A qualitative enquiry into the process of supporting self-directed researchers with learning difficulties

A thesis submitted for the degree of Doctor of Philosophy

by

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Abstract

This dissertation is concerned with the under-researched subject of supporting people with learning difficulties to be in control of their own self-advocacy group while undertaking self-directed research.

Guided by the social model of disability and emancipatory disability research principles I supported a group of people with learning difficulties within a self-advocacy organisation throughout the course of their own self-directed research project. At the same time, drawing upon various sources of data, I reflexively studied and analysed my own support practice, constructing the critical ethnography that is this dissertation. There were two purposes for working in the above way: (a) to provide the most effective support I could for the researchers to gain and maintain control of their research group and (b) to analyse the processes and challenges involved in providing support for self-directed self-advocacy group members and researchers (in order to develop the literature in this area).

Analysis of data revealed the following. Supporting self-directed researchers with learning difficulties requires a broad range of involved, interconnected interpersonal support skills. Working in this way can present supporters with unforeseen time-consuming tasks as well as intellectual and psychological challenges as they respond to the needs and requests of the supported group. Supporting people with learning difficulties to be in control in this way, where the balance of power is actively weighted in their favour, is not only complex it

can lead to the supporter facing institutional pressures to assume control over the group, feelings of psychological discomfort or stress and ethical dilemmas.

Anaysis of the data led me to conclude that drawing specific boundaries around supporter behaviour and monitoring or developing an actively non-authoritarian practice through a process of critical reflection can be an important aspect of providing consistent and effective support for self-directed researchers with learning difficulties.

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Preface

While undertaking the project described in this dissertation I supported a group of people with learning difficulties as they developed and carried out their own self-directed research, which was later published in a book (see below). In turn I researched into the process of supporting them. Therefore this dissertation tells stories about two separate research projects. In order not to confuse the reader it is important to explain the part these two projects played in the construction of this dissertation.

I supported the researchers with learning difficulties inside a People First organisation. People First organisations facilitate people with learning difficulties to practise self-advocacy. The term 'self-advocacy' can have several meanings. Definitions include fighting for one's rights, speaking up for oneself, making choices, finding an identity and having control over one's own life (Walmsley and Downer, 1986). Not all self-advocacy support takes place within People First organisations (which are 'ostensibly' run by people with learning difficulties). However, Buchanan and Walmsley (2006) have claimed that, while there is no clearly established history of self-advocacy in Britain, self-advocacy is said to have started here in 1984 with the establishment of People First London Boroughs.

Self-advocacy can be divided into two models, individual and collective (Sutcliffe and Simons, 1993), although these models can overlap. Individual self-advocacy is focused on the development of the person. Collective self-advocacy is about people working together to achieve their collective aims.

However, there is an inherent tension between individuals utilizing self-advocacy groups to, for example, gain further confidence and/or increase their abilities to be actively assertive, and self-advocacy group members collectively, for example, campaigning for improved circumstances for people with learning difficulties (Buchanan and Walmsley, 2006).

The idea of supporting both the empowerment of individuals with learning difficulties, and their collective empowerment, through involvement in service planning and policy development is now reflected in current government directives. In addition, Department of Health directives on how services should respond to people with learning difficulties are informed to some extent by the principles of self-advocacy, where they focus on the concepts of choice and empowerment (Department of Health, 2001; Department of Health, 2005). In addition, some Department of Health policy documents have, at least in part, been constructed in conjunction with self-advocacy group members, for example (Department of Health, 2001 (b)).

The researchers I supported on this project were all long-term members of, or salaried self-advocacy workers for, 'People First West' [pseudonym] and as such were relatively experienced at advocating for themselves. Five researchers with learning difficulties took part in this project and will be referred to in this dissertation by the names 'Pearl', 'Mary', 'Chantelle', 'Rudy' and 'Bill', or collectively as 'Research Group members'.

In the following brief descriptions of the researchers I have decided not to link their personal details with the pseudonyms I used for them. The reason for this is that it diminishes any risk of them being identified by people who may read both this dissertation and their book, and make efforts to identify who individual researchers are in reality. For the same reason I have also decided not to link details about when they joined or left the group to their personal information, as this information is in their book. However, I can state that two members of the Research Group were involved from the start of the project till the end. One joined when another left to take up a post in a different self-advocacy organisation during the stage when their book was beginning to be written up, and another was invited to join before the Research Group did their interviews. Both of the researchers who joined later also stayed till the end of the project.

Researcher 1 is a Black British man of African heritage who is now in his forties. He works as a manager in a self-advocacy organisation and lives in his own flat with a small amount of support. He is engaged to be married.

Researcher 2 is a black British woman of Caribbean heritage in her forties. She lives in her own flat with her husband. She is also a mother to two boys. She works as a trainer and speaks out for people with learning difficulties at various conferences and meetings.

Researcher 3 is a black British woman of Caribbean heritage in her forties. She now lives in a residential home for people with learning difficulties and

high support needs, and has chosen to give up her campaigning work for people with learning difficulties for the time being.

Researcher 4 is a white British man in his forties. He lives with his parents and now has workers who visit his home to support him to go out into the community. He works as both a voluntary supporter and a trainer.

Researcher 5 is a white British woman of Irish heritage in her forties. She works as a self-advocacy development worker and lives in her own flat with a small amount of support. Recently she has been working on involving mental health service users in People First West.

All the researchers came to meetings regularly during the time they were involved, with one exception who moved quite far away from People First West, very near the end of the final writing up stage. However, that researcher still approved the final draft of the group's publication and contributed to the final amendments that the publishers suggested.

With the exception of the ongoing talks and meetings about their work that members of the Research Group are still invited to, their project lasted from May 2001 (when the group was formed) until November 2007, when their book *What We Know* [pseudonym] was published and launched. From 2001 to 2004 the Research Group met for one morning a week to plan, develop and subsequently write up their work. They also met for three or four additional days to interview their research participants in June and July 2002. There was

a gap of a year from 2004 until 2005 while we waited to hear back from the first publisher they got involved with, who eventually rejected their manuscript. Another publisher approached the group very soon after and the group worked with them, in response to their suggestions for further clarity, from late 2005 until the launch of the book. During this later period the group met on a flexible basis for two days a month on average.

Their research drew upon the Research Group's own experiences (and those of people with learning difficulties whom they interviewed) of what it was like to live as people with learning difficulties. Through analysing their own conversations and the questions that they asked their research participants, they constructed politicised views about their lived experience and what they wanted from their lives, and from the support services that they used.

My research, a reflexive narrative, draws upon an emancipatory disability research paradigm and is informed by the principles of critical ethnography. I focused upon ways of supporting the Research Group members to be in control of their own project and also upon issues (in relation to my support role) that threatened to compromise their gaining and maintaining control of their own research.

What We Know has not been submitted as part of my thesis for the following reasons. In keeping with ethnographic research traditions I have sought to uphold confidentiality in this dissertation, even though the Research Group members all approved what has been written about them here and said they

did not mind if someone worked out who they were. To include the Research Group's published book would reveal both who the Research Group members really are and where we actually worked. In addition, a focal aim of my research has been to keep the two research projects that are discussed here separate. The reason for this has been to prevent conflict of interest arising in my role and to establish clearly that their research is owned by them and not me.

Chapter 1: Introduction

> Pearl: It was really nice going to Oxford to talk about the book. I enjoyed myself so much I did, and I liked looking round the college. We stayed in the college, didn't we? We sold quite a lot of books at the college. I feel really proud of myself (29.7.08).

Pearl [not her real name] is in her forties and lives in an inner city area. She is a Black British woman with learning difficulties. She was talking to me in People First West [pseudonym] a self-advocacy organisation for, and run by, people with learning difficulties. Pearl is a member of 'the Research Group', a group of people with learning difficulties who have undertaken their own research project.

She had recently given a talk at an Economic and Social Research Council research methods festival held at Oxford University. Along with another member of People First West's Research Group, Pearl talked about how the group undertook their research and how they were in control of it. I also talked at the same research festival about how I supported the Research Group to undertake their research. This was the first time I had been asked to talk publicly about my support role on this project. Since the publication of the Research Group's work in 2007, over seven years after they first started meeting, Pearl and other members of the Research Group had been asked on several occasions to talk or write about their research project. Talking at Oxford University was one of several of these new opportunities. Pearl was pleased about being asked to speak at Oxford and, as she said, proud of her

achievements as a researcher. The Research Group's project had been successful and people wanted to hear about how they did their work.

However, for over seven years neither Pearl, any of the other Research Group members nor I knew for certain that their research would be published, let alone well-received. During the time I was supporting them the Research Group's project was dogged with uncertainty across a whole range of areas. These uncertainties are explored in this dissertation in relation to what a user controlled research supporter may have to negotiate or resolve, with limited preparation, when supporting researchers with learning difficulties.

Paradoxical as it may initially seem, this dissertation is fundamentally not about the Research Group's research. For example, it does not document their findings in any detail or discuss what their interview questions were. That information is contained in *their* published research. In essence, this dissertation tells the story of my research. As a researcher I aimed to answer the following research questions in relation to interpersonally supporting the self-empowerment of a group of people with learning difficulties within a self-advocacy group:

- How can people with learning difficulties be supported to be in control of their own research group and project?

- What dilemmas are there in relation to supporting people with learning difficulties to be in control of their own research project?

- Including contextual issues, what does this research show about what can prevent people with learning difficulties from being in control of their own research and self-advocacy agenda?

- What does this research tell us about the process of supporting people with learning difficulties, interpersonally, to be in control of their own research, self-advocacy agenda and self-empowerment?

- What does this research demonstrate about the interpersonal skills that are required to support people with learning difficulties to be in control of their own research, self-advocacy agenda and self-empowerment?

However, my research project was about more than investigating questions. It involved *actively* supporting people with learning difficulties to be in control of their own self-advocacy group, and in case it is not clear, everything that they chose to do within it. Therefore this dissertation, in relation to the above research questions, tells the story of what happened during the time I supported a group of people with learning difficulties in People First West to be in control within their own research group.

I have just described the focus of this whole dissertation. Here is what is contained in the rest of this introductory chapter. To begin with there is a discussion of what is meant, within the context of this dissertation, by the term 'learning difficulties'. Then there is an explanation of what motivated me to

undertake this research and the circumstances that led up to my taking on this research project. Finally there is a brief outline of what is in each subsequent chapter of this dissertation.

Exploring the meaning of 'learning difficulties'

People with learning difficulties have been centrally involved in this research project as a whole, and the term 'learning difficulties' is used throughout this dissertation. However it is notoriously difficult to define who 'people with learning difficulties' are, and what the term 'learning difficulties' means. As Davies and Jenkins have put it:

> It has been argued that the term is essentially meaningless and should be dispensed with… however, this ignores its role in establishing access to some social services and resources. (1997; 95)

The specific labels used by 'professionals' to describe the group of people I am choosing to call 'people with learning difficulties' changes frequently in what Sinason (1992), has described as a futile attempt to deny difference and oppression. The people that are being written about in this dissertation may have been defined by a variety of names throughout the course of their lives, for example 'mentally handicapped', 'special needs' and more recently 'learning disabled', which is the term used in current Department of Health policy such as Valuing People (2001) and Independence, Well-being and Choice (2005).

