerful, since in it he expresses the central and important issue of who has the ‘RIGHT’ to do research. The fill-the-gap game invests the whole sequence with a light, jokey and self congratulatory tone. A good deal of joint work is going on here. This is not just Mark’s speech, but is being followed closely by at least Angela and Ian. Mark is continuing here with the identity work of being a researcher which has been so evidently a theme throughout the session. The vocabulary he chooses is both authoritative and draws on a discourse of rights: ‘inevitability’ (216), ‘information’ (217), ‘RIGHT’ (218). My own final move (220) draws together Angela’s and Ian’s ‘power’ with what Mark has been saying. Without it, we would never have got to the formulation with which Mark concludes:

220. Val: who has got the most power then↑?
221. Mark: people with learning disabilities/

This passage is so fascinating, because members are quite literally building together new possibilities for their own identities, as both people with ‘learning difficulties’ and
researchers. I provide the supportive frame, but it is Mark who pulls together the two sets of meanings in one overarching clause:

Mark: the person who's got the most [...] power [...] inevitability [...] RIGHT [...] people with learning disabilities/ (208-221)

Having a 'learning difficulty' is construed as an advantage, if you want to do research.

8.7 Discussion

This chapter has dealt in some detail with my own part in the research project. I have dealt with it in a separate chapter, partly because I was not a self-advocacy supporter, employed by a self-advocacy organisation. Instead, I was a novice researcher, with some previous history of group work and personal familiarity with these particular group members, and I was engaged voluntarily with them on their project. There is an interesting question here about the extent of the differences between research support and general self-advocacy support, which I will address at the end of this discussion section.

8.7.1 Teaching and learning

Chapter 7 described some of the strategies available to supporters during the course of group discussion and interviews. These were all essentially about keeping the talk going, giving prompts and encouragement to members, and enabling them to see the significance of what they could contribute. Some of this I characterised as identity support, since there were both discourse identities to keep up (in terms of their roles as respondents or questioners) and transportable identities as self-advocates and researchers.

By contrast, in the sessions there was a good deal of preparation work going on. We wanted to have successful sessions, but that was not our sole aim; on each occasion we were trying to either prepare for a future event, for instance by re-phrasing questions, or to reflect on a past event. In Extract 8:4 we were doing both, since our task required us to look back at the interviews, so that we could then talk and write about them. The
central task that faced us in all these sessions was the task of learning how to do research, by:

- organising the group process (Extract 8:2)
- preparing the wording of interview questions (Extract 8:3)
- understanding the significance of research (Extract 8:4).

Just as the supporters in the previous chapter were mostly silent, I too was silent during parts of the sessions, which were generally structured by group members’ agendas, and chaired by a group member. However, I deliberately chose a range of extracts for this chapter in which I played significant and active roles. I was particularly interested in how teaching was done in this context, and so I selected extracts in which I had some degree of pedagogic intent, quite clearly played out in the talk. If the central task was to learn research skills, then my main role in these sessions was that of teacher, and these data represent a resource to consider the ways that research skills can be taught and learnt.

This analysis has revealed a spectrum of different strategies that I adopted in this role, ranging from the agenda-driven in 8:2 to the contingent and responsive in 8:4. Sometimes my didactic intent could be quite subtle, as was seen in 8:3. However, in all of the extracts I quite clearly did have some agenda, whether it was up-front or hidden. In that respect, the talk resembled classroom talk, in which it is the teacher’s job to define what counts as valid knowledge, and to conduct the talk in such a way that the students will make progress towards acquiring that knowledge. However student-centred the methods, students are still expected to learn and teachers to teach. I will summarise some of the strategies that have emerged which seem to be typical of the two situational identities, teacher and student:
Teaching
- **preparing** (‘I had a think about’: Extract 8:2, 57)
- **structuring the session** (‘right come on then Ian do you want to come and join us?’: 8:2, 1)
- **focusing** (‘you can look back and see all the different places you’ve been to’: 8:4, 1-2)
- **summing up** (‘you’ve got a view of what other people think’: 8:4, 27)
- **defining what counts as the right way of speaking in this context** (‘I don’t think I want to answer that now’: 8:3, 64)
- **defining boundaries of relevance** (‘it’s not a matter of beating people is it?’: 8:4, 34).

Student
- **following instruction** (turning to correct page of the minutes: 8:2)
- **coming up with talk to match what I had requested** (‘I’m quite proud of what I did’: 8:4, 9)
- **confirmatory responses** (‘he did’: 8:2, 27).

The paradigmatic initiation-response-feedback structure of classroom talk (Sinclair and Coulthard 1975), however, was largely absent in these extracts. I certainly did not attempt to ask display questions, such as ‘what is research?’ and the group members took up some discourse identities that were quite unlike those of pupils in a classroom, by doing:

- **questions** (8:3)
- **challenges** (8:3)
- **process talk** (8:2).

These were active, not passive, types of talk and arguably part of the way in which members became researchers. By making salient various aspects of their identity during the sessions, they were enabled to try out these identities in a safe environment. In a sense, they were matching up their present actions in talk with the actions required of a researcher. The talk that I did had to be sensitive to that endeavour, and to leave
space for it to happen. Although I might be describable as a teacher, the students were by no means passive receptacles.

8.7.2 Taking the lead from each other

In parts of the data, then, although the agenda was broadly in my hands, I was a less than traditional teacher. It could be argued that I worked up in talk the role of facilitator or enabler in adult learning, rather than that of classroom teacher.

In Extract 8:4, for example, I described how I picked up elements of what members offered, and used them as opportunities for scripting their understanding of research. However, the unfolding of that interaction was even more complex than that summary would imply. The occasion for my scripting work was in fact offered by Angela, who herself had offered something that was contingent on my first move, where I directed them towards the places they'd been to. Angela provided such a useful and vivid framework, with her talk of the photo album, that one could say it was a gift to any teacher. Extract 8:4 is a good example of how far we were in tune with each other's intentions, prepared to build on each other's leads, and to collaboratively construct new meanings for research. The talk did not just belong to me, but we built that learning context jointly. Similarly, Extract 8:3 is one of many examples where members were in charge of the agenda, and provided the conversational context. Although the analysis demonstrated how my didactic intent was played out, Angela clearly had her own intent, which was to find out some personal information about me. On the whole, we were still able to collaborate in our sense-making, by building on each other's contributions.

It is perhaps worth reflecting that this particular project generated such rich interactional data largely because of the free and open nature of its origins and funding. Unlike most research projects, that have their goals, structure and outcomes predetermined, ours was not restricted by funders' expectations, and so all members had considerable autonomy to develop their own ideas at their own pace. I also had the freedom to follow and to allow those ideas to develop. The particular way in which we constructed inclusive research, as a social activity, was dependent on this freedom from constraints.
8.7.3 Supporting ownership of research

Just as a task for self-advocacy supporters was to support ownership of self-advocacy by members, so also a major task for the research supporter was to support ownership of research. This was most clearly observable in Extract 8:2, where my stated intent was to refer members back to their ownership of what they had previously said. The device of using written minutes was one symbolic way of doing that work, but it should be observed how problematic that device was in the present circumstances, where most members did not have full access to the written word.

The dilemma that faced me in Extract 8:2 was how to reconcile a conversational situation in which I had done the planning and the ‘thinking’ (as Angela observed) with my overall goal, which was to stimulate members to take over and own the process. I would be confident in stating that this is a central dilemma for any research supporter in this field, and it has certainly been reflected in other projects I have worked on. This chapter has revealed some conversational strategies by which this can be tackled. For instance, in Extract 8:2, I referred members back to their own talk from a previous occasion, by using the second person plural ‘you said that you wanted’. Elsewhere, I was able to seize on opportunities to help them build a sense of ownership and purpose, as when I helped Angela to build up her scene with the photo album in Extract 8:4.

However, in the end, the task of supporting ownership, like learning research skills, has to be done jointly. If one party directs the talk unduly, as a teacher might well do (and as could be argued I do in Extract 8:2), then the other participants have less than full membership rights within that interaction. This situation must inevitably feed into the transportable identity of those participants; in other words, one cannot become an active researcher, in charge of a project, if another member is directing and controlling the talk. Taking control of the talk has to be part of taking control of research. It is here that we come to the central problem of learning research skills. While it may be true that all novice researchers need to learn, that very process of learning can easily be
disempowering, since it can deprive members of control of the very talk by which the empowerment is supposed to occur.

What happened in Extract 8:2 was that members took over some of the talk, at least, relating to group process. Mark in particular was concerned with the attendance of other members, and how to engage them in the group. The business of who should post the letter was also important, since material actions are important for members to take responsibility for the group. Angela’s ownership of her photo album was a good example of how members used symbolic objects from the research process, and incorporated them into their own social repertoire and identity work, which was then reflected back in the talk within the group. The supporter’s work then became not so much to ‘do the thinking’ in advance, but to interact in such a way that these bids for ownership were allowed space to develop and to be shared within the group. The analysis showed some of the conversational devices by which this was done.

8.7.4 Research v. self-advocacy supporters

How similar, then, was my behind-the-scenes work to that done by supporters in the interviews? At the end of Chapter 7, I argued that all talk requires support, in the sense that an audience is essential. Simply being there, and providing attentive listening gives the speaker status, and this is equally true in facilitating a research group as in facilitating self-advocacy. However, in both contexts, there was far more than that. For instance, it is not true to say that support talk simply follows what members themselves contribute. The joint interweaving of moves is far more complex. Both in the interviews and in the sessions there were occasions on which members were effectively told that their contribution was not relevant. In Chapter 7, this happened when Tracy tried to talk about ‘labels that we are not allowed to use’, and in Chapter 8 when Ian asked ‘do we have to bring sandwiches?’ Support talk, in both contexts, can consist of giving guidance as to relevance and appropriateness.

Many other similarities could be noticed between the two sets of data. Support talk, in both contexts, is not the sole preserve of designated supporters. Just as members supported and prompted each other in Chapter 7, so they also worked together to construct research, as can be seen in the composition of questions in Extract
Nearly all the prompt work that was described in Chapter 7 also took place during sessions; for instance, the device of referring to shared knowledge was very common in both contexts. The reader is referred forwards to the first extract in Chapter 9, where I use the shared experience of a conference that I had attended with a member, to refer her back to what she had said on that occasion. Research support, just like self-advocacy support, draws on relationships that are built up over time.

However, it is equally clear that the data analysed in this chapter are different from those in the previous one. In the sessions, the repertoire of the teacher was never far from the surface, and I brought my own agenda. I certainly had a general purpose of guiding members towards a greater understanding of research, and so I sometimes made bids to take control of relevance in our talk. Equally, it was often me who had 'done the thinking', in terms of preparation and planning. The interviews, by contrast, were occasions on which the Research Group members were expected to take control of the interaction, and so supporters who spoke on those occasions did not have the interactional rights to direct relevance. I have shown how, when they did overstep that mark, they often apologised for doing so, recognising the rights of Research Group members.

The contrast between these two sets of data, then, seems to be more about the situation and the consequent interactional rights of each party, than about any absolute distinction between research support and self-advocacy support. It could be that self-advocacy supporters also do behind-the-scenes work that might look very similar to that done by myself during our sessions. Certainly, my own work during the interviews was less overt than that of other supporters present. I have argued in this thesis (Chapter 4) that self-advocacy was the essential context for this particular research project, and in the same way one could say that the style of self-advocacy support is also an essential foundation for supporting research. Both doing inclusive research, and supporting inclusive research are social activities that go beyond self-advocacy, but must be built on that firm basis of respect and support for members' interactional rights.
Chapter 9
Talking about labelling:
the local management of identity

9.1 Chapter overview

Having explored some of the foundations for the Research Group’s project, from various discursive angles, this chapter now follows through one of their research questions, from its inception to its execution. This is the first, and perhaps the most delicate, of the Research Group’s questions: ‘What do you think about people being labelled?’ (see Appendix E). Showcasing the development and use of a particular question is a way of bringing into focus various themes, and enabling a holistic view of their research process, and by implication other similar research. Additionally, this was a particularly interesting question, as it was central to the Research Group’s initial interests in labelling. It frequently caused particular tensions in use; in the words of Baker (1997: 131), it left respondents free to explore ‘how and as a member of which categories’ they should speak (see 1.7.1). Therefore an additional reason for following through this question is that the data are a site to explore how members did identity management.

This question, like any research question, does not simply exist in a static, written form. The actual writing of the question was also an interactional event, and occurred in the fluid dynamics of a locally managed occasion. Therefore section 9.2 goes back to the session during which this question was written, to investigate its discursive history.

Section 9.3 then goes on to examine the first time this question was used in a research visit. This proved to be an exceptionally interesting event, and so most of the analysis, including video interaction analysis (9.3.3) in this chapter is based on that extract. I became interested in how membership categorisation, as revealed through discursive practices, related to the issue of how people talked about their identities, and their view of others’ identities. Their talk about themselves and their views on
labelling appeared to be deeply intermeshed with how they saw each other's membership.

In 9.4 I follow the labelling question through the rest of the data, to explore some of the variations in positions that members took up. The devices used to do identity work varied according to the local context of the talk. The discussion section (9.5) reflects on this identity work, and also on the achievement of group members in accomplishing what was a very sensitive piece of research preparation and interviewing, and what that achievement entailed.

9.2 Preparing the research question

The first research question was about labelling, and so I will start by situating the term 'labelling' in the group’s own discursive history. The extracts in the first part of this chapter are from one of the first taped sessions (see Preface: second stage). It took place shortly after one group member, Angela, had attended a conference about disability research, where the issue of disability pride had been discussed with her, by some of the very authors who contributed later to the book Disability Discourse (Corker and French 1999). The first extract I want to consider occurred very shortly after the recorder was switched on, and after Angela had been asking other members what they thought about the issue of labelling.