Throughout the course of this dissertation, I am choosing to use the term 'learning difficulty' as opposed to any other because it is the one most often used by people with learning difficulties who are involved in the self-advocacy movement. Walmsley and Downer (1997; 36) described the function of this movement very succinctly with the following statement:

> Self-advocacy is about people with learning difficulties as a group gaining the power to fight for their rights, rather than, as in the past, being passive recipients of the charity or otherwise of others.

Describing the function of People First organisations where the self-advocacy movement continues to be developed, and where the term 'learning difficulties' is used, Andrew Lee, the director of People First UK and a man with learning difficulties, has said the following:

> People First supports people with learning difficulties to speak up for their rights and to fight to be included properly and fairly into society. (National Commission Persons with Disability, 2005: 5)

Walmsley and Downer (1997) have argued that some people with learning difficulties working within self-advocacy groups positively embrace the term 'learning difficulty' because it enables them to be part of a group that celebrates their identity and difference in the same way, for example, that Black or Queer activists do. Even though it is not clear exactly how influential people with learning difficulties were in choosing the term and what part their supporters played in the process, I believe it is important, as far as possible, to call people who share a mutual oppression by the terms they have chosen to describe themselves. This is the principle I have adopted in this dissertation.

The term 'people with learning difficulties' is, and can be, used to describe an extremely diverse and varied group of people with differing strengths, abilities and interests who are using, or have used, services for people with learning difficulties. For example some people with learning difficulties are good at expressing their views verbally and are working, for example, as staff trainers and political campaigners. Other people may have little understanding of spoken or sign language and consequentially little understanding of 'everyday' but abstract concepts such as 'today and tomorrow' or 'up and down'.

People who carry this label can experience similar types of prejudice or treatment within society. Commenting on the stigmatising effects that being labelled as a person with learning difficulties can have, Davies and Jenkins have written the following:

> People with learning difficulties carry a label and an associated identity which is a major determinant of their material prospects and the character of their social relationships. (1997; 95)

The effects of carrying the above label are discussed briefly a little further on in this section. However, intrinsically, people with learning difficulties are no more similar to each other than to other people. They are men and women, lesbian and heterosexual, black and white. In short, having a learning difficulty is only one aspect of their lives and for some people only one aspect of their oppression. For example Black women with learning difficulties can also experience racism and sexism in addition to the prejudiced attitudes they may

encounter in reaction to being perceived of by others as a person with learning difficulties.

In recent years there has been an increasing awareness of the experiences of Black and ethnic minority people who have learning difficulties (Baxter et al, 1990; Lewis, 1996; Hollins et al, 2002; Black Friendly Group, 2004), and a gendered political perspective has also been developed in relation to women with learning difficulties (McCarthy, 1999; Traustadottir and Johnson, 2000). There are specific issues that affect parents with learning difficulties, including the increased likelihood of them having their children taken into care (Booth and Booth, 1994; Booth, 2003; Ward and Tarleton, 2007). Often child protection procedures are set into motion without the person with learning difficulties getting the support they need with their parenting (Wates, 2002). Research has shown it is more common for Black people and poorer people to be labelled as a person with learning difficulties (Walmsley and Downer 1997) and that people with learning difficulties are particularly at risk of developing mental health problems for reasons including social vulnerability (Holt et al., 2004).

People with learning difficulties can be extremely devalued by society (Souza with Ramcharam, 1997). They have a history of being defined and managed by others (Welshman and Walmsley, 2006; Atkinson et al., 2005; Henderson and Wallis, 1991) and can still experience their support as control (Social Care Workforce Research Unit, 2003). They can be infantalised by others,

and often this is manifested as a denial of their sexuality (Shakespeare et al., 1996). It can be especially hard for supported people with learning difficulties to have same-sex relationships. Blake (2003), a gay man with learning difficulties, has argued that this is because some supporters and carers disapprove of same-sex relationships and lesbian and gay people.

However, while people with learning difficulties can be prevented from engaging in mutually consensual sexual relationships, they are also are vulnerable to being sexually abused (Brown, H. et al., 1995). It seems that people with learning difficulties are vulnerable to a range of dangers. In a Valuing People strategy document on 'abuse and protection issues', Brown (2000; 9) has postulated that people with learning difficulties are at risk of ordinary crime, of being victims of sexual abuse, of being excessively controlled or of being the recipients of punitive responses (particularly if they are seen as having 'challenging behaviour'), of being bullied or marginalised, of not getting adequate healthcare and of not being 'served well by the criminal justice system'.

It is over-simplistic to perceive 'learning difficulties' as being only a problem for the person defined in this way. In relation to 'challenging behaviour', Bicknell and Conboy-Hill (1992) have argued that many behaviours that were previously thought to be part of the persons' 'learning difficulties' are now known to be located in the practices and systems of the institutions that provide support for them. Sinason (1992) has postulated that any 'impairment'

that people with learning difficulties may initially be born with or develop is compounded and exacerbated by society's response to those who are identified as people with learning difficulties. She has called this phenomenon 'secondary handicap' and argued that this may lead to the intelligence and awareness of people with learning difficulties being subdued or limited as a reaction to the oppressive ways that they are responded to within society. Smith (1996) has discussed the concept of 'learned helplessness' in relation to people with learning difficulties. He argues that this process happens when people with low self-esteem give up trying to help themselves. McCormack (1991) has argued that learning difficulties are not located within the individual but are a problem of discourse, and as such are not located in someone but exist in between one person and another.

Within the context of this research, 'people with learning difficulties' are simply those people who have used in the past or continue to use services for people with learning difficulties, and as such have been labelled by health and/or social services professionals at some stage in their lives. In addition 'people with learning difficulties' are those people who have suffered the disempowering consequences of being labelled as such by others. However they can also be the people who identify themselves as 'people with learning difficulties' within the context of People First organisations and the self-advocacy movement, and as such choose to work collectively towards furthering their self-empowerment.

How this research came about

My personal motivation and capacity to undertake this research has grown out of my experiences of being with people with learning difficulties over many years. This next section outlines my history of working with people with learning difficulties, and explains why and how I came to undertake this research. In this section I describe, in relation to my own motivation to support the self-empowerment of people with learning difficulties, early oppressive events I witnessed. While, to a limited extent and in some areas, circumstances have improved for people with learning difficulties since I first started working with them, it seems there is still considerable room for improvement. For example, when reviewing People First West's Research Group's research Simone Aspis (2008; 26) an activist and academic with learning difficulties had the following to say:

> [The Research Group's research]…sends out a strong message that Valuing People has not achieved equality for disabled people.… [The Research Group's research] contains one account after another of people with learning difficulties being treated less than human.

I first came into contact with people with learning difficulties over thirty years ago when I started working as a 'craft instructor' in an Adult Training Centre. This was at a particularly formative time in my life, having recently 'come out' as a Gay man and while socialising and living with young feminist, lesbian, gay and transsexual people, who along with myself were beginning to redefine themselves from a growing politicised awareness of their oppression. Coming into the Adult Training Centre with this perspective it seemed to me

that the people with learning difficulties who were working there were profoundly oppressed.

Most of the 'trainees' in the Adult Training Centre worked in an industrial unit. Some took pride in their work. Others did not appear to want to do it. They packed nuts and bolts, perfume, Spanish fly tincture and a spray that was supposed to make men get and keep an erection. However, the main body of the work in the unit was 'meat trays'. The 'trainees' stuck down, with PVA glue, little squares of quilted paper onto polystyrene trays. Thousands of trays, day after day, for most of the two years I was there. The 'trainees' got under a pound a week for doing this. Nobody moved on into open employment.

I tried unsuccessfully to convince the service users who were working in the unit to question what they were doing and to refuse to do it. The manager neither challenged or supported my taking this stance. My efforts were met with disapproval by several of the more outspoken and confident 'trainees' who were proud that they were doing work and being useful. I eventually concluded that my interventions were neither wanted or appropriate. Although my crude efforts in the unit came to nothing, this was the start of my aiming to support the self-empowerment of people with learning difficulties. This research is another, perhaps more appropriate, way of fulfilling the above aim which has preoccupied me ever since then, influencing my career choices and how I interpreted them in practice.

I also had a significant experience early on in my career that showed me, first hand, how badly people with learning difficulties can be treated. During the time I worked at the Adult Training Centre I was taken by the Deputy Manager to visit a hospital for 'mentally handicapped people'. It remains the most horrific and shocking experience of my entire life. The hospital was huge. Living in there were a very large number of men and women with learning difficulties.

My most vivid memory of the occasion was being taken into one of the 'male' wards. There were a large number of metal beds, lined up against the walls, side by side. There were dozens of men with learning difficulties in the room. The noise was awful, echoing around the tall, stark, uncarpeted, strip-lit old ward. Several of the men were moaning and rocking, one man was banging his head against the window. I don't remember there being any staff there. The room was ugly and institutional. There were no personal possessions to be seen. The harshness of the environment was not softened in any way by any decorative elements. The doors to the garden and the outside world were locked.

This visit served to strengthen my resolve to work with people with learning difficulties to help them get a better deal out of life and to live lives that are not 'controlled' by people without learning difficulties. Although circumstances have changed somewhat for people with learning difficulties since I visited the hospital all those years ago, I still feel that the above resolve or focus is as

important and relevant as ever. Throughout the entire course of my career I have never reached a point where I have thought that it was relevant to let it go, that the time had come when it was no longer an important issue. That is why this research focuses on issues connected to supporting people with learning difficulties to be *in control.*

Over the years I have worked within a variety of projects and services for people with learning difficulties in both the voluntary and statutory sector, with a wide range of people who are categorised as having learning difficulties. Most recently I have been working within the field of advocacy and self-advocacy, where I have supported people to give presentations, campaign and give training to service workers. I am experienced in working with people with learning difficulties in ways that aim to support them to be in control of a situation and make informed choices. I have supported people who can behave in ways that are described as being 'challenging' to others, to express their views and opinions and become clearer about their rights. I have also worked with people who are defined as having intensive support needs, supporting them to make choices and indicate their wishes and preferences**.**

Along the way I completed a diploma in client-centred psychotherapy, counselling and applications of the person-centred approach. Brechin and Swain (1988) have postulated that person-centred approaches as developed by Carl Rogers, for example (1967), are of particular use when supporting self-advocacy processes. I originally undertook the psychotherapy training to

be clearer about controlling or directive aspects of support in order to try to avoid them.

Another aspect of my motivation to support people with learning difficulties to further empower themselves is rooted in my own experience of abuse. Growing up on a council estate in Middlesbrough during the sixties and seventies, I failed to be 'one of the lads' because I was defined by others as being less than masculine. I was regularly taunted and physically attacked because I was seen as a 'sissy' (or a 'lad-lass' as they called me). I have some idea from personal experience of what it is like to be marginalised and made to feel less than human, with the resulting low self-esteem and lack of confidence that this experience can bring. I believe that my own experience of being marginalised and bullied has contributed towards any capacity I may have to empathise with aspects of the situation of people with learning difficulties, and fuelled my motivation to be an ally to this particular group of people.

Throughout my career I have continued to try to (a) support people with learning difficulties attempting to further empower themselves, and (b) understand more the reasons behind the continuing disempowerment of this particular grouping of people. In time, I decided that in order to further my aims I needed to undertake academic study to understand the reasons behind the disempowerment of people with learning difficulties and to become clearer about how to support their self-empowerment.

Moving towards undertaking this research

A year before I began studying towards a PhD I completed an MA in Disability Studies at Sheffield University. I had sought out a course that stood outside of a particular profession and focused on the ways that people are disabled by society. I focused mostly upon issues related to the support of people with learning difficulties, for example self-advocacy, equality of opportunity, inclusion/exclusion, and the ways that people with learning difficulties are oppressed or devalued.

It was while studying towards this MA that I came across the concept of supporting disabled people to undertake their own research (Oliver, 1992; Barnes, 1992; Barnes and Mercer, 1997). As a supporter of self-advocacy and an ally of people with learning difficulties I wanted to provide support for interested people to represent themselves and be in control of research processes. After searching round for funding and a supervisor to support me, I was fortunate to receive an offer of a bursary and supervision from the Centre for Citizen Participation at Brunel University to do research that involved supporting people with learning difficulties to undertake their own research.

During the first year of my studying towards a PhD the white paper 'Valuing People' (Department of Health, 2001) was published. Within this white paper the Department of Health states that people with learning difficulties should have more control over what happens in their lives and that the choices or

decisions of people with learning difficulties should be given priority. My motivation to undertake the research that is discussed in this dissertation had grown out of a desire to understand how best to support people with learning difficulties to represent themselves, be in control and make the changes they want within their lives. This aim was and still is compatible, in theory, with Department of Health policy directives.

Outline of this dissertation

Chapter 2, the literature review of this dissertation, is about recent organised responses towards, broadly speaking, 'supporting' people with learning difficulties and how various key practices, and the intellectual concepts that underpin them currently impact upon the lived experiences of service users. Normalisation, independence, self-advocacy and the social model of disability are all discussed in Chapter 2 within the context of both justifying the focus of my research and developing an informed and cohesive support role for people with learning difficulties engaged in the process of furthering their self-empowerment. Within Chapter 2 there is also discussion about how user controlled research with people with learning difficulties relates to the broader category of user involvement and 'inclusive research' with people with learning difficulties. While related research justifies the provision of support for people with learning difficulties to do research, there is little direct evidence about how to offer this effectively. However within Chapter 2 the focus of my research project and my aims and objectives are justified in relation to related research and discussion.

Chapter 3 charts the journey towards the development of a suitable

methodology for my own research and explains the rationale behind the

epistemology and ontology that eventually were chosen to underpin it.

Although the findings of this research have been developed using a reflexive

critical ethnographic approach, this project as a whole has had another layer

above and beyond the above research approach. Chapter 3 explains how, on

a broader level, this project is an attempt at practising emancipatory research

with a group of people with learning difficulties. Within Chapter 3 the political

and philosophical aspects of undertaking this research are examined in

relation to the social model of disability and emancipatory research theory.

Chapter 4 explains both how the methods for my own research were

developed and how I developed a suitable way of initially coming into contact

with prospective researchers within People First West. I explain, in this

chapter, the iterative way in which I collected and analysed data for my own

critical ethnographic research and also discuss the ethical issues that needed

to be addressed in relation to working directly with people with learning

difficulties. I needed to develop preconditions for supporting people with

learning difficulties to be in control of their own agenda on this project. These

are explained in Chapter 4.

Chapter 5 is the first of the findings chapters. This is by far the largest chapter

in this dissertation and in it I begin the process of laying out what I discovered

about the practice of supporting people with learning difficulties to be in

control of their agenda while they undertook self-directed research. In this chapter I draw upon a variety of data sources such as fieldwork diaries, transcriptions of discourse that occurred in meetings and interviews to describe strategies I adopted while actively supporting Research Group members to achieve their aims. This chapter also explores evidence revealing the impact that the researchers being in control had on my role as a supporter. Chapter 5 also explores evidence revealing the influence I had as a research supporter over the researchers' agenda and why (despite wholeheartedly aiming to be non-directive).

Within Chapter 6 I present what was revealed in my research about wider contextual issues encountered while supporting people with learning difficulties to be in control of their project, as they (and myself as their supporter) interacted out of necessity, or choice, with *different projects and organisations* and the people who worked within them. Based on various sources of evidence such as interviews, fieldwork diaries and Research Group minutes, reports and notes, Chapter 6 documents various dilemmas and challenges (stemming from outside of the Research Group) that threatened to compromise the degree of control held by the service user researchers over their own project. Chapter 6 also explores evidence revealing what responding to these dilemmas and challenges inferred about the nature of the supporter role and the skills required of user controlled research supporters working with people with learning difficulties.

Chapter 7, the final findings chapter in this dissertation, focuses on evidence that revealed the part that critical reflection played in the development and maintenance of a user controlled support role on this project. Drawing mainly upon reflective field diary entries I also explore, within this chapter, areas where self-awareness and reflection were required to avoid controlling interventions. Finally, Chapter 7 examines the function and purpose of critical reflection in relation to the user controlled research supporter role.

Chapter 8 contains a discussion of what has been achieved through this project as a whole. It also contains a discussion about what my own research has contributed to the literature. Chapter 8 also contains a list of the skills and qualities that this research has indicated are a part of the role of user controlled research supporter working with people with learning difficulties. The chapter concludes with a reflexive analysis of the strengths, limitations and validity of my research and recommendations for further research.

Chapter 2: Literature Review

Introduction

As stated in the first chapter, on this project I aimed to support a group of people with learning difficulties to be in control of their own self-defined research. My own research was about issues and dilemmas related to the process of supporting the self-empowerment of people with learning difficulties in this way. Therefore I was involved in two separate research projects, theirs and mine.

When I started this project, the processes, challenges and dilemmas inherent in interpersonally supporting people with learning difficulties to be in control of their own research group, or any other self-defined project or group, were very much under-researched and still are. The scant research that has subsequently been carried out in this area only touches upon the subject tangentially and is comparatively sketchy. Therefore when initially mapping out an appropriate and ethical support stance for this project and identifying appropriate theoretical perspectives, questions and methods, I drew upon pertinent research from the broader field of 'disability' as well as research that specifically focused on issues relating to people with learning difficulties.

After an explanation of how I conducted the literature search for this research there are two distinct parts to this chapter. The first part explores issues that I needed to address as a supporter of people with learning difficulties. To

explain further, while I was supporting people to undertake their own research I was also engaged in the more general area of supporting people with learning difficulties. Although my research focuses on issues related to supporting people with learning difficulties to be in control of their own research, more broadly speaking it was also about the issues connected to supporting people with learning difficulties to undertake a project that they were in control of.

This part of this chapter focuses on clarifying the meaning of, and reconciling with each other, key current theoretical principles that have had a significant impact upon recent social care policy about supporting the empowerment of people with learning difficulties: 'the social model of disability', 'normalisation', 'self-advocacy' and 'independence'. These are discussed in relation to offering support for service user self-empowerment on this project. The literature on self-advocacy support is also reviewed in relation to the focus and relevance of my own research.

Within the second part of this chapter I review literature that was pertinent to my own research in relation to service user involvement in developing social care policy and practice, service user involvement in research, and people with learning difficulties taking a full role in research processes. The focus of my proposed research is further justified here by comparing it to the research to which it is most closely related.

Conducting the literature search

This section documents how the literature that is discussed in this chapter was found. Searching for literature was an ongoing process throughout the whole of this project. Sometimes this was a more rigorously structured process than others. However in its entirety the literature search on this project has been rigorous and thorough. Towards the end of the project a final search strategy was put into action in a final attempt to ensure that nothing of relevance had been overlooked.

It is significant that I came to this project having newly completed an MA in disability studies, focusing on issues relating to the disempowerment and self-empowerment on people with learning difficulties. Hence I was aware from the onset of key journals, publishers and research departments that disseminated much of the research that was relevant to this project. Throughout the course of this project I made sure that I kept up with what was being disseminated through these sources and followed up appropriate references that were cited in relevant research.

Also, throughout the course of this project, I have worked within a relatively high-profile self-advocacy organisation and on various user controlled research projects (predominantly in a research support role). This involved me working directly with a significant number of the key research departments or organisations that produced work referenced in this dissertation. I made it my business to ask appropriate people what relevant research they knew of, sometimes emailing key researchers.

Working in a self-advocacy organisation that collected research and other relevant literature (such as training or campaigning materials) by people with learning difficulties, or in relation to their empowerment, was also helpful in enabling me to keep abreast of what was being produced on the subject of supporting self-advocacy. Part of my role was to seek out such research and purchase it for the organisation. In addition, the People First organisation I worked in was often contacted with details of new research in the area of self-advocacy and the empowerment of people with learning difficulties.

This next section explains how I conducted my final literature search. However, it is important to mention that on several occasions throughout the course of this project I had previously visited all of the websites, journals or search engines mentioned here, in an attempt to find relevant literature.

The two main journals for research on the subject of including people with learning difficulties in research and issues relating to the empowerment of people with learning difficulties are *Disability and Society* and *The British Journal of Learning Disabilities*. I searched through every copy of these from the current day back to 1999 (I had already searched further back at various stages of this project and needed a cut-off point in the final search). I also conducted a thorough search through Google Scholar and of Social Care Online (with no limitation on the date). I found this both reassuring and informative, as most of what I had already found throughout the course of this project turned up along with a small amount of additional research that I had

overlooked (including earlier but relevant research from the two key journals that I had already searched).

I used different combinations of appropriate words for the online database searches. Here are some of the words used: 'research learning difficulties', 'research learning disabilities', 'research support learning disabilities', 'research support learning difficulties', 'research support learning', 'research with people with learning', 'involving people with learning', 'supporting people with learning', 'learning disabilities', 'learning difficulties', 'inclusive research', 'service user research', 'user controlled research', 'self-advocacy', 'user controlled research', 'emancipatory research', 'participatory research with people with learning difficulties', 'research controlled by people with learning', 'supporting self-advocacy', 'learning difficulties social model' and 'normalisation'. I carried on searching in this way until I was only getting duplicates or irrelevant information.

The key words chosen in the online database searches were selected to pick up on different terms used for research that actively involved disabled people and more specifically people with learning difficulties, and the broader subject of supporting self-advocacy. Sometimes there was a need to narrow the search down when there was too much information on a subject. At other times the search had to be broadened out. For example, I found relatively little on the subject of supporting self-advocacy. Therefore I broadened the search out to just 'self-advocacy' and still found relatively little on the subject of supporting self-advocacy and nothing that I had not previously identified.

In addition I searched the websites of the following research organisations for details of any relevant research that they might have produced: Joseph Rowntree Foundation, Norah Fry Research Centre, SCIE, Shaping Our Lives, National People First, Elfrida Rathbone, Mencap, British Institute for Learning Disabilities, the Open University and various relevant university departments. I also did searches on individual key authors on Google Scholar and at the British Library. In addition I looked up some of these authors on the websites of the universities or research organisations they were based in to see if I could find further information about what they had published.

When I had completed the above process I accessed and read the books and articles that I had not read before. I followed up citations from the books and the articles and read what was available through the British Library, Brunel University library and the King's Fund library. I was able to order some of the research produced by people with learning difficulties to add to the collection at the self-advocacy organisation I worked in, as it was relevant for the needs of the organisation.