Extract 9:1 (S 2)

27. Val: do you want to say what you think Angela?
28. Angela: what me?
29. Val: yes/
30. Angela: I don’t think - I think it’s horrible/ why have people got to be labelled anyway why can’t people just be called their own names?
31. Val: mm
32. Angela: yeah and that’s what you said at the meeting wasn’t it at the conference?
33. Val: yeah (sighs)
34. Angela: right/ that’s very good/ (.)
35. Val: what’s your views Val?
36. Angela: right well I – I think that you’ve got um as much of a right as anybody to say what you think/ and that you’re the people who are affected by being labelled/
37. Val: we are/
38. Val: so you need to work out your own views/ that’s the most important thing/
39. Ian: [yes]
some talk about asking people at college, then college courses and qualifications. Then I self select with:

62. Val: but there were some people that Angela and I met at that conference
63. who actually um want to be called disabled/ they've chosen that label
64. themselves/
65. Angela: they have/
66. Val: themselves (.) um/
67. Mark: why ↑ why have they done that↑
68. Ian: why have they done it↑
69. Val: because (.)
70. Angela: I don't know/
71. Val: they feel that society is unfair to them and things are wrong/
72. so they want to fight to make things better same as you do/
73. Mark [uuh]
74. Ian: [oh yeah]
75. Val: but they think they're actually stronger by uniting [and] actually using
76. the label to say this is who we are/ [ ] this is what's happening to us/
77. Ian: [uuh]
78. Harry: [uuh](1)
79. Mark: I think that's a very strong point (0.5)/

9.2.1 The discourse of labelling

This extract opens with my explicit selection of Angela with ‘do you want to say what you think Angela↑’ (27). Angela had been asking the others for their opinions, and I now made a slot for her to express her own view. She prefaces her own turn by her procedural ‘what me↑’ at line 28, indicating her surprise. In terms of sequencing, I am doing initiations in this opening stretch (27-36), and Angela is doing responses. At 37, however, Angela self selects, and offers me a turn. Although I hedge at first in my response at line 38, I come back later at 62 with what is essentially another response to the same offer of a turn. My self-selection at line 62 stands out, because it cuts across the talk about college courses that has started in between these two extracts.

What is going on here? All the substantial turns (Angela at 30-31 and myself at 62-64 and at 71-6) are couched as responses. In each case, we have invited each other to express a view. Note that in the second case, Mark also joins in as an inviter: ‘why↑ why have they done that↑’ (67). It appears that we are all exchanging views, listening to each other and making it OK to say these things. This sounds like a cohesive, coherent conversation, and the evaluative third part turns add to this at lines 36 and 79. At least from the evidence on the tape, we are all listening to each other, and focusing on what each other has to say.
It is within the context of this mutually supportive conversational structure that we are enabled to express some very different views on labelling. I want here to focus particularly on the content in Angela’s turn at 30-31, and my own argument at 62-76. Angela starts with a self-correction: instead of ‘I don’t think’, she decides to start with ‘I think it’s horrible’. This is an upgrading of her opening comment into a strong statement of her own feelings, which prepares her audience for what is to follow, and gives them a clue as to how to hear it. She then goes on to use a two-part contrastive structure, with ‘why have people got to be labelled anyway\downarrow’, followed by ‘why can’t people just be called their own names\uparrow’. This is very neat, and she marks the contrast by a falling intonation pattern, followed by a rising one. Everything she does is aimed at persuading her audience of the self-evident truth of her statement. It is interesting also to note her choice of passive voice in ‘why have people got to be labelled’. The deleted subject has the effect of making the act of labelling appear endemic. The labelling is an enforced situation, something that is imposed. By contrast, people’s ‘proper names’ are offered as the natural, self-evident alternative.

Angela’s position on labelling is expressed as a personal, emotional argument. She strongly connects what she is saying with her own feelings (‘I think it’s horrible’). However, instead of expressing my own views, my first response is a hedge (38-43), and my second response refers to other, non-present, social actors (62 onwards). Although my refusal to answer Angela at line 38 could be heard as a vindication of her own rights to speak (and my lack of rights), my hedging could also be taken as an indication that I might not fully agree with her view. The task I faced in this extract was tricky. While not wishing to undermine Angela’s right to have her own view, I wished also to pose the opposite view. However, had I done it in my own voice, this would have been a strong personal attack on Angela, and so I chose to do it through the voices of people we had met at the conference (62 onwards). An alternative, and perhaps additional, interpretation would be that invoking absent and authoritative speakers is a strong move to give validity to the argument.

It is interesting to contrast the vocabulary choices I make in 62-72 with Angela’s earlier ones. Where she used passive voice and deleted subject, I bring in as social
actors the disabled people at the conference, and they are both explicitly mentioned ('some people’ 62) and are the active subjects of verbs:

some people [...] want to be called disabled (63)
they've chosen [...] themselves (63/4)
they feel (71)
they want to fight (72)
they think (75)

I also use the device of quoting direct speech, giving a flavour of what these disabled people might say: ‘this is who we are [...] this is what is happening to us’ (76). All these are persuasive devices. No wonder, then, that Mark concedes that this is a very strong point. The disabled people who have chosen their own label are contrasted with Angela and her colleagues, who feel that they have ‘been labelled’ by others. This is the core of the difference between their two positions: it is the very right to choose your own identity category which is at stake here.

The discourse of labelling, on which Angela draws, is of course not new. As indicated in Chapter 1 (1.1) this was the starting point for the Research Group. By asking about ‘people being labelled’, they were posing a question steeped in assumptions about lack of choice, self-determination, and human dignity. This is why the counter-argument of the people at the conference could not persuade them. Although those actors did indeed have a strong point, in terms of speaking up and making their own choices, it seemed to the group members illogical to embrace a label that had been imposed by others. As argued in Chapter 1, labelling is not a neutral term. By choosing this way of expressing themselves, group members were resisting the dominant discourse or diagnosis of ‘learning disability’, and belittling attempts to assign identity to them. The word ‘labelled’ foregrounds the socially constructed nature of identity. It implies that the identity referred to is impermanent, detached from the person beneath the label. Labelling was, for group members, a word steeped in this repertoire of resistance.

9.2.2 Writing the first research question

I will now pick up the talk at a point slightly further on in the same session, when we were composing the first research question.
After what had been quite a lengthy discussion about labelling, my turns during this extract are hearable as attempts to move things on into a formulation of a written interview question. One of the ways I did this was to stand up, and write what they were saying on the flipchart, taking up what could be seen as an authoritative physical position. What I was seeking was a direct question, which could subsequently be addressed to the potential interviewees: ‘what do you think about’ (144). I am asking the group members to project into the situation of the future interview, and say now what they will say then.

Angela’s turns, however, persist in the indirect option, of the form ‘what does your friend think [...]’ (143). This is what creates the confusion. Throughout this
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In itself this is not so interesting, except for the pedagogical points that could be made (why did I not take time to explain to Angela that what I was doing was writing a question?). Whatever the case, this is how the final formulation of that first question came about, and we ended with the very loose specification of who was being labelled, 'people'. Indeed, if the word 'people' had also been dropped, the reference would have been clearer: in a question such as 'what do you think about being labelled?' the recipient of the labelling is the person answering the question. The unqualified word 'people' has the effect of achieving maximum ambiguity.

However, the wording of that question is not just a quirk of the way in which it was formulated between myself and Angela. Its ambiguity fits well with the frame which Angela provided for the relationship between interviewer and interviewee. She seems to be foreseeing an opportunity for talk with someone (a friend) who is likely to identify with her, in terms of the kind of issues she is facing. Therefore, the entire presupposition is that there is a sharing of membership between questioner and respondent in the future interviews. Later in the talk, I specifically check out this purpose:

Extract 9:3 (S 2)

173. Val: in this research project/ are you interested then to find out what other
174. people have experienced / like yourselves↑
175. Ian: yeah
176. Mark: yeah

The loose wording is tied to the purpose of the questions, which relies on identity links between the questioner (Q) and the respondent (R). The relationship is specified as a peer relationship (your friend, your colleague), and the expressed purpose of asking the question is to get an opinion from R about what is happening to Q. In this
context, then, the question does not have to be specific, and no-one has to spell out who is the labelled party. A shared identity is assumed.

9.2.3 Treating an object as delicate

A final point about the ambiguity of the first question needs to be raised, before I turn to the interview data. There is evidence from that first group session that delicacy was a quite conscious and deliberate intention in phrasing the question.

In Extract 9:2 above (164-8), when Harry tried to introduce the word explicitly, he was shouted down by the others. Use of the term ‘learning difficulties’ is actually heard as offensive, and the very mention of the words is seen as an embarrassment, even within the confines of our own group. If a word is heard as abusive or insulting, then the very utterance of it can have catastrophic effects. Rapley et al. (1998) cite some of Todd and Shearn’s (1995) data, where very bald, direct questions could certainly have been heard as downright rude, for instance:

J: Does your boyfriend have a mental handicap?
K: I don’t know. I don’t know him that well. I know him from school, but not that well. (Todd and Shearn 1995: 21)

The Research Group members effectively decide to talk about labelling without using the word ‘learning difficulty’, which Angela declares at one point that she wants to ‘boycott’. Their reasoning is quite clearly to do with sensitivity to the way in which they are going to be heard, and Mark makes this explicit in his reaction to another proposed question later in the same session:

Extract 9:4 (S 2)

234. Val: do you ever get bullied or made fun of/ something like that↑
235. Mark: I don’t think/
236. Angela: I do I do/
237. Mark: I don’t think it’s a good question myself/
238. Angela: I do/
239. Mark: I tell you for why it’s not a very good question/ one it might offend the person you ask the question to/ and two it might give people bad reactions/ it– it might cause an upset between the person you’re asking the question to and also who’s asking the question/ (...)
240. Val: yes/ it’s certainly worth thinking about those things/
In this case, group members are thinking through how another, candidate, question ‘do you ever get bullied or made fun of’ (234) may be heard by those whom they are about to go and interview. The question carries a strong implication that the respondent is in a category of people who are likely to be bullied or made fun of, and so is, in effect, a reference to that same membership category of person with ‘learning difficulties’. That second question became, in its final version: ‘Have you been in any tricky situations when you’ve been discriminated against?’ (see Appendix E).

Members judge that they would not like to either hear the term ‘learning difficulties’ or have any implication made to them that they are in that category. That is why they choose not to use it in their interview question. This is not only about ‘doing discretion’ (Silverman 1997) but also about foreseeing the need to do discretion. This is a remarkable achievement for these first-time researchers. As will be seen, the resulting ambiguity of the first question leaves participants free to interpret in their own way what was intended, leading to some very rich data. A more restrictive question may well have been interpreted, either as rude, or as a stimulus for stereotyped reactions.

I turn now from the discursive history of the first question, to its use in the interviews themselves.

9.3 The labelling question in the interviews

The extract presented below is from the first of the visits, and includes the very first time that the labelling question was posed. As will be seen, all the careful preparation of ambiguous membership categorisation was immediately upset and challenged with:

like – like us you mean† (89)

It is fascinating to see how this is dealt with, and this is the main reason for focusing on this extract, although I will supplement it with some other data in the following section.
Extract 9: 5 (V 1)

81. Mark: we’re going to ask (.) um (.) yourself/ what you think of the questions
82. we thought↓ the first one/ (1) what do you think about people being
83. labelled↓ that’s to – that to all of you/  
Mark→everyone (+ smile + sweeping hand gesture)
84. John: [well -
85. Darren: [what – sorry (…) you go/
86. John: in what sort of way↑ labelled in what sort of way↑/
(Not on the video)
87. Mark: er -what do you think about people being labelled/
88. being um like being – umm (.) like – like with a learning difficulty
89. William: like – like - like us you mean↑

Video re-starts

90. Mark: no/ like – like learning disa- disability/
91. William: o::h/
92. John: people –dis – (0.5) I think it’s not- it’s not very- not very-very-
93. very meaning - meaningful/ but it was what- it was what was deci-
94. decided/ I can’t remember who decided - who decided to – to use this
95. one/ was it HM her majesty’s government decided this one to be- to
96. be standardised was it↑ / → eye gaze to Mark (1.5)
97. Mark: ummmm
98. Darren: you don’t need to know that/ → John
99. Sheila: ( )we do-
100. Mark: I think ( ) we (0.5)
101. William: we’ve gone off the wrong track now haven’t we↑ /
102. Mark: yeah we have actually↓
103. General noises – ‘uuh’
104. John: I think it’s a bit of a cruel one don’t you/ because it doesn’t - it
does- it makes- it makes the people feel - it makes their problem wo-
105. worse the learning difficulty/ it doesn’t break down the- down the –
106. down the bar- the barriers/ it makes it – makes it bigger doesn’t it
107. learning difficulty↑→Mark
109. Mark: yeah it makes it – it affects a lot of people with a disability/
110. we found that in the group ourselves/
111. Harry: mmm yes/
112. Mark: especially when it comes to day centres ↓ colleges↓ and (.) other
113. places that people go/ →everyone + hand gestures

9.3.1 Trouble in the talk: ‘we’ve gone off the wrong track’

In this extract, Mark has eight out of the 18 turns, and is most often selected by others. Visually he is also the focus, with others directing their gaze towards him, and he is also the contributor of the first turn, which is an open invitation to anyone to take next turn. He makes this quite explicit with: ‘that’s to – that to all of you’ (83) and with his hand gesture and smile. There is some confusion about who should take up the response slot, with both Darren and John starting to ask for clarification. Darren defers to John with ‘you go’ (85), thus indicating that both have equal rights to be next speaker. Mark is then selected to do another turn, which occurs at 87, which again is
met with a request for clarification (89), and he responds at 90. Finally, it is John who takes up the main response slots, in his two turns at 92-6 and 104-8.