Supporting people with learning difficulties

This part of the chapter draws on existing knowledge from a variety of sources that I found could be used to underpin an ethical approach to supporting the self-empowerment of people with learning difficulties in relation to face-to-face support. It focuses on how professionals can best behave and think when

supporting the self-empowerment of people with learning difficulties. The reader may wonder how more general support issues relate to supporting people to do research. Consequently it is important to explain that I was not just supporting people *to do research* in the role of, for example, a teacher or a supervisor. I was *supporting a self-advocacy group* (who were undertaking research). Therefore supporting the self-empowerment of service users and their self-directed agendas was a fundamental aspect of my role as a self-advocacy group supporter on this project.

This section of the chapter explores underlying theories and principles that inform support responses to people with learning difficulties. Literature on various key concepts in the field of 'supporting' people with learning difficulties is reviewed here. The social model of disability, normalisation, independence and self-advocacy are discussed here to clarify their meanings within the context of establishing an appropriate and ethically rigorous support stance. Appropriate standpoints on these concepts in relation to engaging with people with learning difficulties in ways that are supportive of their self- empowerment are made clear within this section. The subject of self-advocacy support is also reviewed in relation to the significance and relevance of my own research.

The social model and support for self-empowerment

The idea that it was society that disables 'physically impaired people' and that there was a distinction between disability and bodily impairment was first

made in the 1970s by members of the Union of the Physically Impaired

Against Segregation (UPIAS) (Oliver, 1996). This idea was first promoted

academically by Vic Finkelstein (1980), and in his influential book *The Politics*

of Disablement (1990), Michael Oliver wrote about the binary framework of

'social' and 'individual' models of disability he had developed from the Union

of the Physically Impaired Against Segregation's idea (Oliver, 1996).

The idea of making a distinction between disability and impairment and the

ensuing social model of disability challenged the notion of disability as a

'personal tragedy'. Advocates of the social model have claimed that

individuals are not disabled by bodily impairments and that disability is socially

constructed, not physiologically determined (Shakespeare et al., 1996).

Oliver has defined the social model of disability in the following way:

> …disability, according to the social model, is all the things that impose
> restrictions on disabled people; ranging from individual prejudice to
> institutional discrimination, from inaccessible public buildings to unusable
> transport systems, from segregated education to excluding work
> arrangements, and so on. Further, the consequences of this failure do not
> simply and randomly fall on individuals but systematically upon disabled
> people as a group who experience this failure as discrimination
> institutionalised throughout society. (Oliver, 1996; 33)

The social model has been criticised as inherently flawed because bodily

impairments as well as social barriers can also impose restrictions of activity

on disabled people (Shakespeare and Watson, 2001). However in an

important reappraisal of the social model Thomas (2004) has pointed out that

both Finkelstein and Oliver did not deny that bodily impairments can restrict

people, and that there was a need for further clarity around the meaning of the

term 'disability'. Thomas argues for 'disability' to be clearly framed as a form of social oppression and states the following is her preferred definition of the term:

> Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being. (Thomas, 1999, p.60 cited in Thomas, 2004; 580)

Thomas's redefinition of 'disability' serves the purpose of reemphasising the political and social aspect of the term while accepting the restrictive aspect of some bodily impairments. For the purpose of clarity the above definition of the social model of disability is the one that I am working with on this project.

The traditional view of disability where impairment is labelled as disability has been called by Oliver (1996) the 'individual' or 'medical model' of disability. There is also another related model of disability that has been called the educational model. The ethos behind the educational model is that the person should be helped to overcome 'their' disability through training and education. The 'educational' and 'rehabilitation' work that goes on in colleges, day centres and within residential support can be implicitly informed by this model (Brechin and Swain, 1988).

Brechin and Swain (1989) have discussed how, in relation to people with learning difficulties, it can be understood that the educational model is in one way the opposite of the medical one because it focuses on self-improvement or change rather than subscribing to the idea that medical interventions alone will assist the individual to be able to overcome or alleviate their 'disability'.

However they argue that ultimately they are closely related because both the medical and the educational model locate 'disability' within the individual rather than understanding it as being manifested within society. As such the educational model of disability requires the 'disabled' person to build up a pattern of skills that approximate 'normal behaviour'. Campbell (1996) has postulated that in the above circumstances dependency becomes an integral part of the professional and service user relationship.

There are few publications which consider the social model in relation to people with learning difficulties (Boxall et al., 2004). In his article about what the social model means in practice, in relation to supporting people labelled as having profound and complex learning difficulties, Coles (2001) has argued that it is important that staff understand about letting service users take the lead and about disabling attitudes within society. Goodley (2001) has postulated that self-advocacy support (that recognises the social nature of learning difficulties and values the abilities of people) can be a tool for putting the social model into practice in relation to supporting people with learning difficulties.

Using the social model, supporters can see disability as social oppression that can be counteracted with social action and self help (Oliver, 1996). Andrew Lee (2005, National Commission Persons with Disability), the Director of People First UK and a man with learning difficulties, has pointed out in an accessible way what the social model means for people with learning difficulties. He has stressed that it is society that needs to change to include

disabled people, including people with learning difficulties, rather than disabled people need to change to be included in society.

Simone Aspis (2002; 2), a disabled activist with learning difficulties, has argued in her article on updating the social model that the model should be used towards changing society so that it becomes more inclusive for everyone. She also argues that people should get the support they need to be in control of their own lives. As she puts it:

> The measurement of our success must not be on how well we are able to adapt (with appropriate support / equipment) to fit into this world. Our yard-stick must be how much we are able to change the world so that everyone including Disabled People is able to determine their own life-styles, and to be supported to live the lives we want and to have the financial means to have real choices.

In order for many people with learning difficulties to take an equal part in society they need interpersonal support. While people with physical impairments may require interpersonal support around their physical access needs, many people with learning difficulties require a profoundly different and arguably more complex type of support that is focused around their intellectual access needs. From analysing the literature on the social model and reflecting upon how it could be applied to actively supporting the self-empowerment of people with learning difficulties, it seems that the following focus could be helpful: supporting service users to work together to understand their collective disempowerment and to define and control what happens within their own lives on their own terms. Taking this into account it seems fair to state that this research may have a contribution to make towards the literature on the practical application of the social model of

disability in relation to supporting people with learning difficulties. This is because of my focus upon the issues connected to supporting people with learning difficulties *to be in control of* their own group and its agenda within the politicised context of a People First organisation.

Normalisation and support for self-empowerment

The next part of this chapter discusses an extremely influential concept that still has an impact on how people with learning difficulties are responded to, 'normalisation'. While there are interpretations of this concept that are compatible with the social model of disability, other interpretations, if put into practice, have the potential to disempower people with learning difficulties.

The concept of normalisation was originally developed in Denmark in the late 1950s. The original principle of normalisation was relatively simple and focused on human rights, self-determination and choice for people with learning difficulties. A decade later a new version of normalisation was formulated by Wolfensberger. This became the dominant version in the UK and was at its peak in the 1980s (Emerson, 1992).

Wolfensberger's version of normalisation, which he continued to work on and eventually called 'social role valorization', drew upon deviancy theory and focused on reversing the consequences of the social devaluation of people with learning difficulties (Walmsley, 2001). At the core of Wolfensberger's theories was the idea of actively integrating people with learning difficulties

into society and his version of normalisation is closely associated with
deinstitutionalisation and community care in the UK Walmsley (2001) has
argued that social role valorization has also been instrumental in opening up
participatory research, as involving people with learning difficulties in research
was seen as promoting a valued social role for them**.**

Wolfensberger identified the main aim of social role valorization as being 'the
good life' for people with learning difficulties. He argued for the full inclusion of
people with learning difficulties in society and developed explanations of how
people with learning difficulties are stigmatised and devalued by society and
how this affects them (Race et al., 2005).

Up to this point Wolfensberger's work is compatible with self-advocacy and
the social model of disability. Race et al. (2005) have argued that
Wolfensberger's insights into how people with learning difficulties are
devalued and where they are excluded from society could even be helpful to
people attempting to implement the social model with people with learning
difficulties.

However there is a fundamental element of normalisation/social role
valorization as developed by Wolfensberger that does not appear to sit
comfortably with self-advocacy or the social model of disability. His theories
(at least in part) appear to advocate that people with learning difficulties
should be changed to be more valued by society. This could be a fundamental
ethical flaw because adopting this stance may be ultimately abusive towards

people with learning difficulties and also works against the idea of groups of

disadvantaged people working together to define who they are and empower

themselves. As Szivos (1992; 128) has put it when writing about the

assumption (apparently inherent in social role valorization) that disadvantaged

groups should be encouraged to aspire towards 'society's idealised norms':

> These assumptions seem to promote an essentially negative conception
> of differentness, thereby making it impossible to avoid dissafiliation,
> derogation and shame. One of the cruellest aspects of stigmatised
> identity is that it makes it so difficult to value friendships with other
> stigmatised group members; normalisation does little or nothing to
> redress this. As Brown and Smith (1989) put it, it is still the advantaged
> group which defines what is and is not valued. Second, because passing
> is an option which is essentially pursued at an individualistic level,
> normalisation also makes it difficult to engage in group activity to
> renegotiate value and status in society.

As a referred to 'term' or approach in relation to the support of people with

learning difficulties 'normalisation' is perhaps no longer quite as fashionable. It

was at its peak in the 1980s. However it is broadly recognised that

Wolfensberger's theories of normalisation/social role valorization had, and

continue to have, a fundamental impact upon the nature of services that

people with learning difficulties receive (Race et al., 2005).

Race et al. (2005; 508) have discussed how the connection between

normalisation/social role valorization and current service practice or policy is

not always made clear:

> Though it is still correct to say that SRV theory underlies much of current
> UK policy, including the White Paper, *Valuing People* (Department of
> Health, 2001), the links are not made explicit, and SRV is now rarely
> included in training or used in looking at support for individuals in the
> learning disability field.

They have also argued that normalisation can be reconciled with the social model of disability and that Wolfensberger's core theories have been misunderstood. Wolfensberger's theories are complex and comprehensive and he continued to develop and refine them in response to criticism (Race et al., 2005). When reading for this section it seemed like nearly everyone interprets Wolfensberger's work significantly differently. If academics seem to miss the point or misunderstand subtleties in Wolfensberger's theories it is not likely that the subtleties of the theories will filter down into day-to-day practice in social care.

Writing in 1989 with Burt Perrin, Bengt Nirje (one of the people who developed the early principle of normalisation) had the following to say about what the term normalisation originally meant and one of the main ways that it continues to be misinterpreted in practice:

> Probably the most common misinterpretation of the normalisation principle is the mistaken belief that it means mentally handicapped people must be expected, indeed forced, to act 'normal', to conform in all respects to society's norms for all dimensions of behaviour. Normalisation frequently has been confused with normalcy.
>
> No, no, no! Normalisation does *not* mean normalcy; it does *not* mean that people should be normalised; it does not mean that anyone's behaviour should be forced to conform to any particular standard (for example, what 51% of one's neighbours do or what 'experts' feel is best); it does *not* mean that mentally handicapped persons are meant to be made normal or to act like other people. It *does* mean that opportunities and support should be provided to permit a life-style similar in nature that of other members of society, including similar opportunities for individual variation and choice. Normalisation means the acceptance of persons *with* their handicap within 'normal' society, with the same rights, responsibilities and opportunities as are available to others. (Perrin and Nirje, 1989; 221)

Therefore although this interpretation of normalisation may not have been quite what Wolfensberger was advocating, what can happen in practice is that people with learning difficulties are encouraged or made to behave in ways that the people who support them approximate as 'normal' or 'normality'.