There is some hesitancy about the flow of the turn structure, for example the 1.5 second pause at 96 and a long 'mmmm' by Mark. There are also interruptions at 98-9, which give a sense of interactional trouble. However, on the whole the turn structure corresponds to what one would expect in a research interview (see Silverman 1973; Baker 1997), with respondents doing longer turns, and displaying their own interpretations, while Mark assumes the role of interviewer, and has shorter turns. By virtue of what he does within the turn structure, Mark assumes the situational identity of interviewer, while William, Darren and John all assume the identity of interviewees.

Turning to the organisation of sequences within the extract, there is an underlying three-part sequence organisation: initiation, response, evaluation (see ten Have 1999: 113). There appears to be one overarching adjacency pair, with a first part at line 81 (re-iterated at 87), a second part at line 92 (re-iterated at 104). This is followed by a third part at 109. In other words, the underlying structure of an interview is basically adhered to, with Mark’s question, followed by John’s answer, and an evaluative comment (third part) given by Mark. However, this basic organisation is interwoven with much interactional trouble, and considerable collaborative work has to be done by everyone to achieve the three-part interview structure that eventually emerges.

For instance, following the initial posing of the labelling question, a strong expectation is built up that the next turn will constitute a response. By inviting ‘everyone’ to speak, Mark increases the chance of a response statement. That would be the preferred option. However, it is met instead with a request for clarification, delivered jointly by Darren and John. Therefore, Mark’s renewed question at line 87 fulfils not only the function of an initiation, but is also an attempt to respond to the request for clarification: ‘labelled in what sort of way’ (86). Similarly, the preferred response at line 97 would be an acceptance, or an evaluation by Mark. He instead gives a non-committal: ‘ummmm’ (97), which violates the expectation of a confirmation. Because of this violation, Mark’s turn has the effect of indicating that John’s first
response was not adequate, and this leads to the very interesting sub-sequence from line 98-101, started off by Darren’s ‘you don’t need to know that’ (98).

The five turns within this sub-sequence constitute a kind of evaluative meta-sequence, concerning the process of ‘what we are doing’. Darren’s remark (98) is interpreted by others as a comment about the relevance of what John has said, a kind of meta-comment, or talk about talk. It is followed by two interrupted fragments, and then by another meta-comment from William, commenting on the course of the present talk: ‘we’ve gone off the wrong track now haven’t we?’ (101). The tag question ‘haven’t we?’ opens a very strong expectation of a slot to be filled by a confirmation, and Mark does then provide this at 102. This is joint work about the nature of what needs to be said on the present occasion, and some agreement appears to have been reached by line 102 that they are on the wrong track. Note that it is Mark (a Research Group member), Darren and William (host group members) who jointly work up this sense of irrelevance.

Much of what has gone on so far could be called repair work. Breakdowns of understanding are countered with self repairs, and Mark repairs the original question by specifying ‘like with a learning difficulty’ (88) and then replaces ‘learning difficulty’ with ‘like learning disa-disability’ (90). It is this repair attempt that leads to John’s first candidate response (92-6) about the term ‘learning disability’. The sub-sequence from 98-103 is meta-talk about relevance, with everyone wondering who should speak next, and what in any case is the acceptable thing to say. However, Mark, Darren and William’s joint work, on agreeing that they are on the wrong track, concludes this interactional trouble.

This extract shows how responsibility for the direction of the talk is a joint affair. It depends on all parties playing the part assigned to them, in quite a complex way. Interviews, just like any other institutional form of talk (appeals to a football referee, Mean 2001; doctor-patient interviews, ten Have 1999: 109-125), have to be worked up, and in this extract, we can see how the success of the interview depended on each member playing their part. Each member’s contribution was both occasioned by the local context and was also part of the collaborative sense-making that was going on.
9.3.2 Who has a ‘learning difficulty’?

The design of turns in this extract brings us even closer to the heart of the interactional trouble, and it is here that the issue of membership categorisation emerges. The initial response to Mark’s question, is a clarification request, ‘labelled in what sort of way?’ (86). This request is not just a general one, like ‘what do you mean?’ John is asking quite specifically what label is referred to, and Mark does respond to this: ‘like with a learning difficulty’ (88). Immediately following this specification, and the mention of the word ‘learning difficulty’ which members had wished to avoid, comes William’s immensely challenging request to clarify further the reference of the term: ‘like – like – like us you mean?’ (89). William appears to be asking: ‘are we the object or the subject here?’ Are they expected to give their views about something, or to consider that they are the object being discussed – or are both things true? In four words, William raises the whole issue of membership categorisation, looking for an answer to the question: ‘as a member of which category should I be speaking?’ (see also Baker 1982 who describes the same process in talk with adolescents).

Moreover, his question is not simply framed as an individual request for membership clarification. Instead, he uses the pronoun ‘us’, indicating his assumed commonality of membership with others, possibly referring to others in the room with him, or to others in the centre at which we were visiting. All that we know for sure is that he counts himself as part of a category of ‘us’, and he offers the possibility that this ‘us’ could be seen as a group of people who are labelled as having a learning difficulty.

How is this dealt with? As I have pointed out, this is potentially a very threatening situation. In the first five turns of the very first time the labelling question has been asked, the attempts to treat the issue as a ‘delicate object’ by not using the words ‘learning difficulty’ and by giving a non-specific reference, have been effectively thwarted. Mark’s response at line 90 is hearable as an attempt to deal with this. If he had merely agreed – ‘yes, like you’ – this would have run counter to all the group’s
preparation in ways of not giving offence. Instead, he negates what John has said with a ‘no’, and shifts the focus from who is being talked about, to the actual words in the label: ‘like - like learning disa- disability’ (90). This distances the term ‘learning disability’ from the current situation. It appears to have the interactional effect of depersonalising the issue, and this is what occasions John’s first response (92 onwards), in which he takes up the invitation to discuss the ‘issue of learning disability’.

In this response he starts to make lexical choices that both de-personalise, using actors like ‘HM - her majesty’s government’ (95) and that give a professional feel to the debate: ‘standardised’ (96). The subject deletion (‘it was what was decided’: 93) gives a more professional, or even ironic, air to the talk. Instead of taking offence, and perhaps reacting emotionally to the label, John offers a response that starts to set out terms of an argument that exists independently of his own assigned identity. The response is delivered as from an outsider, not necessarily someone who has been labelled himself. The issue moves from one in which people need to discuss their own membership categorisation, to one in which they are reflecting on the way in which very high level forces in society are imposing, or standardising, the use of language.

There is no particular evidence in the text of what occasions Mark’s rejection of this first response. Video evidence shows Mark breaking gaze with John immediately after the tag ‘was it↑’. Dropping his face, and his mouth, he looks down and remains like that for a good four seconds. One could speculate that Darren’s ‘you don’t need to know that’ relates to his interpretation of that pause. He may have heard it as a statement that they are not doing what Mark intended. Perhaps the question was hearable as a stimulus for them to talk about themselves. There is no way of telling whether this interpretation is correct; all that is observable is the trouble in establishing what is called for.

However, in the clarification sequence (98-103) turns are designed that start to build a ‘we’ which includes all the present speakers: ‘we do […] we’ve gone off the wrong track […]we have actually’. Choice of the word ‘we’ and its reflection by each subsequent speaker, serves to underline the commonality of membership – not as
people with ‘learning difficulties’ but as members of the current situation, as people who are building up an interview context together.

Lines 104-8 constitute John’s second candidate response, which this time (109) is accepted as relevant. It contains some interesting lexical choices. He frames this response, as he did the previous one, with an ‘I think’, which draws attention to his identity as a respondent, rather than as a labelled person. The choice of the word ‘cruel’ is strong, bringing with it the possibility that one person (or group of people) is engaging in cruel actions towards another group. The designated people, though, again are kept unspecified (‘the people’), and John goes full circle, returning to Mark’s original formulation of the question: ‘what do you think of people being labelled?’. John’s second response gives a reasoned argument for the choice of one term over another, and it does some contrast work to show that ‘it’ (= learning disability) is both ‘cruel’, and ‘makes their problem worse’, while the opposite term (learning difficulty) is at the least not such a problem. The metaphor of ‘doesn’t break down the barriers’ brings the argument about labelling into the frame of other social barriers that are faced by disabled people, and this interpretation could be what occasions Mark’s positive evaluation of John’s response. This interpretation is backed by some interesting video evidence, and I will now present the micro-analysis of a very small fragment between lines 91 and 113, when Mark and John are both visible.

9.3.3 Making a contribution relevant

Fragment of video transcript (from 9:5)

Page 8:
M: looking down at table...........................................................................................................

I think it was a bit of a cruel one don’t you because it doesn’t

J: * definite look to Mark......................................................→ Mark......................................................
Arms folded.................................................................
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Page 9

M: looking down.........right down........................* looks at John........................................................ Hand to nose/ strokes........hand on face..........................keeps hand there.

it does – it makes – it makes the people feel – it makes their problem (.)wo

J: → Mark............................................................* looks away........................
Arms folded.......................................................*puts one hand on arm..................

Page 10

M: → John.........................................................→ ................................................ hand over mouth..........................................................

worse the learning difficulty/ it doesn’t break down the – down the – down

J: → Mark............................................................→→→..............................................
Right hand on left arm..........................................................

Page 11

M: gaze down..............................................................
*hand to mouth
* slight shake of head

the bar the barriers/ it makes it – makes it bigger doesn’t it learning difficulty↑

J: → Mark ............................................................* eyebrow raise
(a glance) looks away
slight smile..............................................................*slight nod
right arm up/ finger movt. * Hand to mouth

Page 12

M: * looks up → J...........................................................looks ahead........................
• hand off face......................................................* slight smile............................
* open hand gesture

M: yeah it makes it– it affects a lot of people with a disability we found

J: → Mark.........................................................*folds arms again.............................

At the beginning of this fragment, John can be seen, coming back in with his second turn. It will be noticed that this is quite an achievement of self-selection, since his turn is not directly linked with the preceding one. Mark and Darren have just finished their procedural sub-sequence, but John does not link to this. Instead, he elaborates on his response to the original question. How does he achieve this? He folds his arms and engages Mark in a very definite gaze, simultaneously with the start of his ‘I think’. In view of this, Mark’s non-verbal behaviour on Page 9 could be seen as avoiding (he
puts his hand to his nose, strokes his face, then holds his mouth – while looking down). John carries on, however, with what he wants to say, and his gaze direction is mostly towards Mark, sometimes glancing away. He appears to be monitoring his audience, and his facial expression remains set in a serious mode with slightly raised eyebrows.

It is at the word ‘people’ that things seem to change. Mark does a definite look towards John, and John then starts to release his arms from their folded position, with one arm ready to gesture. He looks away shortly after Mark looks towards him, but then re-establishes gaze at about the word ‘learning difficulty’ (p.10). Through the whole of the next nine seconds or so of John’s turn, Mark is looking down towards the table and his papers, with his hand over his mouth, while John keeps him in his gaze and carries on with what he wants to say. Why doesn’t John give up? What keeps him going, and how do they both achieve joint sense-making in the end?

What I ended up focusing on was a very short (two-second) burst of events that took place at or around the word ‘barriers’ (p.11). At this precise point, Mark can be seen to slightly shake his head, and John immediately becomes slightly more animated in his facial expression (a slight twinkling of his eyes?) which might be understandable as a sign he is becoming more engaged with the interaction. He moves his right arm up from the elbow, with a definite finger movement. This seems like the start of a pointing gesture. It could well be that these very slight movements on each side are occasioned by each other, or even by the sense of the word ‘barriers’. Mark’s head shake could have been interpreted, for instance, as an acceptance that barriers are dreadful and so are relevant to the present conversation, and John’s raising of his hand could be seen as a renewed confidence that his contribution is being accepted.

Whatever the case, at the end of John’s turn (‘bigger doesn’t it learning difficulty†’), John does a slight eyebrow raise, like a glance, and then a slight nod as he finishes what he is saying. Together with the rising tone of his voice, the whole tone becomes definitely more confident. John appears to be signalling that he feels OK about what he has said, and that he is now ‘on the right track’. Perhaps Mark’s very slight head shake on ‘barriers’ is understood by John to indicate that Mark is listening, and it gives him the confidence to continue.
There is a definite feeling of collaboration, then, as the turn passes back to Mark, who looks up at this point, takes his hand off his face, and makes an open hand gesture. With a slight smile towards John, he embarks on his evaluative turn (page 12). All these things appear like markers that things are now OK, and that John’s achievement is recognised. John himself sits back, with his arms folded, and smiles slightly.

Achieving collaboration is done by some very fine and detailed body work. Both Mark and John are as finely tuned to each other’s non-verbal activity, as to the sense of what each is saying. It is interesting how such a very small head gesture on Mark’s part can occasion this. He has power to arbitrate on relevance, and this is immediately picked up by John, who appears to be more pleased by successfully accomplishing his turn, than outraged by being labelled someone with a learning disability.

9.3.4 Sharing identity

Finally, I would like to note Mark’s evaluation turn at 109-113, where he validates what John has said, by confirming the general truth of the issue (‘it affects a lot of people with a disability’) and then turns back to the personal: ‘we found that in the group ourselves’ (110). His choice of ‘we’, as well as the definite article ‘the’ indicates that the group is in fact the group here present, while ‘found’ relates this to another context of talk that had taken place in that group. He effectively makes John’s contribution relevant to these other context(s) and to other possible locations – ‘day centres ↓ colleges↓ and (.) other places that people go’.

All this is hearable as an admission that Research Group members also faced these problems, in day centres and colleges, and so had discussed them from a personal point of view. It is by virtue of this admission that the two groups, represented at this point by John and Mark, can relax slightly in the knowledge that they share some aspects of identity, and this is shown by John’s more confident body movements, and Mark’s hand gestures at the end of line 113. It will be recalled that one of the researchers’ aims was to establish a relationship of friendship, or a peer relationship, between interviewer and interviewee.
With this final turn, Mark is doing two things. Firstly, he is treating John’s responses as appropriate in the context of the research interview. Secondly, however, he is also widening the context to his own group, and to other people with a disability, in other locations. By doing this, Mark is including himself and his fellow group members in the same category as the interviewees: they are all people who have to face social oppression. The business of doing research is intricately bound up here with the topic under discussion, and both come together in an affirmation that they have the right to define themselves.