As a supporter of people with learning difficulties I have witnessed people with learning difficulties being forced to conform to other people's standards against their will on several occasions. This quote from a chapter I wrote on supporting self-advocacy in an intensive support unit is just one example:

> ….Stephen had moved to a new house and no longer came into the centre every day. In addition the staff in the new house were trying to change his habit of sitting on the floor (normalisation at its most negative). At one time a worker from his new house 'escorted' Stephen into the session and immediately started dragging him up off the floor and towards a chair while shouting at him to stand up and sit in a chair. It took some discussion to prevent this worker doing this within the session and to get her to leave the session as she thought it would destroy their 'programme' if we didn't do the same to Stephen. (Forrest, 2002; 52)

However the interpretation of normalisation that Perrin and Nirje (1989) offer is clearly not based on the process of making people normal. They define it as acceptance within society, equal rights and equality of opportunity. As such this definition is compatible with both the social model of disability and my research aim of supporting the self-empowerment of people with learning difficulties on a research project, while collecting and analysing data on this support process.

'Independence' and support for self-empowerment

The concept of supporting people with learning difficulties to be independent is at the core of current social care policy (Department of Health, 2001; Department of Health, 2005). Within organisations for people with learning difficulties the meaning of the word 'independent' can be interpreted as being able to complete tasks unaided or with little support, or living outside of a residential home. Here is an example of the word 'independent' being used in this way in a recent piece of research by supported people with learning difficulties:

> We think Linda and Peter have most choice because they are
> independent and they live in a town so they can go out when they want.
> (Hart et al., 2007)

I could find no comprehensive or clear definition of what 'independence' means within influential Department of Health policy documents such as the White Paper, *Valuing People* (2001) and the Green Paper, *Independence, Well Being and Choice* (2005).

However Morris (1993) has commented on the lack of clarity around the term 'independence' and discussed the interdependent nature of human relationships, pointing out that disabled activists have defined 'independence' as having control over what happens in one's own life. Coming from this position, supporters taking a pedagogic approach towards teaching skills for 'independence' would risk denying the independence of people with learning difficulties by placing them in a dependent position as people who need to

learn skills and 'improve' before they can become 'independent' of other people and have control within their own lives.

One definition of 'independent' (of several) in the Concise Oxford Dictionary is 'self-governing' (Thompson, 1995; 690). In order to be self-governing people with learning difficulties often need support. Bearing in mind the interpretation of independence that has been developed by disabled activists, people with learning difficulties could need support to be self-governing and in control of what happens in their lives.

Barnes (1997) has pointed out that individualising dependence and independence is both unhelpful and inaccurate in when considering the empowerment of people with learning difficulties. In her writing on empowerment in relation to people with learning difficulties within families Barnes (97; 73) has made the following point:

> It is at best unhelpful, at worst damaging, to pose dependence and independence as dichotomies with one bad, the other good. It is also both inaccurate and unhelpful to assume that an individual always occupies one position in relation to others within their family or in other relationships. Empowerment needs to be understood as relating to the nature and quality of people's relationships with others, rather than as a feature of unconnected individualism.

The Learning Difficulties Research Team with assistance from Catherine Bewley and Linsay McCulloch (2006; 21) have drawn attention to how supported people with learning difficulties can and do support each other and their supporters:

> But we also worked hard to use people's individual strengths and to

support each other [people with learning difficulties and supporters] where we needed it. This went for supporters as much as group members.

They went on to state the following in the same report:

We [people with learning difficulties and supporters] got to know and trust each other, we helped each other out, we shared personal information. We were there when one group member's Mum died. We were there when two group members had a tough time in an interview. We helped each other when we were ill. We were there when one supporter's grandson was seriously ill and when another supporter had a baby. (2006; 39-40)

Therefore, while it seems important that people who are working to support the self-empowerment of people with learning difficulties acknowledge and understand the interdependent status of people within society, it also seems important that supporters recognise that people with learning difficulties are not fixed in a state of constantly needing support and that they can and do give support themselves.

In relation to this project, it was important to work with a definition of independence, and an approach that stemmed from this, that would not contribute towards the disempowerment of people with learning difficulties. I would not argue against supporting people to move towards undertaking some tasks unaided if they were comfortably able to. However, in relation to my support role on this project and my research into support for user controlled research, a constructive interpetation of 'independence', that seems compatible with both the social model of disability and the aims of my study, is one that has *control of support* at its core, rather than 'undertaking tasks unaided'.

Self-advocacy and support

From the onset of this project I aimed to support people with learning difficulties, within a self-advocacy group, to be in control of their own research and research meetings. Therefore, irrespective of the group's agenda, my role on this project was to be that of a non-directive self-advocacy supporter. My own research involved observing, gathering other data and writing about the issues and dilemmas that were present in that role. Therefore I sought to find out what was written in the self-advocacy literature on supporting people with learning difficulties to direct and be in control of their own meetings and projects.

Within the self-advocacy literature not a great deal has been written about the *supporter's role*. The following statement written by Simons in 1992 still remains appropriate today (the title of the role varies across the literature, 'supporter' is the most common but 'facilitator' is sometimes used and also 'advisor'):

> What should advisors be doing? What are the boundaries of their role? There are remarkably few models for advisors to follow or adopt. (1992; 62)

Williams and Shoultz (1982;114), early writers on self-advocacy, put forward the idea that people with learning difficulties should be in control of the *content* of self-advocacy meetings:

> The members themselves – that is mentally handicapped people – should

remain in control of the content of the meetings and should make the major contribution to the discussions; helpers should suggest and advise but never coerce.

However they do not specify that people with learning difficulties should have power over of the *process* of the meetings.

People with learning difficulties, quoted in Dowson and Whittaker's 1993 book on self-advocacy support, offer the following statements about whom they think should be in charge of the whole group process:

> "The group belongs to the members – the group is in charge not the supporter"….
> "The group does what the self-advocates want, not what the advisor says". (1993; 9)

They also make clear their views about the balance of power between themselves and their self-advocacy supporters, stating that it should be weighted on the side of people with learning difficulties:

> "We are their bosses - they are working for us". (1993; 20)

Dowson and Whittaker (1993) have stated the following about people with learning difficulties holding the power within self-advocacy groups:

> Clearly it is important to self-advocates that the group belongs to them – that they are in control. (1993;9)

> The advisor must make sure that the power remains with group members. (1993; 11)

However, all of the literature mentioned above is relatively early. I could find nothing in more contemporary literature on self-advocacy that clearly put

forward the idea of supporting people with learning difficulties to be in control

of their agenda or the process of their self-advocacy meetings, or that

discussed how to do this effectively. In the Social Care Institute for

Excellence's 2006 position paper on self-advocacy support, (which Research

Group members and myself were consulted about, along with other

supporters and people with learning difficulties involved in self-advocacy),

Lawton (2006; 44) the writer of the paper concluded that only the following

was being said on the subject of 'control' within self-advocacy groups:

> Supporters should value people with a learning disability as individuals
> who are in control and who know what they want to do and say.

At best, this statement is ambiguous in relation to a group of people with

learning difficulties being in control of what happens in a self-advocacy group

(over and above the supporter). The statement can be read as suggesting

that individuals with learning difficulties should be valued as people who have

control over their own actions and statements.

Writing from a social model perspective Goodley (2000) found, in his

ethnographic research on self-advocacy in the lives of people with learning

difficulties, that supporters had considerable power over what happened in all

four of the different models of self-advocacy groups he observed. As he put it:

> In the four groups, advisors had the power to take big decisions but self-
> advocates were not powerless (2000; 195).

He argued that 'advisors' who supported well, listened and behaved in ways

which challenged the discourses that silenced and disabled people with

learning difficulties. He concluded the following:

> …people of any (oppressed) social group are capable of individual and collective determination. Consequently, there may be a need to move away from paternalistic notions of 'empowering' people to practices that incorporate those self-empowering actions that already exist. Self-advocates can be supported, by listening and acting in ways that challenge those discourses that silence and disable. (2000; 195)

Goodley's (2000) research illuminates the importance of the supporter's understanding of disabling practice and their commitment to working against it. However, although Goodley argues for ways of working that support the self-empowerment of people with learning difficulties, he does not appear to be clearly stating that he proposes they are fully in control (over and above their supporter) of the process and content of their self-advocacy groups, although his focus on 'self-empowerment' could imply this.

Dowson and Whitaker's 1993 book is unusual as other literature about (or that touches on) how to support people with learning difficulties to advocate for themselves does not clearly put forward the idea of supporting people with learning difficulties to have the power *over* what happens in their own group on a process level. Sutcliffe and Simons (1993; 4) are a possible exception. They briefly state the following:

> A self advocacy group is run by people with learning difficulties and not by professionals.

However I have not been able to find any other literature that makes clear that people with learning difficulties should hold the power over what happens in the group, both over the process of the group and the nature of the support

they receive. Nor could I find any literature on how a supporter can effectively facilitate or support this process.

When power is mentioned in other self-advocacy literature, it is suggested that it is shared between the supporter and self-advocacy group members or 'given' to the people with learning difficulties when they have learned enough about self-advocacy to be able to deal with it. For example, when discussing self-advocacy support, Whitaker (1989) argues that the supporter should be aiming towards an equal balance of power between themselves and 'self-advocates' [as opposed to the power being weighted on the side of people with learning difficulties]. Wertheimer (1988) argues for power sharing, through working in partnership with people with learning difficulties.

In her book on supporting self-esteem and self-advocacy, Mosely (1994) (who has a therapeutic background) argues that there is an innate imbalance of power between people with learning difficulties and supporters. She argues that there is a need for the supporter to address their own attitudes in relation to how they view themselves in relation to people with learning difficulties. As she puts it:

> To understand how to work effectively with others we must first understand ourselves. We must acknowledge our own strengths, weaknesses and areas of need.
>
> Whether we like it or not, our choice of occupation gives us power over others. However much we wish to believe that we do not abuse this power, we as staff have learned that this is a constant challenge…The world we inhabit, with its superficial values promoted largely through media images has, often without us even realising it, encouraged us to value people who are more attractive, successful, witty people who are

> 'more' than ourselves. We admire, envy and even fear these people because we recognise their power to either bolster or diminish our self-esteem…it takes energy and commitment to constantly put aside such conditioning and look beyond the initial poor self-presentation… skills of the people we work with, to their unique but often hidden, strengths and qualities.
>
> People who value themselves are not driven by self-esteem motives to seek more recognition at all costs. If we do not value ourselves and our self-esteem is low, we are a danger to the people we work with. (1994, 23)

Mosely's argument appears to be based on her personal view that it is not possible to have low self-esteem and value people with learning difficulties, as she produces no evidence to back up this claim. However within the self-advocacy literature I could find no other examples of how the personal values of the supporter may influence the amount of value or status they place on people with learning difficulties.

Brechin and Swain (1988) have postulated that person-centred approaches [as developed by the psychotherapist Carl Rogers (1967)] are of particular use when supporting self-advocacy processes. However, the practical ways that such person-centred approaches can be put into practice to support self-advocacy processes for people with learning difficulties do not appear to have been written about in the literature on self-advocacy and self-advocacy support. Opening up, to some extent, this area of discussion is another function of my research.

McCarthy (1999) has argued that 'normalisation' has had more impact on services than self-advocacy. As she puts it:

Despite its many achievements and the irreversible nature of the development (it is hard to imagine that any service provider is going to say in future: 'we've changed our minds we don't think service users' views are important after all'), the self-advocacy movement has not had anything like the same impact on services as the normalisation movement. This is because although normalisation meant a radical reshaping of services, it did not fundamentally alter the power base – non-disabled people were still left in charge of the direction services should and would take and there was, and still is, an attitude of 'we know best (1999; 48).

However, not everything that is called self-advocacy or self-advocacy support does alter the power base between non-disabled and disabled people. For example Werheimer (1988) advocates that the supporter teaches formal meeting skills such as 'voting', 'listening' and 'taking turns' to the group. The suggestion is that the advisor comes to the group with an agenda for teaching self-advocacy. This theme is also echoed in Mosely (1994; 71), who suggests that to 'help [people with learning difficulties] start *their own* work towards self-advocacy' the supporter should approach the group with a structured agenda and implement it, [and therefore be directing or controlling the group from the onset]:

I introduced myself to the group and thanked them for inviting me to help them start their own work towards self-advocacy. I explained that I saw my role initially to weld the group together into a strong team, thus increasing their ability to support each other in whatever changes they wanted to initiate.

I asked the group to pair off and talk to each other about the things that they presently liked in their lives. Each member had to introduce her/his partner to the group and relate one thing which that person liked.

In the above quotation Mosely is clearly demonstrating that she is in control of the agenda in these initial meetings. What is being demonstrated above is that Mosely is directing the group members.

Sutcliffe and Simons (1993; 3) have postulated that self-advocacy can be

divided into two different models: 'individual' and 'collective'. They have

pointed out that individual self-advocacy is needed for the following reasons:

> Many adults with learning difficulties will have been through experiences that have disempowered them as individuals, leaving them passive and reluctant to express an opinion or make choices.

They define collective self-advocacy in the following way:

> People forming groups to discuss things and to try and change things collectively. (1993; 4)

However these models overlap. For example, Goodley (2000) has discussed

how productive it is for individuals to have the opportunity to speak together

about the experience of being labelled as having learning difficulties.

Much of the early literature on the subject of self-advocacy support focuses on

teaching *individuals* 'self-advocacy 'skills. Buchanan and Wamsley (2006;

135), in their recent literature review of British self-advocacy within an

historical perspective, have the following to say on the subject of the early

self-advocacy literature:

> …these lay a heavy emphasis on education and skills development in areas like taking part in meetings and using the phone.

Mosely (1994) stands out as she focuses on supporting people with learning

difficulties to develop confidence, assertiveness, self-esteem and the skills to

make choices. However she does not address the issue of how to support the

collective self-empowerment of people with learning difficulties.

Criticising this focus on individual self-advocacy, Dowson (1990) has argued that self-advocacy needs to address the issue of supporting people with learning difficulties to change their lives for the better. He also clearly states that self-advocacy needs to involve a shift in power in favour of people with learning difficulties and make a move from self-expression towards self determination.

Aspis (1997) argues that people with learning difficulties need *training* to aquire the skills to advocate for themselves, and as such she does not address the power dynamics between the self-advocacy supporter and group members within self-advocacy groups. However she postulates that while people with learning difficulties are being 'trained' in meeting skills (for example, working with agendas and minutes) and in making decisions for themselves they are not being 'trained' in how to bring about changes in the rules of the institutions that oppress people with learning difficulties and the implementation of their collective rights as citizens.

There are some (albeit few) guidelines on how self-advocacy group supporters can interact interpersonally with people with learning difficulties to be supportive of them making choices and speaking up, for example Dowson and Palmer (1994) and Mosely (1994). However, there is even less in the self-advocacy literature that is directly about how the supporter needs to behave in relation to the collective self-empowerment of people with learning difficulties. Where a recommendation is made that the self-advocacy group members 'do

things for themselves' (Simons, 1992; 63) and that the supporter not be in charge (Simons, 1992;) there are no guidelines or detailed discussions about how this might be actively achieved. The same can be said about Goodley (2000) and Aspis (1997) who both advocate social model thinking in the supporter, but have not gone into detail about the practical ways that the 'advisor' can work with social model values to support the self-empowerment of people with learning difficulties.

There is little in the literature on how the politicised collective identity of people with learning difficulties involved in self-advocacy can be framed. However when discussing self-advocacy in relation to the wider disability 'movement' Dowse (2001; 133) has argued that while self-advocacy has some way to go before it could be described as a social movement ,it has helped towards shaping a politicised collective identity of people with learning difficulties:

> People with learning difficulties who have assumed a political collective identity are predominantly represented within Self Advocacy.

Within the book that is based around his PhD research, Goodley (2000; introduction) claims that self-advocacy is a social movement, that is being used to counteract the oppression of people with learning difficulties. As he puts it:

> Self-advocacy can be seen as a counter-movement to state paternalism, wherein people with learning difficulties conspicuously support one another to speak out against some of the most appalling examples of discrimination in contemporary British culture. The self-advocacy movement has invited people with learning difficulties to revolt against disablement in a variety of ways, in a number of contexts, individually and

collectively, with and without the support of others. The movement captures resilience in the face of adversity.

However, Walmsley and Downer (1997; 37) (who also describe self-advocacy as a 'movement') have written about the status that can be attached to people without learning difficulties who work in 'fashionable' areas of work such as self-advocacy, and how people may be aiming to advance their careers by being involved in such apparently innovative work. They claim that the self-advocacy movement can appear to have a degree of political power and people without learning difficulties can gain a certain amount of kudos through being involved with it. As they put it:

> A movement which appears to have some power may attract people with or without learning difficulties, who are more interested in gaining power for themselves than promoting the interests of a broad constituency.

Aspis (1997; 652) has commented on how as more service providers fund independent self-advocacy groups to work with them, or offer self-advocacy support within their services, they will have greater control over what people with learning difficulties speak up about. She argues that self-advocacy groups could become less independent and that this will result in the following situation:

> …self-advocates will be forced into only speaking up about choices of services which are provided by the local health authority.

Aspis (2002; 3) has also argued that a relatively recent profusion of different parties offering self-advocacy support has led to a situation where it is difficult

to establish which self-advocacy support is genuinely supportive of the self-empowerment of people with learning difficulties. As she puts it:

> Over the decade, a lot of work has been carried out on supporting people with learning disabilities to advocate what they want in their lives. The most significant move came when People First was set up with assistance from the King's Fund in the 1980s. Since then, everyone has jumped on the bandwagon of self-advocacy, including service providers, course tutors, academics and therapists. What has happened is that everyone is doing self-advocacy which makes it difficult to establish what is real and what is superficial.

Aspis' comments suggest that there is a need for supporters of self-advocacy groups to ensure that what they are offering is really contributing towards the self-empowerment of people with learning difficulties.

In relation to this research I have decided to place the following meaning on the term 'supporting a self-advocacy group', which fits with the principles underpinning Thomas's (2004) definition of the social model of disability: *supporting the collective and individual self-empowerment of people with learning difficulties within a group that they are in control of.* From analysing the literature it is clear that, within the context of the small amount that is written about self-advocacy support, literature on the role interpersonal support can play in facilitating people with learning difficulties to be in control of their own self-advocacy groups is extremely scant. My literature search revealed no previous in-depth research that had focused on the interpersonal issues connected to supporting people with learning difficulties to be in control of a self-advocacy group. Therefore, as well as making a contribution towards the literature on supporting people with learning difficulties to undertake research, my research could also contribute towards the literature on

supporting self-advocacy.

Involvement and research with people with learning difficulties

This section of the chapter draws upon the following approaches that have informed the development of research with and by people with learning difficulties: service user involvement in social care and social care development, service user research and research with and by people with learning difficulties. These approaches are looked at here in relation to supporting the self-empowerment of people with learning difficulties. This section further justifies the relevance of this research by comparing the focus of it to previous related research.

Service user involvement

Beresford and Turner (1997, Summary xi) have discussed why service user involvement is important. As they put it in their report of the Citizen's Commission on the future of the Welfare State:

> One of the main problems which welfare state service users identified was that it [the welfare state] was frequently insensitive, unresponsive and unaccountable to them. They felt they generally had little say or control over it and how it treated them. As a result they were often treated carelessly and badly.…Increasing the say of service users was seen as an important way of ensuring that future welfare state services were of good quality, flexible, appropriate and accountable.

The Department of Health have promoted the idea of service user involvement and in 2001 provided the means to support a group of people

with learning difficulties to contribute towards the development of the white

paper *Valuing People* (2001). At the time this was a ground-breaking initiative.

This is how it is described in the report produced by the above supported

group of people with learning difficulties, *Nothing About Us Without Us*:

> The 'user' group was set up to make sure that people who knew about services were able to give their views about the future of those services. This is the first time that people with learning difficulties have been involved in advising the Government on a strategy. New strategies don't happen very often, so this was a rare opportunity to get involved (Department of Health, 2001; 2).

In recent years there has been an increased interest in and focus upon

service user involvement, which has become an integral part of the

development and implementation of social care policy.

However service user involvement is not always effective and does not

necessarily lead to improved services. Writing about responses to policy

directives to implement involvement or public participation in service

provision, Dockery (2000) has argued that despite the rhetoric on service user

involvement he fears that there is a lack of political commitment to service

users having any real power or control within the process. Dockery points out

that as managers and funders of services can set the parameters on

'participation' they can apply a less radical understanding of the term, that

could be interpreted as them not wanting to share power with service users.

Carr (2004) has postulated that while the principle of service user involvement

has been well established, and processes for participation have been

developed, there is a need for a further stage of development before

participation can make a substantial difference to social care services. She

argues that further cultural and structural changes within organisations are

needed and that power relations were at the root of the majority of the

problems identified with the effectiveness of user-led change. As Carr (2004;

vii) puts it:

> Power issues underlie the majority of identified difficulties with effective
> user-led change. User participation initiatives require continual awareness
> of the context of power relations in which they are being conducted.
> Exclusionary structures, institutional practices and professional attitudes
> can still affect the extent to which service users can influence change. It
> appears that power sharing can be difficult within established mainstream
> structures, formal consultation mechanisms and traditional ideologies.

Carr (2004; 28) goes on to argue that in relation to critical enquiry,

participation provides a unique opportunity for service development:

> Many people want to improve and have greater control over the disparate
> elements of support and service in their lives and require participation
> strategies that can reflect this. The political and philosophical methods of
> the service user movement seem to be exposing the limitations of
> traditional, fragmented service categories for organising participation
> designed to promote strategic change. Participation provides a unique
> opportunity for organisations to develop and transform through critical
> enquiry with service users using the social model of disability, ideas about
> control, oppression, rights, poverty and citizenship.

So services can apply less radical interpretations of 'participation', and power

sharing can be difficult to achieve within established mainstream cultures.

However, it would seem that participation can offer organisations a real

opportunity to develop if it is viewed as a process of critical enquiry and

grounded in the politics of the social model of disability, which has at its core

the principle of self-empowerment for disabled people.

Scrutiny of the literature has led me to conclude that in relation to the literature on participation there has been no previous in-depth study of the role that interpersonal support can play in facilitating people with learning difficulties to participate in ways that are valued by them in service development and management. While the focus of this research is not linked directly to service user participation in service development and management, it may have a role to play in contributing towards the literature on ways of supporting people with learning difficulties to put across their opinions about the services they use.