9.4 Alternative strategies open to members

The analysis above has illustrated how members can distance themselves from the category of Learning Difficulty, by discussing it as a general issue. However, there are many other possible positions that can be taken up. A trawl through the data revealed some of these.

9.4.1 Introducing other social actors

Extract 9:6 (V 4)

101. Mark: do you (1) do you have strong points about labelling† smiling, gesture with left hand
102. Andrew: I think it demoralises er what you're like as a person because it
don't-/ people- if people get to hear that you're learning disabled ↓(.)
104. they automatically think you're not capable of doing what they're doing
105. you know/ → Mark, brief hand gesture
106. Mark: yeah yeah/
107. Andrew: = I don't particularly like that iss- that point about it you know/ gesture with right hand (sweeping something away)

In the above example Andrew starts with ‘I think’ (102). He has been asked for his ‘strong points’, and so he has a conversational right to an opinion. He follows that by using the impersonal ‘you’ (‘what you’re like as a person’) leaving slightly open the issue of whether he himself is in the category of people who are ‘demoralised’. Finally, he introduces at line 103 ‘people’ who ‘get to hear that you’re learning disabled’. Thus in this turn, Andrew at first keeps a neutral distance from the problem.
He explains the issue by setting up three groups of people, the ‘I’ who can make a judgement, the general ‘you’ who are labelled, and the ones who do the labelling. This use of a third party (‘people’) is very similar to what Rapley et al. (1998) noticed about their subjects, who used a strategy of mobilising others’ perceptions as witnesses or warrants of their status.

By bringing his own experience into the argument, Andrew moves closer to admitting that he himself is in the category of people who are misjudged by others. However, his own category membership is never made explicit. Instead, he focuses on his negative feelings about a particular ‘point about it’ (107), the misjudgements of other people. Focusing on others’ misperceptions and discriminatory treatment is a very common way of dealing with the membership of Learning Difficulty, as Angela had done when originally composing the question.

9.4.2 Taking action

The extract above continues as follows:

Extract 9:7 (V 4)

108. Mark: have you talked to anybody about it↑
109. Andrew: um well I've spoken to Sarah about it/ right hand gesture → Sarah and people in this group/ and you know changes coffee cup over, and left hand gesture → round the group people with similar learning difficulties/ but ( ) some of them feel 111. 112. it's a good thing and some of them feel it's a bad thing you know → M

I would like to focus on line 108. Mark moves the talk on towards Andrew’s own actions. The ‘you’ here is not the general ‘you’ that Andrew had been using, but refers directly to Andrew as an agent – what have you done? This implies strongly that the labelling issue does apply to Andrew himself. Andrew does hear it that way, because in 109-112 he sets up a scenario in which he himself is explicitly centre-stage, and within a group of people with whom he identifies, and who moreover have ‘similar learning difficulties’. Andrew’s move from general argumentation (you/they) to explicit identification of himself, as someone with ‘learning difficulties’, is effected by Mark’s question relating to action; the talk to which Andrew and Mark now refer is category-bound, and Andrew makes this quite clear by including people in the group.
It is thus possible to identify as a person with ‘learning difficulties’, by explicitly identifying with a group. On just a few other occasions in these data, the identification with a group of labelled people is seen as a positive source of action, as was explored in Chapter 4 (Extract 4:6). Being part of a group can on occasions be a source of action and strength, and a positive way of referring to one’s own identity.

9.4.3 Use of locations

Another common way of dealing with the issue of membership is by reference to place names. In the case of people with ‘learning difficulty’, this is not hard to do, since for many people, their lives are defined by the special places where they live and go to in the day. For instance, following Andrew’s contribution in Extract 9:7, the following occurs:

Extract 9:8 (V 4)

113. Harry: the house I live in up at Scarborough Road/ they’ve got people there
114. with learning difficulties/ the girl I live with Jane Robinson she’s she’s
115. got learning difficulties because she has fits you see/ left hand cupped gesture
116. but she she is my girlfriend actually you know/ (2)
looks down, away from group
117. you know um she goes to St John’s during the daytime/ she goes to
118. work/ we: 11 you know/ shrugs shoulders
119. well you know (. ) I feel quite sorry for her sometimes/

‘The house I live in’ is not the way that most of us would describe our social context. If we live with our family, we would be likely to say ‘in my family’. The reference to a house in this context is part of a shared interpretative repertoire, where people with the label of learning difficulties are grouped together (‘they’ve got people there’: 113) because of the category into which they are assigned. It is also the way a student might describe their temporary accommodation. The fact that Harry can use this phrase unchallenged is an indication of the shared backdrop of understandings we all had about Learning Difficulty.

The location defines the person and Harry also adds another location: the name of a day centre, where his girlfriend goes during the day. The use of these special locations effectively categorises the people who are associated with them. Later in the same
interview, other members talk about ‘houses’, as well as day centres. In all these cases, the location is not only definitional, but is associated with discriminatory misjudgements of inhabitants.

9.4.4 Setting up contrasts

In the above extract Harry does not only use locations, but he also uses other social actors. He sets up his scene very carefully: first the ‘house’ (113) then ‘people there with learning difficulties’ (113-4) and finally one social actor who steps out of this cast ‘the girl I live with [who has] got learning difficulties’. He carefully distances himself from the others in his house, and this is underlined by two further strategies. One is the use of the word ‘but’ in line 116, which implies that the normal expectation would be that ‘I’ would have a girlfriend without learning difficulties. The second strategy is his final statement ‘I feel quite sorry for her sometimes’ (119). This rather clinches Harry’s position as someone who is distant and pitying her. The position of the person who is ‘sorry for her’ resembles the patronising ‘other’ of the charity tradition.

Setting up contrasts between oneself and others is a very general strategy. On occasions, this is done by referring to one’s own competence, as compared with that of others. For instance, Andrew’s story in Chapter 5 (Extract 5:1) positions him in the role of a competent social actor, by contrast with the others whom he helps, and who therefore can be rightly assigned to the category of Learning Difficulty. This kind of identity work, then, effectively takes the speaker out of the membership category to which he or she assigns others, implying that there is a group of people who are rightly called ‘people with learning difficulties’. Both Harry and Andrew admit, in effect, that the category exists and that the argument is not just about the toxic effect of labelling.
9.4.5 We are people first

The final position that ought to be included here, since it is defining for the People First movement, is the one that Angela took up during the session in Extract 9:1 above:

30. Angela: I don’t think - I think it’s horrible/ why have people got to be labelled anyway/ why can’t people just be called their own names↑/

She echoes this during Visit 4:

Extract 9:9 (V 4)

138. Angela: I think it’s horrible/ I don’t think it’s necessary/ why can’t you just be - why can’t you just be called a normal person↑/
139. voices: yeah yeah
140. Mark: I think it’s (.) in a way er (.) it’s not a – not an expression but a label/[…]

This clearly draws on the People First discourse, but it is interesting here to see how it is occasioned by the local unfolding of the talk. Prior to line 138, Mark, Harry, Andrew and another speaker have all expressed positions that effectively inoculate themselves against categorisation, or given themselves an ambiguous semi-membership, while implicating others. It seems as if Angela is rejecting the subclassifications that have been made by Harry and others, and her turn is hearable as a bid to throw out all the labels, for everyone. Angela’s use of the word ‘normal’ is also interesting, since it sets up a contrast between two categories, implying ‘abnormal’ to contrast with ‘normal’. Angela draws on the discourse of a common humanity, where everyone has a right to be called normal. She is claiming the right to talk about herself as a human being. This brings them back to the discourse of labelling, with Mark’s final evaluative comment at 141. A label is something that can be thrown away, and does not have to define you as a person.
Chapter 9: Talking about labelling

9.5 Discussion

9.5.1 The nature of preparation talk

This chapter has examined talk in two different, but related contexts: the interview visits, and the sessions, and it has revealed some of the intertextuality, the links between these two events. The talk on identity issues in the interviews was not simply part of casual talk between self-advocates, but was carefully rehearsed and prepared in the session. In addition, the analysis of preparation talk has shown how closely the initial purpose of the question, and of the whole activity of questioning, was linked with group members' own concerns. Angela wanted to compare her experience of troubles with that of the people she would encounter on the visits, and that is what they did accomplish. What is also remarkable to me is how well all four of the group members collaborated on this purpose. On that very first visit, the group members put themselves over as a united team, intent on their purpose of comparing their own views with those of their peers.

The aspects of preparation work for this question included:

- envisaging the purpose of the talk ('to see if your friends think the same as you')
- the discourse of labelling
- deliberate ambiguity in the cause of delicacy.

On future occasions, when analysing and writing, group members commented frequently on how the same question could be heard differently at each interview. They became very aware of the wording of the questions, and there were some suggestions for changing the first question, to make it clearer. However, I feel now (and argued with them at the time) that this analysis has demonstrated quite clearly how the ambiguity of the question led to some very rich talk. A balder, more open question would have been less interesting, as Rapley et al. (1998) found in Todd and Shearn's (1997) data. The openness of reference meant that membership categories were not given, and so interviewees had to establish their own interpretations. It was
precisely the freedom of the wording that led to William's 'like us you mean?' in that first visit.

The use of the word 'labelling' and the discourse on which it draws, proved to be a very useful tool in the interviews. It was this discourse of resistance that enabled John, in Extract 9:5, to talk disparagingly of the government's standardisation of the label 'learning disability'. This is part of a model of disability that is particularly associated with self-advocates; labelling is seen as a kind of oppression, caused by others' attitudes and actions, and is positioned as a social barrier.

9.5.2 Further elaboration of some features of inclusive research

In all the previous chapters, but particularly in Chapters 5 and 6, a number of characteristics of inclusive research emerged. This current chapter has deepened the understanding of some of these, by looking in detail at how they are worked out in the course of the labelling question. In particular, the analysis revealed how important collaboration is in the interview situation, and how it can be achieved by fine details such as small movements or facial expressions. Achieving such collaboration is not, however, just a learnable, rote performance; it will work out differently on each occasion, and members had to be very sensitive to each context of talk and non-verbal interaction as it unfolded.

What proved to be very important was the developing relationship between researcher and researched, which had been started by the introductory work explored in Chapter 3. Especially because the labelling question occurred towards the beginning of their meeting, members were still working to establish who was who. Sharing of identity had to be worked at, and respondents were not only considering their own position in relation to other social actors that are invoked in their accounts, but also in relation to the person who has asked them the question. This was made very clear by the analysis of Extract 9:5. Their primary interest was not only 'who am I?', but 'who are you?' and both had to be jointly constructed.

A final point about inclusive research that this chapter has emphasised is the blurring of role boundaries, noticed in Chapter 5. For instance, in Extract 9:5 Darren
did supportive work in helping the Research Group to define relevance, with ‘we’ve
gone off the wrong track haven’t we?’. Keeping things on track was not just the job
of interviewers in this project, but also of interviewees. In summary, then, this
chapter has added to knowledge of:

- how collaboration is done in the course of interview talk
- how the relationship and membership categories of interviewer and
  interviewee are vital to the talk
- blurring of the boundaries between the discourse identities of interviewer and
  interviewee.

9.5.3 Managing assigned identities in talk

In this chapter members were exploring issues around their own assigned
identity; these data therefore may be of interest in the light of other studies, such as
Todd and Shearn (1997), who found that people with ‘learning difficulties’ were
unaware of their own label. Rapley et al. (1998), it will be recalled, re-examined that
data, and concluded that:

A person with an intellectual disability can, like any other, avow or disavow such an identity
according to the demands of the situation in which they find themselves.

(Rapley et al. 1998: 807)

Like Rapley et al., this study proceeds from the assumption that talk should be
examined in the fluid, local context. From this point of view, the current data have the
great added interest of being part of a context that was prepared and set up by people
who had the same label of learning difficulty assigned to them. Therefore it would not
be surprising if the present study yielded different findings from those earlier ones.

The analysis nevertheless revealed some strategies that were very similar to those
mentioned in Rapley et al. (1998) and by other researchers (Simons: personal
communication). For instance, members commonly turned to the device of
introducing other social actors who were less competent than themselves. This seemed
to be a very potent way of saving one’s own identity, as competent, while admitting
that the category of Learning Difficulty was rightly assigned to others. Moreover,
researchers and interviewees frequently identified with each other as mutually skilled, through the competence they were displaying in actually managing the research interview. As was pointed out in Chapter 5, the discourse identities of members fed into their transportable identities; how they put themselves over was influenced by their view of what they were doing at that point.

This analysis also demonstrated other membership categorisation devices open to members in establishing their shared status as labelled people. One, for instance, was the use of locations. Much of the talk about special places was only understandable against a backdrop of assumptions about people with the label of learning difficulties: that they live in shared, supported housing; that their living place has not been their choice; that they share their life with many others who have been similarly labelled. These assumptions are all part of the interpretative repertoire of Learning Difficulty, shared by all members in these data, and can be invoked to signify their membership categorisation as people with the label of learning difficulty.

Finally, there were some clues in these data as to how group membership as people with 'learning difficulties' can give members a new way of using that identity, as a powerful force for renewal and action. Occasionally, members spoke as a powerful 'we' group, and this is part of their quest to be in control of their own self-definition.

9.5.4 Self-definition

This chapter has shown how members are able to challenge the dominant discourse of Learning Difficulty, by drawing on resources associated with an alternative discourse of labelling. This was a position of power, and it must not be forgotten that it was associated strongly with the nature of the occasion itself, in which members with 'learning difficulties' were taking on untypical and powerful roles as researchers.

In all the interview extracts examined, members were in control of the talk. They had the interactional rights to ask questions, to decide whether responses were relevant, to problematise and evaluate. These rights of interaction, which were central to the research interview context, are absolutely vital to the project of self-definition. Thus inclusive research, such as this project, could be seen as a very important tool for
members to take forward their own identity work. More recently, in another similar research project, self-advocates have come up with the statement that ‘our learning difficulty is our advantage’. In the current data, one could see the seeds of such a position, with members linking their identities as researchers with their identities as people who have been labelled.

By asserting, either that they are wrongly labelled, or that labelling itself is a problem, self-advocates are demonstrating strong identities as people who can think for themselves. This is the very opposite of what is often thought of as a ‘learning difficulty’ identity, which is associated almost definitionally with ‘incompetence’ (see 1.5.2). The very act of doing the research interviews together is an act of defiance, and the right to define oneself is not only the topic of the talk, but is also part of the process of self-advocacy research.
Chapter 10
Conclusions and reflections

10.1 Chapter overview

In this final chapter I will discuss what has been revealed in this thesis, and then reflect on its significance. Section 10.2 is a brief outline of the main findings from each chapter. The thesis has followed through and analysed in detail the talk in one particular research project, undertaken by a group of People First members. In 10.3, I reflect on the characterisation of inclusive research in this particular project, and then on the extent to which it can help us to understand other inclusive research projects.

Each chapter in this thesis has been based on some close textual analysis of talk, followed by discussion of an interpretative nature. The social explanation of the significance of the findings has been left largely to this last chapter, and is dealt with in section 10.4, where I attempt to set the Research Group’s project in the wider socio-political context of discourses about Learning Difficulty in the 1990s, and to consider how far their project contributed towards addressing problems of social oppression.

The evaluative spotlight must also be turned on the present analysis of discourse, which in effect is research about research. It is vital to consider the potential gains or threats posed by such an endeavour, which I attempt in section 10.5. Finally, section 10.6 looks towards the future, and poses challenges and questions for new projects, both within inclusive research but also within discourse analysis.

10.2 Outline of findings

Chapter 1 set out the social problem that was the origin of the Self-Advocacy Research Group’s project. Their problem about labelling was not simply about the stigma of a socially devalued identity, but also had real consequences for their lives, since they were judged as incompetent to decide for themselves and to take ownership
of their lives as full members of society. In Chapter 2 I sought an analytic method which would support the socially committed nature of this project, but would also be firmly grounded in naturally occurring talk, and which would help me to explore how members achieved change.

In subsequent chapters I explored various aspects of the group’s work, as they were displayed in the talk. Firstly, Chapter 3 reported how the group members introduced themselves, and answered questions about their own identity and intentions. There were various devices available to them for establishing the events as research interviews, such as working up group identities and using the format of a meeting. The tight interconnections between identity and event were glimpsed here for the first time.

Chapter 4 explored the relationship between this research project and its self-advocacy context. The chapter aimed to characterise what is meant by self-advocacy talk, for instance the moves between personal and political talk. The talk was also characterised by resourcefulness, or finding your own solutions, and by a shared interpretative repertoire of rights. People First and other such organisations are about collective, group action, and there was evidence in the data to show how members’ talk was jointly produced. It was collective talk, and was based on a shared understanding of group membership and ownership. The self-advocacy context appeared to be essential for understanding the nature of this research project.

Chapter 5 examined the talk involved in doing interviewing. Research Group members took on the right to define relevance and control what counted as valid knowledge, but they did this quite openly, in discussion with their interviewees. This openness about meaning-making was viewed as a hallmark of this research, together with a blurring of the distinction between researcher and researched. I showed how these interviews depended for their success on establishing a dual identity, both that of researcher but also that of person who had been labelled as having a ‘learning difficulty’. Identity work, at many levels, was seen to be central to the task of becoming a researcher. In Chapter 6, I analysed some counter examples, or deviant cases, in which it was hard to establish the frame of research. The concept of threats was useful to explain what was happening on these occasions. There are many
dominant repertoires that could intervene and threaten the establishment of this project as research.

In **Chapters 7 and 8** I recognised and described the supported nature of the present project. For instance, one strategy for support talk was to share knowledge and reference to other conversations, in order to bring in members. Referring to stories of personal experience was shown to be particularly useful. Supporters themselves often downplayed their own expertise, in order to boost the rights of members to speak as experts on their own experience. It was often through this kind of work that members were enabled to talk about their own experiences as instances of political or institutional change. Not only was self-advocacy talk supported in the interviews, but the researchers themselves had support in developing their own skills for research. I found that some of the strategies I used in these group sessions were similar to the agenda-driven talk of teachers, in defining what counted as valid ways of talking about research. An important aim of my work was to encourage members both to understand the significance of what they were doing and to take ownership of it, and I analysed and discussed some of the strategies I used for doing that work.

Finally, **Chapter 9** followed through one complete research question, the first question about labelling, from its inception to its execution. Their subtle and insightful preparation of research questions was shown to be rooted in their own discourse about labelling. In the interviews, members made use of generally available strategies for dealing with identity issues, and their identity work was linked closely with each emergent conversational context. Making salient a common identity was shown to be part of the original intention of Research Group members, and was an essential influence on the identity work done within the talk, which was not only about 'who am I?', but 'who am I in relation to you?'
10.3 Inclusive research

10.3.1 Drawing on established repertoires of qualitative research

The literature on inclusive research often assumes that people with the label of learning difficulties who do research are entering the world of academia (Ward and Simons 1998; Stalker 1998). It follows that they will want to use models that have been built up within social research. Inclusive research with people with 'learning difficulties' is sometimes likened to other types of qualitative research, such as life history research (Goodley 1996). I will therefore start with some reflection on the ways in which this project draws on repertoires that already exist within qualitative research in social science.

Authors have occasionally questioned whether it is feasible for people with 'learning difficulties' to participate meaningfully in all phases of the research process (Stalker 1998; Walmsley 1997; McClimens 1999). The present project, in common with other similar projects (March et al. 1997; Bright 1999; Gramlich et al. 2000) demonstrated that people with the label of learning difficulties were capable of planning and managing the research, albeit with support. For instance, there was some very precise and sensitive work done by the Research Group members, in handling the wording of the question relating to labelling, as was demonstrated in Chapter 9. The analysis laid bare the way in which they planned and formulated their own aims and research questions, as well as their approach to doing interviewing.

It will be recalled that in Chapter 5 Research Group members outlined some of the main characteristics of research for them. This included a sense of power, of being in charge. This is something that they often write and talk about:

Member: It is definitely a challenge to me, more of an upgrading challenge. It was other people who we tried to interview – the questions that we are trying to find out. We were finding out what other people were doing, and the questions that other people were asking us were different to the ones we were asking them.

(D 7)
Throughout the thesis, I have examined extracts and examples where Research Group members did take control of the situation, exactly in the way that Silverman's (1973) model interviewer does. They used generally available conversational resources, such as allocating turn taking rights, and defining relevance, to be effective as researchers. They came with their agenda, literally printed out on a piece of paper, they demonstrated ownership of that agenda, and they exercised the right to decide what counts as the correct way of interacting in this context. All of this was skilled work, and the skills had to be acquired. In the same discussion session, Mark spoke in particular about the skills of communication that are necessary for researchers:

Mark: There are ways of encouraging people to talk – sometimes you have to follow up the question, to encourage people. I might ask people for instance what tricky situation they were in, and get them to tell their story.  
(D 7)

Throughout the data, there are examples of members taking on powerful researcher roles, by defining their own questions within the interviews, and by taking on the interactional rights of researchers. The data include many features of mainstream qualitative interviewing, where each party has distinct interactional rights. The researchers/interviewers had the right to literally take away the interview tape, and to make some kind of meaning out of it. Interviewees, on the other hand, were expected to display their experience for the benefit of the interviewer, and talk was understood to be on the record. It was public talk created for the specific purpose defined by the researcher.

So far, this all sounds very much like the traditional skills of a research interviewer, particularly in qualitative research, where the aim is to produce stretches of relevant talk from the people being interviewed. The only difference is that the interviewer in this case is not a supposedly objective academic researcher, but is a person who is affected by the issues being discussed. This is perhaps what Oliver (1992) referred to, when he wrote of the breakdown of the traditional distinction between researcher and researched; blurring of boundaries is also to be observed within other fields of qualitative research, such as feminist research (Gluck and Patai 1991) where it is now considered to be appropriate for the researcher to take up a more involved stance, and to share concerns with the interviewee.
10.3.2 Benchmarks of inclusive research

What then was different and distinctive about this project? The blurring of the distinction between researcher and researched seemed in many ways to be a basic part of their project, since as was shown in Chapter 9, members set out to find whether their peers shared their own experiences of discrimination. Part of their technique was to share personal experiences within the interview context, to a far greater extent than most traditional researchers. Therefore one of the distinctive features noted was the public nature of meaning making in the interviews. Often, the analysis was performed out loud, and in situ. This necessarily meant involving the interviewees in that process, as well as the interviewers. For instance, if a member of the interviewee team did not agree with some evaluation or summary, then they could say so. Equally, interviewees also took responsibility for procedural aspects of the interview at times, as was seen in Extract 9:5.

In summary, the first two features of inclusive research observed in this project are:

- the public nature of meaning-making
- the frequent blurring of the strict distinction between interviewer and interviewee.

It is hard to discuss the nature of research talk within this project, without putting it within the framework of People First, or self-advocacy, talk. One of the outcomes of the analysis was that this type of research is not just accidentally situated within a self-advocacy context. There are features that essentially link it to that context, and mean it would not work without it.

In Chapter 4, it was seen how individual stories of personal experience were often the springboard for members to move into political or collective action, and how this process of talk was jointly accomplished, with members supporting each other. There was a discourse here of self-reliance, with an emphasis on solving problems for yourself. All these features were also a bedrock for the research process, where both interviewers and interviewees could explore their situations together. on the
assumption that they were capable of reaching their own conclusions. When this was not the case, then the research frame could break down, (see Chapter 6), where an interviewee was assigned an incompetent identity. Such threats also existed from within, since the discourse of incompetence exerted a powerful pull over members.

Both self-advocacy and research talk, in this context, are predicated upon strong feelings, and to that extent this type of research had a campaigning edge to it. Members did not set out on a neutral search for some objective truth, nor were they doing academic research just for its own sake, but they recognised that they wanted to change things about their own lives and the way that they were treated. There was, therefore, a sense in which collaboration between researcher and researched was also an essential part of the process. The interviews were occasions for both parties to establish some kind of common cause, as was illustrated clearly in many extracts, including Extracts 4:1 and 5:1. It is hard to imagine that this project would have been successful, had the researchers pursued questions that did not fully engage them.

Certain features of self-advocacy talk underpinned this research project, namely:

- a discourse of self-reliance
- strong feelings about one's own situation
- campaigning for change and collective action.

10.3.3 Doing identity work within a research context

Different contexts of social interaction give us all the opportunity to make salient various aspects of our identity, and to a large extent we respond to the nature of the occasion and to our particular purposes within that occasion (Antaki and Widdicombe 1998). Members in the present project were no different. They were well able to reflect on their own identities, and to use various aspects of those identities, in quite subtle ways.

However, it is also apparent that the research was built on a measure of identification between researcher and researched. Collaboration was something that
had to be worked at, and this thesis has unearthed some strategies for doing this. Quite often this occurred through the fine details of body language, as was seen in Chapters 5 and 9, or the devices of adding an appeal such as 'isn’t it?’ to the end of a turn. When identification did not occur, then the research frame could break down, almost irretrievably, as was shown in Chapter 6. Lack of understanding of a common identity was one of the main threats to doing research.

The analysis adds to the arguments about whether it is possible to be both a person with ‘learning difficulties’ and a researcher. In fact, it is not only possible, but for this kind of research it is actually necessary. The common experience of being labelled becomes a positive tool for change, and there are specific ways that members worked up these aspects of their identity together. The significance of this was that the people central to this endeavour, namely those who were affected by problem identity labels, were active in working up their own solution identities. This assumption of a common identity is borne out also by my subsequent work with self-advocates, and I feel it is an extremely important finding of this thesis.

Identity work in the research interviews included:

- working at collaboration
- identifying with others who have a common experience.

10.3.4 Gaining full interactional rights

A theme that has recurred in each chapter is that of interactional rights, sometimes referred to as membership rights (see 2.7.1). Full membership rights are routinely denied to people with the label of learning difficulties, just as they are to children (Ochs and Taylor 1992), and to older or confused speakers (Shakespeare 1998). They are considered incapable of defining a relevant topic of conversation for themselves, or of problematising their own contributions. They may also be expected to perform, to narrate stories about their own lives, but not to demand these of others. The power of defining what counts as valid knowledge is vested in those who control their lives, define and diagnose them, constituting a pervasive form of social oppression.
Self-advocacy is a social activity which is defined by participants taking back their interactional rights as full members, and a detailed textual analysis of talk can reveal exactly how interactional rights are distributed. Doing research, as this thesis has revealed, is a particularly potent way for participants to reclaim their rights as full members, by asserting the right to define themselves (Chapter 9), asking questions of each other (Chapter 5) and solving their own problems (Chapter 4).

Doing identity work is not simply about making salient certain aspects of one’s transportable identity, or talking about who you think you are. Throughout the thesis, analysis has revealed the tight and dynamic links between the discourse, situational and transportable identities of members. In other words, by assuming the right to ask questions and give evaluative comments, members were taking up certain discourse identities. These led to a construction of them as research interviewers, a construction which both surprised and challenged all participants, since it conflicted with other aspects of their transportable identities. For instance, they openly reflected on their own lives as people with ‘learning difficulties’, and about their feelings about being labelled. It was this tension which literally created something new for their identity record. They were not simply becoming researchers in the sense in which I might, by entering an already established field. They were creating the identities into which they were stepping, as researchers with ‘learning difficulties’. Becoming a researcher creates a powerful identity, both for groups and individuals.