Service user knowledge

Service user researchers Branfield and Beresford et al. (2006) have argued that in order for service user involvement to work there is a need for service users to organise autonomously and network to share knowledge. In short they argue that service users need to unite to have a stronger voice and be in control of their own research.

Service user researchers Turner and Beresford (2005) have argued that in order to describe more accurately the collective experience of service users and move away from the academic abstraction and distortion of their experience, there is a clear need for service users to be in control of their own research. The approach they advocate, 'user controlled research', has its roots in emancipatory disability research and survivor research. These last two research approaches also focus on empowerment and are informed by the social model of disability, and they also promote the idea that service

users rather than non-service users hold the control of the research (Turner and Beresford, 2005). Emancipatory disability research is discussed in more detail in the methodology chapter of this dissertation.

In an attempt to challenge or counteract tokenistic involvement of people with learning difficulties in research projects, Aspis (2002), a researcher and activist with learning difficulties, has developed a checklist of involvement 'rules'. However like the majority of the self-advocacy literature Aspis's suggestions are apparently not based on research, although it is fair to say that they are written from an informed position by someone who is a researcher, a person with learning difficulties and a disability activist. Interpersonal support issues are not addressed in depth in the above short article. However, while identifying levels of involvement across the whole of a research project and promoting transparency, Aspis focuses on the issue of people with learning difficulties being in control of the project. In relation to the role of what she calls 'non-disabled researchers' working with researchers with learning difficulties Aspis (2002;18) has the following to say:

> People with learning difficulties must be in charge of the research project especially, if a People First or another speaking up group is involved. The researcher's role should be seen as supportive/advisory. People with learning difficulties should have 100 percent control over how the research project is carried out. There must be room for people with learning difficulties to reject the advice or to do something different from what the non-disabled academic is recommending. Action should not necessarily require consensus between the people with learning difficulties and the one or more non-disabled researcher(s).

At the onset of this project I could find no research that claimed to be controlled by people with learning difficulties. Although during the time I

worked on this PhD dissertation some research that claimed to be controlled by people with learning difficulties was published, and this is reviewed later on in this chapter. However it is still fair to state that in most of the published research in which people with learning difficulties have been actively involved, a claim is made that the research project is *shared* by people with learning difficulties and academics without learning difficulties. The issue of ultimate power over aspects of the research process is not discussed or exposed. In short the issue of who holds the power over different parts of the project remains, to say the least, vague.

Research with people with learning difficulties

A noticeable gap in all of the literature on service user involvement, inclusive research with people with learning difficulties and service user controlled research is how people with learning difficulties can be actively *supported* within face-to-face relationships to gain and maintain control of user involvement or a research project. Walmsley (2004) has drawn attention to the lack of information about what supporters actually do to support people with learning difficulties to be actively involved in research projects. She has pointed out that while people with learning difficulties involved in self-advocacy projects are stating they need ongoing support and supporters, the role that researchers without learning difficulties play in inclusive research projects is played down and so far has not been discussed in enough depth.

At this point it would be useful to outline some key ways that people with learning difficulties have been actively involved in research. My aim here is to

explain how my proposed research compares to other related research. There are two inter-connected strands running throughout this section: the level or type of involvement of service users in different related research projects, and what these projects reveal about the subject of research support for researchers with learning difficulties.

Several academics without learning difficulties have worked with the 'stories' of people with learning difficulties, for example Atkinson, Jackson and Walmsley (1997) and Booth and Booth (1994). With this way of working, academics have arguably still been in control over how the stories are analysed and presented. This is not to say that the academics who have worked in this way have not been working with the best interests of people with learning difficulties in mind. For example, the work of Oswin (1991) and Booth and Booth (1994) focuses on the oppression of people with learning difficulties and argues strongly for changes in the ways they are responded to by services. Atkinson and Williams (1990) have presented life stories and poetry of people with learning difficulties that not only demonstrates the oppression of people with learning difficulties but also their sensitivity and awareness**.

Goodley (2000) has worked with the stories of key figures in what Walmsley (2004) has called 'the movement' [self-advocacy movement] in his research on self-advocacy. Goodley has presented life stories, that have provided data for his research, as being written by service users, or at very least approved by them. He has explained only briefly how he supported people to produce

these life stories. Yet his work still has the following in common with the other academics mentioned in this section, people with learning difficulties are not included in the analysis of the research data of which their life stories are a part. As such they are not named as authors or co-authors of the completed research. People with learning difficulties have gained support to write and/or to publish their own life stories, for example Potts and Fido (1991), but while these accounts can draw attention to the inequalities and exclusion many people with learning difficulties face, presenting a life story is not the same as producing research.

There are examples within the literature of individuals with learning difficulties working in conjunction with an academic to discuss a particular research subject, for example Walmsley and Downer (1997) and Souza with Ramcharan (1997). Within these two texts the person with learning difficulties is presented as collaborating with the academic without learning difficulties and named as a co-author. Researchers without learning difficulties have also collaborated with people with learning difficulties on service evaluations, for example Whittaker (1997). I have not found any examples within the above types of collaboration that discuss in any depth how the person with learning difficulties has been supported to take part in these projects. Also I have not found any discussion in these types of collaborations that make clear what is the work of the academic without learning difficulties, what is that of the person with learning difficulties, or what the power balance was between the co-authors.

In 2003, Walmsley and Johnson presented a thorough review of inclusive research with people with learning difficulties. Within their book they identify, describe and analyse research projects that people with learning difficulties have actively participated in. They state the following in relation to 'emancipatory' research and people with learning difficulties:

> …the conceptualization of such an approach is much easier in the abstract than in its implementation (2003; 28).

They directly equate emancipatory research with the amount of control that researchers with learning difficulties have over the research project, viewing it as moving away from co-researching so that people with learning difficulties take charge. They state that this is very rare and only offer two examples of this (and one they say consists of theoretical papers rather than research). They cite Williams' PhD thesis (2002) as a record of the most developed emancipatory research to date involving people with learning difficulties. As they put it:

> Although she [Williams] places this piece of work within the participatory paradigm, it emerges as the most developed piece of emancipatory research to date in the field because so much of it was determined by the self advocate researchers. (Walmsley and Johnson, 2003; 154)

Williams' thesis (2002) will be discussed in more depth later on in this chapter in relation to the development of this research. However at this stage, it seems safe to state that at the start of my research project emancipatory approaches to supporting people with learning difficulties to undertake extensive or developed research projects were at best rare, and that there was significant room for further development in relation to researching the

process of supporting people to be in control of their own research project and documenting, in a critical way, how this was done.

Research by people with learning difficulties

Since I started working on the research that this dissertation documents three major research projects have been published that are described as being written 'by' people with learning difficulties. These are reviewed here in relation to two issues; how the issue of people with learning difficulties being in control of the research is addressed within them, and what is written about the process of supporting people with learning difficulties to be in control of their own research within these texts.

Journey to independence: What self-advocates tell us about direct payments by Gramlich et al. with Williams and Simons was published in 2002, a year after the fieldwork for this research began. *Let me in – I'm a researcher!: Getting involved in Research* by The Learning Difficulties Research Team with assistance from Bewley and McCulloch was published in 2006, five years after the fieldwork for this research was initiated and *Our lives, our communities: Promoting independence and inclusion for people with learning difficulties* by Hart et al. was published in 2007 when the fieldwork for this PhD was completed and towards the end of the time I spent writing up this dissertation.

Journey to independence (2002) is written in a way that initially suggests it is

the work of a group of people with learning difficulties. Here is how the

preface begins:

> This report is about direct payments for people with learning difficulties. It is written as a journey – a journey to independence. We are three self-advocate researchers, Natasha Snelham, Gordon Mcbride and Stacey Gramlich…. (Gramlich et, al. 2002; 6)

However, the text that immediately follows on from the above statement

shows that people with learning difficulties were not the only people actively

involved in the writing up of *Journey to independence*, or the research itself:

> …and we are the people who made that journey, together with our research supporter Val Williams and our People First supporter, Brian Myers. The senior researcher on our team was Ken Simons. (Gramlich et al., 2002; 6)

It is made clear within the text of *Journey to independence* that their research

project is a partnership between people with learning difficulties and

academics. The following is stated about the relationship between the People

First organisation that took part in the research and the organisation that the

two academics were part of:

> This report is written by Swindon People First Research Team in partnership with Norah Fry Research Centre. (Gramlich et al., 2002; 6)

The above statement makes clear that the research and the report of it is the

result of a collaboration between people with learning difficulties and others.

However at one stage in the book the following comment is made:

In the 'Journey to independence' project we have done all the research. We are people with learning difficulties, and the research is about how we think and see and understand… We had a research supporter, Val Williams to assist us. Her role was not to do things for us, but to give us the support so we could do it for ourselves. We also worked together with Ken Simons throughout the project, and we all had regular team meetings with Swindon People First. We were like one big team, all working to the same goals, but in different ways. (Gramlich et al., 2002; 120)

It seems that a suggestion is made in the text of *Journey to independence* that people with learning difficulties took the lead in this project, or that they devised and undertook the research that the report documents. However issues of power and control in relation to co-working with people with learning difficulties are not addressed in this book or any of the text that has been written by Williams about the way she supports research with people with learning difficulties (some of which will be discussed later in this dissertation). The above statement, 'Her role was not to do things for us, but to give us support so we could do it for ourselves' could suggest that the people with learning difficulties were supported to be in control of their project over and above their co-workers without learning difficulties. However this is unclear because there is a radical difference between supporting people with learning difficulties to undertake tasks by themselves and supporting them to be in control of their own agenda.

It would be fair to say that the issue of the balance of power between supporters, researchers without learning difficulties and the people with learning difficulties themselves is not discussed in depth within any of the three texts that are being reviewed in this section. However, on this subject, there are still differences between what is written in the three documents.

Let me in - I'm a researcher! (The Learning Difficulties Research Team with assistance from Catherine Bewley and Linsay McCulloch, 2006) is written in a way that suggests it is solely the work of people with learning difficulties, with support. In it a mention is made that researchers with learning difficulties were, in relation to their supporters, 'decision-makers' even though the text states that supporters contributed 'as equals' to the research. This is how it was put in the above report:

> It was also important for us that supporters contributed to the project. We felt strongly about everyone working as equals and this was reflected in our decision to pay everyone the same daily rate. However, it was always clear that we were the decision-makers and in charge of the money. (The Learning Difficulties Research Team with assistance from Bewley and McCulloch, 2006; 93)

However it is unclear whether the above statement and the term 'supporters' also refers to decision-making processes between the two academics who were involved in this project and the researchers with learning difficulties.