It is worth pausing to consider how far this identity impinged on their own lives; Oliver (1997: 19) posed the evaluative question: ‘who gained?’ One member of the original group is still active in research, and has gained considerably in stature, self empowerment and ability to analyse both his own position and that of others. Others have not remained so actively involved, but their status as researchers may still be relevant. For instance, one member decided to retire from research work when she moved, but took with her an annotated book of photos to illustrate all the work she had accomplished. This is now a part of her identity, and is talked about with others who meet her. All members have publications to their names, and are aware of the status this gives them.
In all these ways, then, doing research can be seen as fertile ground for challenging a social status in which one is denied full membership rights. By doing research, members took on aspects of a researcher identity, and so their challenge to the received social order was achieved not only by what they talked about, but by the action of doing research. The comment by a supporter cited at the end of Chapter 2 will be recalled: ‘oh you’re doing it - you’re doing it’. This was in fact the working title for the present thesis.

The interactional rights associated with this research project were:

- **asking questions of each other, problematising one’s own contributions and solving one’s own issues**
- **creating a powerful identity for oneself as a researcher with the label of learning difficulties.**

10.3.5 Supported research

This research, and the interactions which constituted it, were jointly constructed, with support from people who were non-disabled. Some writers therefore (Zarb 1992; Walmsley 2001) might place it within the category of *participatory research*, in opposition to *emancipatory research*. However, Oliver’s (1992) definition of emancipatory research (see 1.7.2) relates more to the purpose of the research within the agenda of disabled people, and does not exclude the possibility of support. It should be remembered that many of the individuals within this project had significant support needs, most of which were played out in different arenas. Simply in order to get to the venue and to manage the practicalities of the occasion, supporters were essential. Moreover, it has been argued that these researchers, like any others, should have access to proper training and support for their own skill development: any novice researcher requires some such induction, and self-advocate researchers are no different. The difficulty of this task is to support ownership and empowerment, while imparting skills. The repertoires of teaching and empowerment are difficult to reconcile, but not impossible, and we all had to take responsibility for this task.
The essential question that emerged from all this was: 'Did the members themselves have control over the content of the research?'. Just as disabled activists (Morris 1993) have long argued that independence does not mean doing everything for yourself, in the same vein research does not necessarily mean taking all the steps in isolation. On the contrary, the analysis presented in this thesis contends that this very ownership of the research process has to be supported. Perhaps the most subtle, but necessary, task for the research supporter is to find ways of enabling members to appreciate the significance of what they are doing as researchers.

In supported research, this thesis has demonstrated how:

- talk is jointly constructed
- research skills can be learnt and developed
- members can be in control, with support.

10.3.6 Other inclusive research

The present research project was one of a growing number of similar studies that have attempted to include people with the label of learning difficulties in a variety of capacities (Ward and Simons 1998; Walmsley 2001). It is timely therefore to consider how far the findings from this one project can be generalised to other projects, all of which are actually very different, as I have acknowledged elsewhere (Williams 1999). Was this project typical of others in the genre of inclusive research?

There are no comparative sets of discourse data from other similar projects, and so any final answer to the question of generalisability would have to wait for such work to be carried out. However, it is possible to consider the types of features in the present project that perhaps had an influence on the kind of talk that developed within it. In addition, since working with the group on this project, I have carried out another study where self-advocates took on roles as researchers. This was a much larger, fully funded project, accountable to both the academic and professional research community, to self-advocacy organisations, and to the funders (Swindon People First Research Team: in press). I have also supported self-advocates in many other smaller
ventures, and so all these experiences add to my confidence in several of the hallmarks of inclusive research that I have detailed above, such as the blurring of boundaries, and the importance of identity issues.

McClimens (1999) poses the useful question of who initiates the research. He maintains that most projects that include people with the label of learning difficulties are initiated by academic researchers, who then look for potential partners:

In the field of participatory research with people who have a learning difficulty the relationship between the originator of the research question and the participants is hopelessly one-sided. For as long as research continues to be dominated by academic interest, it is likely to remain so. (McClimens 1999: 226)

Although I would agree in general with that statement, and also with the contention that academics are most often in a position to identify suitable research projects and funding opportunities, I would argue that the present project was relatively free of such constraints. The idea for the project belonged to the group members, who could pursue their thinking and action in any way they wished. This was because the working relationship between myself and the group pre-dated the project, and because of our relative lack of funding. The total project funding was some £6000, from the regional fund of the National Lottery. I did not have my own agenda for the research, nor was I constrained by any research proposal, employers' expectations or funders' timetables. Therefore, the Research Group members were exceptionally free to develop their own interests, skills and power in any way they chose. This may well have had an influence on the talk, as I considered in Chapter 8. Projects with greater funding bring higher expectations of specific outputs, and so members may be more constrained by those.

Another significant feature of the present project was its positioning within a self-advocacy context, as has been explored in this thesis. Members considered themselves part of People First, and they interviewed others who were similarly allied with the self-advocacy movement. Other projects may be quite different. For instance, inclusive research is part of the Department of Health's research programme to accompany the Learning Disability strategy, Valuing People (Department of Health 2001). People with 'learning difficulties' may be included within those research projects in varied capacities. Research that is carried out by academic researchers, and
simply consults with a reference group of people with 'learning difficulties', may not have any of the hallmarks of self-advocacy based research, with its emphasis on the interactional rights of members. At the other end of the scale, some research is now being carried out by People First organisations themselves, under the guidance of a members' committee, and may draw in research consultants to help with the process as and when necessary. The institutional identities of participants in the research team is likely to have a significant effect on the talk.

A final significant variable would seem to be the skills and experience of all participants, both researchers with the label of learning difficulties and those who support them in their endeavours. As was shown in Chapter 5, members themselves thought of research as a skilled activity, and the current analysis revealed how very skilled this group of researchers quickly became, both in preparing and understanding their task, and in carrying out the interviewing. I have argued elsewhere (Williams 1999) that not all people with 'learning difficulties', any more than all members of the population at large, will aspire to be researchers. The business of establishing the discourse frame of research, as was seen throughout this thesis, is a very delicate one, and in many ways is diametrically opposed to the discourse of Learning Difficulty that normally dominates people's lives. The difficulty of managing this new type of discourse should not be underestimated, both for supporters and self-advocates, and therefore projects that recruit inexperienced or unskilled people as researchers will need time to develop those skills. The nature of the talk, and the characteristics of inclusive research, will be very dependent on the way in which both members and supporters understand their task and develop their ability to interact in this new context. Factors that may differentiate inclusive research projects include:

- **who initiated the research**
- **whether it is accountable to funders, research proposals and other stakeholders**
- **the institutional identities of all participants, in relation to the self-advocacy movement, academia or any other body**
- **the skills and experience of all participants.**
10.4 Social explanation

10.4.1 The social and legal context in the UK in 1997/8

In this section I will attempt to situate the project within the wider context of laws and social trends in the 1990s, recognising that knowledge making is always historically contingent (Foucault 1980). It is essential to understand that context in order to appreciate the challenge and change inherent in this project and other similar ones. The essential questions are:

- Could this project have happened at any other time?
- In what ways was it rooted in what was happening at that point in the wider social sphere of disability?
- How did it consequently contribute to challenge and change?

My discussion here builds on the account of the background laid out in Chapter 1.

In the late 1990s, the concept of normalisation (see 1.5.2) was considered in the academic literature to be outdated and in need of development (Brown and Smith 1992). However, there were certainly many service providers who still felt that normalisation was their guiding principle, as noted by the present author during an evaluation project in 1997-8. Just as academic views tend to outstrip practical policy, so does policy often outstrip what is happening for people at grassroots level. For instance, the 1991 NHS and Community Care Act instituted the nature of community care for all disabled people. People with the label of learning difficulties, like other disabled people, were to be assessed for their support needs in their own right, and not as adjuncts to their family (Walmsley 1999). However, the reality for many people living at home was that their carers and parents still had a very strong voice (Williams and Robinson 2000a). In essence, their rights to determine for themselves what their own lives should be like were often negated by the view that others had of them (see 1.4) and Walmsley (1999: 165) noted the ‘huge gaps between theory and practice’ in this field.

Into this context, in the late 1990s, came a number of influences for change. For instance, disabled people themselves lobbied for control over their own services, and
the Direct Payments Act was passed (Department of Health 1996), coming into effect in 1997. Disabled people could now become employers of their own support staff. This move entirely accorded with the newly forged ideas of independence, as more to do with autonomy and control, and not about doing everything for oneself (Morris 1993). People with the label of learning difficulties, however, still remain largely excluded from direct payments provision at the time of writing (2002), due to a large number of factors, which include certainly their own ideas about independence being a difficult and distant goal (Swindon People First Research Team 2000).

Another new discourse related to independence in the 1990s was that of empowerment (1.6.2), based on a recognition that the situation of people with ‘learning difficulties’ is essentially one of a lack of power. Giving people power over their own lives was now seen positively by policy makers, as witnessed by the Direct Payments Act, by many service providers and certainly by academics (Ramcharan et al. 1997). The self-advocacy movement itself (1.6.2) is often referred to as part of this process of empowerment, and there are chapters on self-advocacy in Ramcharan et al.’s book. Is it possible to empower people? Many, including disabled activists, would say that empowerment is a nonsense, or a comfortable delusion (Dowson 1997). People have to decide to take power themselves, literally to empower themselves. It is not something that can be given as a gift:

Unless people with learning difficulties, perhaps in alliance with other disabled people, can find a way to take the power, there is little prospect for change.

(Dowson 1997: 119)

From the viewpoint of people with the label of learning difficulties, power was still a distant goal. The discourses that surrounded them were those of the powerful others who traditionally determine their life course, in the main their parents and other family members, various care staff in residential settings and in day centres. These individuals had little access to the latest academic trends, but were bound to have far more influence on people themselves, since theirs is a spoken discourse which has a real effect on the day-to-day texture of their lives. At grass-roots level, then, the fine ideals of empowerment and rights to community support were tempered with notions of incompetence and risk, which still abounded (see 1.5.2).
The discourse of Learning Difficulty in the late 1990s was therefore very unstable. It could be likened, perhaps, to the multi-layered effect of an onion with many skins. In the main people with 'learning difficulties', although at the centre of this onion, had little access to the outer layers in which the liberating discourses of power, choice and direct payments were being aired. Perhaps the sole exception to this situation was the position of self-advocacy groups themselves. The People First movement had achieved a level of political awareness and visibility by the end of the 1990s (see 1.6.1), and one of the leading members of that movement had had some contact with the Research Group members through an organisation called Europe People First.

I should also perhaps place myself within this historical context, since my role was probably very similar to other non-disabled allies (Walmsley 2001), who have helped people with the label of learning difficulties see beyond the centre of the 'onion', and have confidence in their own ideas. It would not have been possible for me to take part in this project, without the existence of a discourse around trust and support between non-disabled people and self-advocates. This existed because of the pioneering work of others such as John Hersov, Andrea Whittaker and Steve Dowson, who supported the UK self-advocacy movement in its early stages (Dybwad and Bersani 1996).

However, there were still considerable disjunctions in the social practices that constituted people's lives, and perhaps these were exemplified most clearly when a seemingly empowered self-advocate could step from the glittering world of international conferences, back into the reality of a non-supported and devalued personal life. It was into this shifting situation that the Self-Advocacy Research Group stepped, when they embarked upon their project.

10.4.2 Tackling social oppression by defining yourself

The Research Group's project was very contingent on that period of flux and unstable meanings and identities. There was clearly a gap between the rhetoric of empowerment and the reality of people's lives, which was integral to the project. As argued by Janks (1997: 38) 'as members of a society, we are constituted in and by the available discourses, and [...] they speak through us'. However, the project did not
simply reflect its historical context, but it had the potential for re-forming it. As Wetherell (1998: 401) shows, an analysis must also take account of the ‘emergent and transformative properties’ of each interaction. It is important not only to trace the extent to which members drew on existing discourses, but also the extent to which they created something new and challenging.

The discourse about labelling at the heart of this project is very challenging, even to progressive discourses of empowerment. Self-advocates were saying that they wanted rights as individual human beings, rather than as members of a devalued group. In so doing, they were drawing very strongly on the self-advocacy discourse of People First. The discourse of labelling is one that enables members to resist their categorisation within the dominant, naturalised discourse of Learning Difficulty.

The ideological dilemma in this position will be immediately evident to those considering People First as a social movement, or indeed as part of the wider movement of disabled people. All the policies, laws or discussions referred to above rely on the existence of the category Learning Difficulty, with the exception of the Direct Payments Act, which groups them together with other disabled people. Even research carried out at the Norah Fry Research Centre (where I had just started working in 1997) is about services for people with ‘learning difficulties’, a fact that did not pass unnoticed by members of the Research Group. To further one’s own rights as an oppressed group, one has at least to recognise that one is part of that group, to ‘embrace a disabled identity’ (Corker and French 1999). Yet it is only very rarely in the data that the identity of ‘learning difficulty’ was made salient. Paradoxically, though, it was only by invoking a common identity and experience, that the research process actually worked. As we saw throughout the thesis, it was this identification between researcher and researched that was fundamental to the talk that went on in the project. How can we account for this paradox?

What self-advocates have in common, as members commented frequently, was a similar experience:

109. Mark: it affects a lot of people with a disability/
110. we found that in the group ourselves/

(Chapter 9, Extract 9:5)
Their experience includes the view that others have of them, the control exerted over them, and the downplaying of their own competence and integrity as human beings. The discourse of labelling is about this common experience. It is not about having the label but about being labelled, and the consequences it has for people. People want to take back the right to define who they are and to be in charge of their own identity record. When others define you, this is experienced as discriminatory.

The issue of who has a ‘learning difficulty’ is still a contentious one. On the face of it, the rejection of categorisation by members makes nonsense of most policy provision and even any theorisation of the People First movement itself. It is certainly an issue that is still hotly contended within those circles, and the strength of these discourses is that they belong to members themselves. The present research project is but one part of this ongoing debate.

10.4.3 The discourse of self-reliance

Related to the right of self-definition is the right to solve one’s own problems. Throughout the data, members drew heavily on the discourse of self-reliance, of being an active member of society, of resilience (Goodley 2000). ‘Solving your own problems’ was one of Mark’s refrains, and it was also evident in the very discourse identities that are taken up. Members continually solved their own discourse troubles in these data – for instance, by supporting each other (Extract 7:4), sorting out speaking rights (Extract 5:1), and defining their own questions. In what sense does this constitute a challenge to dominant discourses?

Service provision, and the policies and laws on which it relies, such as the 1991 NHS and Community Care Act, is premised on the fact that people with the label of learning difficulties need support to manage many aspects of their everyday life. In order to gain access to support provision, therefore, people have to be assessed, and to highlight aspects of need. This is not generally to do with physical needs (such as getting up in the morning, or getting dressed). Rather, it is about needs to manage decisions, to be safe in getting out and about, to have meaningful activities planned for
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each day and so on. People with the label of learning difficulties are constantly submitted to a discourse controlled by others, in which they have to portray themselves (or be passively portrayed) as having an incompetent identity, where others have to analyse their needs. The discourse surrounding needs-led services (see 1.4.3) positions people with 'learning difficulties' as objects at the centre of a service system, which is, in effect, an array of ways in which those needs can be supported.

The discourse of active self-involvement, very much associated with the self-advocacy movement, thus constitutes another challenge to the policy and legal background in which this project took place. If you prove that you can cope by yourself, then by definition, you do not have needs for a community care service as it is currently conceived. The potential socio-economic consequences of being self-reliant are that resources will be denied, that people will not get any support at all. There have been frequent occasions on which leading self-advocates (particularly those involved in research) have been accused of not really having a learning difficulty. It is certainly a dilemma for people who are trying to obtain a direct payment, since the original Policy Guidance (Department of Health 1997) stated that they had to be 'willing and able' to manage the direct payment. By proving yourself willing and able, however, it is hard simultaneously to prove that you have a need for a community care service. In the measure to which members draw on this discourse, they are effectively risking the whole structure of support which has surrounded them all their lives, and indicating that they can and should be allowed to determine their own life course and to take their own risks.

10.4.4 Re-defineining competence and incompetence

The main focus throughout this thesis has been on how members took charge of the process of research, adopting a new range of competent discourse and situational identities. This is why the act of doing research is considered such a challenge to received discourses of Learning Difficulty, premised on incompetence (see 1.5). Members have often commented on this, and chose to introduce the chapter they wrote with the words:
However, as Simpson (1999) points out, becoming competent may be part of the emancipation process for some, but by definition it cannot be the whole answer for everyone with a ‘learning difficulty’. In fact, many people with that label spend their whole lives jumping through the hoops of the learning/training cycle, and therefore being a learner can be considered to be part of their oppression.

This was clearly not how the people in this project thought about the skills they were acquiring. Instead, the discourse surrounding competence is about being capable to manage various aspects of one’s life, including the ability to speak for oneself, and indeed to manage a research project for oneself. The present analysis brings a new understanding of what competence can mean. Members of the Self-Advocacy Research Group, in common with other self-advocate researchers, have achieved high levels of specific competencies, demonstrated in the project data, and which have continued to be developed since then. However, they are still facing the barriers of being people with the label of learning difficulties: one of the factors that holds them back from further research work is the uncertainty of their position as salaried workers, due to their reliance on the benefits system. According to this system, a person receives incapacity benefits by virtue of the fact that they are generally incapable of work, and any attempt to take on a job may endanger continuing eligibility for benefits. Therefore, no members became regular, salaried researchers through the project. Again, we are left with a paradox. At one point, a member may present as a capable, confident person in charge of their own research project. At the next moment, the same person is restricted by a benefits system predicated upon their incapacity.

What must be concluded is that competence is not an all-or-nothing entity. Competence and context are linked. Some contexts are simply more conducive than others, if one is setting out to re-invent oneself. The discourse of needs, where service users have to adopt an identity of generalised incompetence, has to be replaced by a discourse of rights to support. Having support in some aspects of one’s life does not imply total incompetence. Self-advocate researchers are challenging received
discourses, and creating a new discourse, predicated on their own individuality as human beings with particular competencies.

10.4.5 Was their project emancipatory?

The three sections above have considered ways in which the project challenged received discourses through talk. Talk is, however, but one social practice, and we must look beyond talk to see where it is situated in a wider social reality. The present project set out quite deliberately to challenge and change. Group members started with an issue about their own social oppression. Because of the label of learning difficulties, they did not have full ownership of their own lives. They set out to make common cause with other self-advocacy groups, and to find out ‘whether they were hitting their heads against a brick wall like we are’ (see Preface: third stage). This is, potentially, part of an emancipatory agenda, as defined by Oliver (1992, 1997). A first step towards emancipation can be an increased understanding of one’s own position in society, so that one is enabled to ‘fight back’ (Aspis 2000), and it is worth considering how far the project progressed that agenda.

Throughout the analysis, we have seen how members were enabled to move from purely personal or individual issues towards a collective agenda, for example by working up concepts such as discrimination. Since the project, members have taken some of the stories from the data to a meeting of Europeans with ‘learning difficulties’, about combating discrimination. Two members have recently (November 2001) worked on a piece of work funded by the European Commission, to identify and network with projects which have enabled disabled people to have a say in political processes. Although they remain dependent on support to achieve their goals, they have continued to move towards Oliver’s (1992) definition of emancipation, by developing their own collective research agenda, explicitly challenging the social causes of their problems.

When we look at the contribution of the project towards the progress of inclusive research for self-advocates, the gains are probably more considerable. This project certainly contributed towards strengthening the likelihood of similar research projects being funded. A conference held in January 1999 called Researching Together
attracted a wide range of self-advocates who were interested in research, and representatives of some funding bodies also attended that event. Since then, a major piece of policy research (Swindon People First: in press) has been funded by the Community Fund, with a participatory proposal based partly on experience of the Research Group's project. There is now a network of self-advocates in the south-west of England who are interested in research, and who would like to take forward their own ideas and issues through research. This became evident at the mini-conference that the Research Group members held for those who participated in the original project (March 2001). At that event, the present project became a case study for a national scoping project (Baxter, Thorne and Mitchell 2001) about what was termed 'lay involvement in research'. Members of self-advocacy organisations have taken part at national level in seminars about inclusive research (May 2001), and there is also an international forum for their work through IASSID (International Association for the Scientific Study of Intellectual Disability).

Therefore, in all these ways, the project did become part of the wider movement of inclusive research emerging at that time, and it made its own significant contributions to that movement, and to the process of emancipation.

10.5 Discourse analysis and social oppression

10.5.1 Who gains from doing the analysis?

Since the project itself ended (the booklet based on the Finding Out project was written and published by the time of the conference in January 1999), my engagement with the group and their project has continued on two fronts: as a general supporter and friend, and as discourse analyst. Where discourse analysis is concerned it is quite clear that I have control, through access to a wide range of techniques, ideas and practice of which they are hardly aware. Therefore the same questions about emancipation can be asked about this phase of the research as about the original project:
• Who has gained, and who is likely to gain?
• Has this phase of the work made a contribution to the empowerment that disabled people have undertaken for themselves?

I will deal with these questions in order. Firstly, the question of gain has been discussed in the group on several occasions. In terms of the PhD itself, if anyone gains it will be me, and I have tried to be honest with the group on this count. Group members have on several occasions asked why they themselves cannot get a PhD, and so I have explained to them about the academic ladder which makes it possible for me to write a PhD thesis, but constitutes a big obstacle for them. As I have mentioned above, both the Research Group members and the Swindon People First Research Team have contributed ideas towards a ‘Self-advocacy Research’ curriculum, and we are currently testing this out at Swindon as I write. Discussions are underway to have this accredited, so that the original Research Group members could have their achievements formally recognised. In terms of publications, the Research Group members have done much better than I have (in publishing about the project, or about research in general), and this is one area in which non-disabled participatory researchers do have their power effectively curtailed. The usual expectation of a string of publications from a project just is not possible, without usurping the rights of the self-advocates.

In terms of the academic game, I cannot deny that I continue to reap rewards from the group’s project, in terms of qualifications and career. Interestingly, a large part of this comparative gain is due to the contrast between our positions in society. This project led directly to a new, paid job for me as a research supporter to the Swindon People First project, which I was free to take up at that point. None of the Research Group members, however, chose to apply for positions with the Swindon project, despite my encouragement, and this reluctance can largely be traced back to their position as people with the label of learning difficulties. As explained above, they are all still dependent on the benefits system, and they were also all very reluctant to consider working away from their home town.
Thus the story continues, and one can only hope that this sharing of gains can continue to be open and reflexive. We all need to be continually vigilant about who runs away with the prizes.

10.5.2 The wider contribution of discourse analysis

The second question raised above is of a different order. Does this type of discourse analysis have the potential to add to (or to undermine) the empowerment of self-advocates themselves? Has it made a contribution? Ultimately, of course, this will be for others to decide.

Oliver (1997: 28) calls the postmodernist worldview as a 'safe harbour', referring to the non-committed stance, the intellectual back-step with which the postmodernist can judge of what is going on. There is a sense in which all basic analysis of interaction simply exists, as basic research does in any arena. It can be used for good and for bad ends. The type of analysis I have attempted here has attempted to contribute, rather than to detract, from the group’s emancipatory project. As will be recalled (1.1), it is intended to be ethically committed research.

In terms of Oliver’s six criteria for evaluating emancipatory research (1.7.2), I would argue that the present discourse analysis has contributed chiefly on the third and fourth points, which are:

3) a challenge to the ideology and methodology of dominant research paradigms.
4) the development of a methodology and set of techniques commensurate with the emancipatory research paradigm.

(Oliver 1997: 20)

While it was the Research Group members themselves who developed and practised their own methodology, it is my hope that through the current analysis, we can all better understand these methods and the ideology underpinning it. A discourse analyst can help members to amplify and clarify what they have achieved, in such a way that others can benefit, and the movement of inclusive research as a whole can move forwards. This is the practical value which can be gained from some of the findings summarised in section 9.3 above. I am not claiming that discourse analysis in itself is
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emancipatory, but that it can support the emancipatory activities of others, giving voice to Foucault’s (1980: 81-2) ‘disqualified knowledges’.

In a similar vein, the discussions above about challenges to dominant discourses (e.g. to notions of competence and Learning Difficulty) will hopefully contribute to the debate about these issues. In that sense I hope that this analysis will support group members in their own re-definition of their position in society, which was the original purpose of their quest, contributing towards Oliver’s second criterion (see 1.7.2), a ‘re-definition of the problem of disability’. One could even argue that this type of analysis of talk, grounded as it is in real data, is a ‘description of experience in the face of academics who abstract and distort the experience of disabled people’ (Oliver’s first point). By returning to real texts, one gets as close as possible to what actually happened in the research. It is a feature of this type of analysis that the analyst’s own comments are always subject to re-inspection of the data by readers, and so some of the generalised positions adopted in the academic literature can be fleshed out and challenged.

10.5.3 Discourse analysis: a support or a threat to inclusive research?

There is, however, a fundamental paradox in the present endeavour, which should not be overlooked. This is the paradox of a non-disabled academic, such as myself, taking away the meanings and substance of what has been achieved, and re-working it into a form that is acceptable to the academic world. By definition, that activity can never be fully emancipatory. It can only hope to have a place in the developing emancipatory research agenda of people with the label of learning difficulties, and as non-disabled academics we must remain open to the challenges to our role within that agenda.

Consequently, I have been continually aware of the need to maintain the participatory process. For instance, the analysis itself was not done in isolation. Instead, I returned to the Research Group members, to seek their advice about the main parameters of self-advocacy and research, recognising their own expertise in these areas. Similarly, there are several findings I was able to check out with them, including the characterisation of inclusive research as ‘research that is based on strong
feelings’ (see Chapter 5), and the importance of self-advocacy talk within this kind of
research. Some of this work was done before and during the mini-conference we had
in March 2001, when some of the fundamental insights of the project were aired and
shared.

At the same time, I fully realise that their own interests as researchers will not
everly coincide with mine. Without my enthusiasm for discourse analysis, it is most
unlikely that they would have maintained any detailed interest in this process.
However, I would argue that their research has gained in depth and interest largely
through the process of analysis underpinning it, rather than the findings of the original
project. It is only through our continuing analysis that we have all acknowledged the
complexity of talk: the way in which people talk about themselves, the importance of
their own identity as researchers with ‘learning difficulties’, and the implications that
this has for their lives.

A continuing issue, however, is the problem of accessibility. As was recognised in
Chapter 1, one of the great oppressions of people with the label of learning difficulties
is that their lives have been theorised by others, in ways to which they themselves have
no access. Members have a right to develop their own knowledge about themselves,
and it is important that this work is enabled to contribute, rather than to detract, from
that process. What comes next is therefore of the greatest importance, with the
accessible version of this thesis. In this way, I hope that the process of analysis will
provide support to self-advocates who wish to take part in thinking and theorising
about their own lives. I will conclude by considering some of the issues that we all
face in this endeavour.
10.6 The future

10.6.1 Future directions for inclusive research

As has been discussed above, the discourse and context of self-advocacy were of essential importance to the present project. Since it took place, many more research projects by and with self-advocates have been funded, and are underway.

The People First movement needs now to be proactive in building its own infrastructures, to include research within its groups, on its own terms. Instead of research projects being carried out by just a few individuals, People First organisations should increasingly take ownership of what that research activity can mean for them, and where it fits into their structures. As they gain more confidence and understanding of this process, they will increasingly develop their own ideas for the research that they need to do. This must be the main direction for the future, with the research agenda being developed and funded within the organisations of people with ‘learning difficulties’. What then is the future role for non-disabled allies, such as myself?

Certainly, in the foreseeable future, most self-advocates will wish to have support in their research. This could be sought from researchers, or from the ranks of their own staff, who will also then need to develop their skills. In any case, an important role of the non-disabled researcher must be to help build the capacity of self-advocacy organisations to carry out research.

This thesis has also demonstrated the importance of skills development for researchers with ‘learning difficulties’, including the subtle skills of identity work. Developing jointly a curriculum for research skills will be an exciting venture for the future.

10.6.2 Taking control of knowledge making

It is easy for academics to embark on creating knowledge about a new field, that of inclusive research. As McClimens points out:
The participants tend to remain outside the loop. They may be a part of the process but they are likely to remain apart from its conclusions. (McClimens 1999: 221)

It is important that researchers with the label of learning difficulties take action now for themselves, if they wish to avoid becoming part of someone else’s theory once again. The field of knowledge, which I have termed inclusive research, belongs to researchers with ‘learning difficulties’, and, as this thesis has indicated, it may have different parameters from research done by non-disabled people. In theoretical discussions with self-advocates, for instance, I have noted how the concept of research is often linked with campaigning and action. Research is about changing lives, and finding solutions for one’s own life and that of others.

The important practical implication is that space should be accorded, within any research project, for:

- networking and discussion with similar inclusive projects
- a meta-discussion about the process in which one is engaged.

10.6.3 Future applications for discourse analysis

The current project has been about challenge and change within discourses, from the perspective of people who have been silenced and excluded by a dominant discourse. A further, parallel area for critical discourse analysis would therefore be to examine the dominant discourse itself in naturally occurring interactions, and this has been suggested by group members. For instance one could approach this by examining assessment procedures and other encounters between social services professionals and their clients. This kind of work has occasionally been attempted (Peter 2000; Danforth 2000), but not with a discourse analytic approach, and not to my knowledge in a participatory fashion. Similarly, encounters at a day centre or in residential homes would be sites of interest. This kind of project would lead perhaps to an even greater challenge to the assumptions on which service practices are based. In particular, the decision-making capacity of people who do not use conventional communication is a current topic of interest, and the issue of how to support their decision making could be usefully approached through close analysis of interaction.
Equally, some of the practical findings in this thesis could be further tested and elaborated, using wider samples to generate a larger corpus of data. For instance, the findings relating to supporters’ work are potentially important, with the planned growth and strengthening of the People First movement. It is vital that supporters, both non-disabled and disabled, understand the approach they need to adopt, and this thesis has helped to reveal some of the conversational work done by supporters. Successful descriptions of such work are the basis for development of that role, and for training. This is another area of research that is ripe for an inclusive approach, as People First members themselves should dictate what it is that they wish to see in their support.

10.6.4 Equal partners

The final, but important, recommendation for future action in this field is to engage in a more open process of communication between all parties involved in inclusive research and its development. It seems a nonsense to conduct exclusive debate about inclusive research, with those who are at the heart of the process not able to participate on an equal basis. What is needed is more action, from self-advocates as well as researchers, to commit to a real exchange of views, in such a way that we can all learn from the research that has already been carried out by and with people with ‘learning difficulties’.

The hardest part of this meeting of minds might well be the deconstruction and explanation of literature about Learning Difficulty. We should be sharing what we have written about people with ‘learning difficulties’ and their lives more widely. This must include some of the findings that are more painful or embarrassing to relate to our colleagues from the self-advocacy movement, such as tales of deficits and diagnoses. It is only when we judge our academic Learning Difficulty literature by the standards we would apply to ourselves, that we will achieve a partnership in which each party respects each other’s dignity.

It goes without saying that self-advocates also have a responsibility within this dialogue. If members of the self-advocacy movement do not want to engage with non-
disabled people, then the dialogue cannot occur. Therefore, members of the People First movement and the growing community of researchers need to work out for themselves whether and in what ways they wish to develop their ideas with the support of academic researchers, supporters and others in the disability movement. The means for this development will undoubtedly be wider than the traditional events such as conferences or seminars, and could include increasing access to new means of electronic communication.

It is hoped that the present thesis has made a contribution to this dialogue, and will assist the growth of inclusive research, as an exciting and powerful tool for change. Above all, it is hoped that members of the self-advocacy movement will continue to realise the power of talk to change their own lives.
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Appendix A

Transcription conventions

The transcription conventions for data extracts that are analysed draw largely on those suggested by Jefferson (1979), and were influenced both by the desire to fall into line with other writers in the field, but also to mark certain features that turned out to be relevant to analysis. For instance, in large group talk it is often useful to mark the fact that one person is addressing a particular person, if there is evidence for this.

→ When a speaker is addressing comments to another person (as indicated on video), an arrow is used, with the name of the person addressed.

/ End of a tone unit. This is done to avoid standard punctuation (full stops and capital letters marking sentences), so that no assumptions are made as to sentence completion.

(.) Slight pause. Pauses of 0.5 seconds or longer are marked for approximate length.

[ ] Overlapping speech. Brackets aligned to show where the overlap starts.

- Interruption, or self-correction

= Latching, where there is no gap between one utterance and the next. Also used where one speaker’s talk continues through an interruption.

↑ ↓ Noticeable rises or falls in intonation.

CAPS Word or phrase is particularly loud, compared with the surrounding talk.

Underlining Emphasis

Lo:::ng Extended sounds. The greater the number of colons, the longer the sound.

(WH) Whispering (LF) laughter: where they accompany talk.

LF Laughter without talk.

(......what......) Unclear passages are within round brackets, with a dotted line to indicate the approximate length of the utterance. Tentative readings may be within the bracket.
Italics
Any comment relating to the physical setting, extraneous remarks or non verbal features.

Numbers
In extracts presented in the text, the line numbers are given from the original complete transcript, to give a feel for where the extract is situated in that occasion.

For an explanation of the conventions used for full video interaction analysis of fragments, see Appendix B.

Quotations from discussion sessions (D 1 – 9) are transcribed for content, using ordinary punctuation, without the attention to detail used for analytic extracts.
Appendix B

Video transcription conventions

Detailed transcription of video data has only been done for selected extracts, where two participants are both visible on camera, and are interacting with each other. The methods used were influenced by Heath (1997), and were designed to indicate the interplay of some features of non-verbal interaction. Timing was thus critical, because a judgement of whether or not one act is occasioned by another depends on appreciating its temporal placement.

Each page contains a six-second time line.

The speech is written (to show how it fits into that 6 seconds) within lines, centrally on the page.

One participant’s data are then written above those lines, and the other’s below.

For each participant, I attempt to track the following three non-verbal behaviours, which are marked in order, one under the other:

- gaze direction
- facial expression or other facial movement
- hand or arm gesture

.............. continuous behaviour (a gaze which spans a stretch of talk).
* discrete action (as Kendon’s 1983 ‘gesture stroke’).

Page numbers in the text relate to the pages of handwritten transcript for each extract. Where they are presented in the text, I refer to them as fragments, indicating that they are only a part of the larger extract.
## Appendix C
Details of visits

<table>
<thead>
<tr>
<th>Visit</th>
<th>Geographical location</th>
<th>Type of venue</th>
<th>Type of room</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>V 1</td>
<td>On outskirts of small town</td>
<td>Day centre</td>
<td>Kitchen/ cooking area</td>
<td>12</td>
</tr>
<tr>
<td>V 2</td>
<td>In a city</td>
<td>Sports Centre</td>
<td>Room overlooking swimming pool</td>
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<td>V 3</td>
<td>Group from a large town visited Bristol</td>
<td>Community Centre</td>
<td>Meeting/ activity room</td>
<td>10</td>
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<tr>
<td>V 4</td>
<td>Small town in rural area</td>
<td>Community centre</td>
<td>Meeting room</td>
<td>11</td>
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<tr>
<td>V 5</td>
<td>Small town</td>
<td>Council building</td>
<td>Meeting room</td>
<td>18</td>
</tr>
<tr>
<td>V 6</td>
<td>Village on outskirts of town</td>
<td>Ordinary residential house</td>
<td>Living room</td>
<td>10</td>
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</table>
Appendix D
Consent issues

Informed consent was gained in the following ways.

1. Consent from participating groups to take part in Finding Out project.

- Groups were recruited to the project by a letter dictated by Research Group members, and sent by myself to all participants who had attended a self-advocacy seminar held in December 1996.

September 21st 1997

Dear Self Advocacy group,

We’d like to come along and meet you, to ask you some things for the research project we are doing.

We are the Norton Group, coming from Norton. We do research work, and we are self advocates.

We have some Lottery funding to do our own work now, and we are interested in finding out things about what you think. What are your points of view?

We would like to visit a group on Friday 10th October, in the afternoon, if that is possible, or on 31st October - or on another day if we can arrange it.

Could you let us know if you’d like us to come and meet you - by sending us a letter, or phoning our supporter Val Williams (address and phone number above).

We look forward to meeting you,

Yours sincerely

(Names of Research Group members)

- During the visits, Research Group members explained the project, and sought verbal permission to use audio and video recorders (see Chapter 3).
• A copy of the video and audio tape made on each occasion was sent back to the relevant group.
• The Research Group sent out draft copies of the ‘Finding Out’ book to all participating groups, to seek their approval by letter for printing and circulation.

2. **Consent from Self-advocacy Research Group for PhD work**

• Members initially gave verbal consent for me to take copies of their data, and to consider it for my PhD work.
• A series of discussion sessions with the Group (Preface: 6th Stage) enabled them to understand what I was intending to do.
• Written consent was given for me to continue with the work.

3. **Consent from participating groups and their supporters for PhD work**

• Following the first discussion session with the Research Group, an accessible document on ‘Talk’ was produced (Appendix G). In 1999/2000 I visited each participating group, and explained to them what I wanted to do with the data, using the Research Group’s handout.
• I showed some of the video clips where possible, to discuss how I could handle the data.
• The ensuing discussions were tape-recorded.
• Written permission was obtained from each group, and their supporter(s), using the following format:
How we talk together

Dear (name of group)

- Thank you for having a meeting with me today.
- We have talked today about the research interview that the Self-advocacy Research Group did about two years ago.
- Thank you for giving us permission last year to write about the interview and the tapes that we did together.
- I have now tried to explain what I am trying to do in my PhD.
- I would like to look at the things that the _______ Group said for my PhD.
- We met up with other groups as well. They will also be a part of this.
- I won’t use anybody’s real names (or the name of your group) unless you want me to.
- I will be looking at how we all talked together. It is about HOW TALK WORKS.
- The Research Group are still helping me, but this is my work. It is for my PhD.
- If you are happy for me to carry on with this, could you sign below.
- We will add here any suggestions you have, or anything you would like to say about this.

Signed:

In March 2001, the Self-advocacy Research Group and myself held a mini conference, to which we invited all participating groups (see Appendix F). Not only did this ensure that all participants were aware of how we used their data, but they also demonstrated that they felt part of the research process.
Appendix E
Questions for research visits
(as written by Research Group members, and used at first three visits)

1. What do you think about people being labelled?

2. Have you been in any tricky situations, when you’ve been discriminated against?

3. What work have you done?

4. What qualifications have you done?

5. What services or transport do you go on?

6. What do you think self-advocacy is?

7. How does your group work?

Extra questions (added between visits 3 and 4)

8. What do you think of your support staff?

9. What do you achieve out of life?
Talking in self advocacy groups

Just think you are from outer space.

You land in a People First meeting.

How would you know it was a self advocacy group?
What makes it different?
Appendix G
Notes made after session on June 4th 1999, and subsequently used to explain to other groups what we were doing.

Talk

**Communication** is about people telling each other things.

They can do it -

**By speaking**

**By phone**

**By body language**
(smiling, the way they sit, using their hands.....)
Putting yourself over

When people talk, they are also telling you something about themselves.

They are telling you about who they are:

Your boss at work wants to see you.
- He is trying to support you.
- He may be telling you how well you are doing.
- Or what other things you could do.

He puts himself over as a professional, as your boss.
He uses the language of ‘being a boss’:
People put themselves over in different ways. It depends on what they are doing. It depends on who they are with.

*Your social worker talks to you about moving house.*

Then she goes and talks to the home leader where you live now.

These are two different ways of talking. She will come over in different ways. She will use a different kind of language.
Putting yourself over

When people talk, they are also telling you something about themselves.

They are telling you about who they are:

*Your boss at work wants to see you.*
- He is trying to support you.
- He may be telling you how well you are doing.
- Or what other things you could do.

He puts himself over as a professional, as your boss.
He uses the language of ‘being a boss’:
People put themselves over in different ways. It depends on what they are doing. It depends on who they are with.

*Your social worker talks to you about moving house.*

Then she goes and talks to the home leader where you live now.

These are two different ways of talking. She will come over in different ways. She will use a different kind of language.
Why is talk important?

Talk does things.

- You can make a friend by talking.
- You can get a job by talking.
- You can put someone down by talking.

Some things take a lot of talk. Moving house?

*It takes a lot of talking, and a lot of people talking to each other for someone to move house.*
Who am I?

When we talk, a lot of what we are doing is about **WHO WE ARE.**

You can be:  
A researcher

A chairperson

A self-advocate

A supporter
THESIS CONTAINS

VIDEO  CD  DVD  TAPE CASSETTE
Being researchers
with the label of learning difficulty

To find an extract on the CD, follow the time guide on your computer.

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<th>Chapter 6</th>
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<td>Chapter 2</td>
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