This research was commissioned by the Department of Health who decided what the focus of the research should be. There is no evidence in the report to indicate that the subject of the research was decided by people with learning difficulties. In his foreword to the report Rob Greig who was the current 'National Director of Learning Disabilities' at the time said the following about the role of the researchers with learning difficulties involved in *Let me in – I'm a researcher!*:

> The Research Group has been impressive in what it has done. They have demonstrated that people with a learning disability can be full and

effective partners in academic research. They have also helped to highlight good practice and expose where the commitment to the involvement of people in research does not go beyond the words in the application process. (The Learning Difficulties Research Team with assistance from Bewley and McCulloch, 2006; 8)

Rob Greig appears to be stating that *Let me in - I'm a researcher!* demonstrates that people with learning difficulties were full and effective *partners* in academic research on this project. However the text goes on to state that the project was 'done by' and 'managed' by people with learning difficulties and is 'a first'. This is how it is described in the text:

Our research is a first!... Our project was groundbreaking because the research and the management was done by people with learning difficulties. Research is often something that is 'done to' people with learning difficulties not 'done by' us. But this project gave us an active and independent role in the process of research. (The Learning Difficulties Research Team with assistance from Bewley and McCulloch, 2006; 8)

However their research may not have been a first in 2006 because it was (as they put it) 'done' by people with learning difficulties. It seems that all that can be said, with any degree of certainty, is that the researchers with learning difficulties involved in the research documented in *Let me in - I'm a researcher!* were research partners with their supporters and the two academics involved. It seems that the people with learning difficulties involved in this project may well have chosen to work in partnership in that way. However *Let me in - I'm a researcher* may have been a first because it was *officially* run and managed by people with learning difficulties:

Values Into Action (VIA) was asked to do the day-by-day support of the project…VIA supported us…VIA's role was only to support: we managed

the project and the budget. (The Learning Difficulties Research Team with assistance from Bewley and McCulloch, 2006; 42)

Power may have been shared to the satisfaction of the people with learning difficulties involved, which is very positive in itself, and they may well have been supported to manage the project and the budget to the best possible standard within the time allocated (having relatively less experience than the academics and meeting once a month for less than three years). However, there is no evidence in the text to indicate that the researchers with learning difficulties had ultimate control over all the decisions made in this research that either were or could have been important to them. That is not to categorically state that they did not. It is just that the issue of ultimate control is not addressed within the text of *Let me in - I'm a researcher!* which reads as an important, and to all intents and purposes, effective example of power-sharing rather than an example of people with learning difficulties having full power over how this complex and involved research project was developed and run.

It is not my intention to suggest that people with learning difficulties did not 'do' the research that is mentioned in any of the three texts that are reviewed in this part of this dissertation. What I am suggesting is that giving further attention to the issue of supporting people with learning difficulties, on an interpersonal level, to be fully in control of a research project (and the dilemmas, contradictions and challenges this may entail) is an important subject for research. It seemed to me from the onset of this research towards a PhD that studying this subject with the aim of opening it up for scrutiny and

discussion could contribute towards further levels of control being held by people with learning difficulties in future research that was 'done' by them. The three recent research projects by people with learning difficulties that are discussed in this section have not weakened my view that this is still an under- researched or overlooked and potentially valuable area of study.

The issue of control in relation to the research process is mentioned in *Our lives, our communities* (Hart et al., 2007; 1). This is what is said in the text on this subject:

> This research is very special to us. We are members of Fresh Start, the research and training part of Central England People First (CEPF), and this project is built on CEPF's work over many years. It uses our ideas in ways that we want to use them.
>
> CEPF is an organisation of people with learning difficulties, run and controlled by people with learning difficulties. Over the years we have tried to work in ways that allow us to control our activities. There is a lot of research that is done by researchers with learning difficulties and by researchers without learning difficulties. Some of this is very good but, in the end, the ideas that people with learning difficulties put forward are usually taken over by the researchers.
>
> This is our first research project and we have done it by ourselves. We have had control over the whole project. It says important things about the lives of people with learning difficulties. This does not mean that we have not had support, but we have been very careful about how and when we have used it.

It is stated in the report that on this project there were 'support people', whom the researchers with learning difficulties worked with, and a 'research supporter'. The 'research supporter' wrote a separate appendix to the research on how he supported this project. This is how he titled his appendix:

Appendix 1: Being a research support person in a user-controlled project (by Ian Buchanan). (Hart et al. 2007; 32)

Buchanan (Hart et al. 2007; 33) states that his role as a 'research support person' was to be responsible for the following:

- support for the development of the project (discussing and sometimes explaining ideas, big ideas or concepts, and ways of working or skills and techniques)
- advice on how to do the research and how to analyse or see what the information that is collected means
- support in making sense of the findings
- support in the preparation of reports and other outputs.

He explains that the rest of the support was carried out by 'supporters' (with some experience of supporting people to undertake research) who had the role of supporting people to speak up or advocate for themselves. Buchanan (Hart et al. 2007; 33) makes the following important point about the role of self-advocacy support within user controlled research with people with learning difficulties:

Research is a special activity but is part of speaking up for self-advocacy organisations like CEPF.

He goes on to make the following statement about the 'research supporter' avoiding influencing the research by not being part of the research team:

Working in this way means that, within a user-controlled research project, the research support person is a different kind of support person. The research support person is not part of the research team. The research support person doesn't take any of the important decisions and has as little influence in the research as possible. However, it is more like good research supervision that does not decide what the project is, its ideas or ways of working. (Hart et al., 2007; 33)

However there were other (unnamed) people without learning difficulties who were supporting people with learning difficulties to undertake research on this project. Buchanan writes that they were there to support self-advocacy as well as research processes. They may not have been called 'research supporters', but nonetheless they supported people with learning difficulties to be involved in the various elements of the research project that Buchanan did not support. Buchanan pointed out that the people with learning difficulties in the research group were not experienced researchers. As he put it:

> Although Fresh Start have a great deal of experience in research, the team was not made up of experienced 'star' researchers. (Hart et al., 2007; 34)

Although the person who was given the title of 'research supporter' on this project stated that he avoided influencing certain aspects of the research by not being part of the research team (Buchanan also stated in his appendix that he did not attend the research team's meetings) other people without learning difficulties were at the research meetings in a support role. Therefore they too could also be viewed as research supporters and have the potential to influence the research by their presence. So while Buchanan has inferred that avoiding influencing the research could be part of the user controlled research supporter's role when working on projects with people with learning difficulties, how this can be achieved still remains largely unclear. There is certainly plenty of scope for further examination of this aspect of user-controlled research support.

Within the text of *Our lives, our communities* nothing is written about how

either Buchanan or the other 'research supporters' on this project managed

not to influence this project when on the one hand they, as people without

learning difficulties, were in a powerful position and they (at the very least in

Buchanan's case) had considerably more experience of research than the

people with learning difficulties they were supporting and advising.

Buchanan's statement about user controlled research support with people

with learning difficulties being like 'good research supervision' indicates what

he saw his role as being in relation to the researchers. However the

researchers with learning difficulties on this project were not in the position

that many people who receive research supervision for such a significant

piece of research are. Often researchers have already achieved a degree or

higher degree and are able to maintain a considerable amount of control over

their own work through having the experience and skills to write it themselves.

In addition, having confidence in their own skills as writers could contribute

towards their ability to withstand advice from their supervisor assertively,

should they choose to. This was clearly not the case on this project. This is

how it is put in the text:

> We have asked our research support person to edit our words into the
> final report. We did this because we are not experienced writers and our
> research support person is used to research report writing. Even though
> he did this using 'our words', we have been over the report three or four
> times and changed what it says and added new bits. (Hart et al., 2007;
> 34)

The research support person on a user controlled research project with

people with learning difficulties is in a position where she or he has far more

potential to influence the content of the research than someone who is supervising a person without learning difficulties to undertake research towards an MA or PhD, for example. Again, how people with learning difficulties can be supported to be in control as fully as possible under such circumstances is an under-researched subject.

Buchanan's comments about the user controlled research supporter are all contained within a six-page appendix and as such are not detailed or in depth. Williams (2002) has written about the subject of supporting people with learning difficulties to do research in far more depth. The following section of this chapter reviews what she has written in relation to supporting people with learning difficulties to be in control of their own research project.

For her PhD Williams (2002) undertook transactional analysis research that focused on observing the reactions of a group of people with learning difficulties she supported to do research. In her dissertation Williams explains how the group of people she worked with participated in a research project. In her research she mostly observed the verbal communication between her co-researchers with learning difficulties. This is how she described that process:

> My aim thus became to examine in detail the ways in which talk-in-interaction works within inclusive research. (2002; 31)

One of Williams' main contributions to the literature has been to present evidence that people with learning difficulties can take responsibility for research processes and to show how, on the project she was involved in, they

did that. Williams closely observed the way that the group of researchers with

learning difficulties interacted throughout the research process and how they

made sense of it. In her research she demonstrates the understandings and

perceptions about research processes that were held by the researchers with

learning difficulties she worked with, and how they worked with these

productively. Williams also explains that her co-researchers saw their

inclusive research as a way of accessing more power within their lives. One of

Williams' co-researchers had the following to say about this issue:

> People with learning difficulties have been unempowered for a long time, and it's about time that people with learning difficulties have the power to themselves. (Williams, 2002; 115)

Williams also drew attention to some approaches she took to encourage

people to keep focused on their research and take responsibility for specific

research processes. For example, she explains about how she held back at

times to encourage researchers with learning difficulties to take responsibility.

She points out what she and her co-researchers with learning difficulties did to

give or maintain a research focus in their meetings. Here is an example of one

such explanation from Williams' text:

> …I as a research supporter did quite a deliberate move a couple of turns after this to deflect Harry [a researcher with learning difficulties] back to the interviewer role. (2002; 147)

Although she does at times draw attention to an action she may have taken to

focus group members or encourage them to constructively undertake

research, as opposed to another activity within the group, Williams does not

focus a great deal on her own interventions, except in one chapter within her

thesis on the subject of support. Overall, throughout the thesis as a whole, Williams focuses on describing the reactions of the researchers with learning difficulties. Within her chapter on support Williams, who identifies herself within the research as a teacher who is working in a student-centred way, focuses on the role she played in enabling supporters to see the significance of what they could contribute, and how she could support the researchers to stay focused on the research subject.

Williams worked with people with learning difficulties in a People First (self-advocacy) organisation as I was proposing to do and called herself a 'supporter', which is traditional in People First organisations. However when discussing the research she was a supporter on Williams makes a point of describing it as inclusive rather than emancipatory and as co-research. From reading her work, it does not seem that Williams was assuming a role that focused on supporting people with learning difficulties to be in control of the research over herself. It seems that the focus was more on sharing power. The issue of the power imbalance between herself and the co-researchers with learning difficulties is not addressed explicitly in Williams' dissertation.

Although the subject is not discussed in Williams' chapter on support, at a different point in the dissertation she draws attention to a support dilemma in relation to other people without learning difficulties who worked alongside the researchers with learning difficulties on the project her dissertation describes. Williams states that there is a fine line between support and control and she puts it even stronger, between support and threat:

> …Mark [a person with learning difficulties] was about to move on to a new question when the supporter stopped him…In all these cases the line between supporting and threatening is very fine. (2002; 148)

Williams also strongly drew attention to how certain support responses could place people in what she describes as the 'interactional' position of children. This is how she explains it:

> 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 [with learning difficulties] to be placed in 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 [a 'staff member' without learning difficulties] effectively put Brendan into the position of a child who had to perform in talk – to make his own experience public. (2002; 151)

In relation to threat and infantalisation Williams has demonstrated how support practices can easily move into being oppressive and controlling.

Conclusion

The Department of Health (2001) claim in *Valuing People* that the social model of disability underpins their social care policy on services for people with learning difficulties. It is interesting to note that very little has been written anywhere about how the social model of disability can be applied to working with people with learning difficulties. However, recognising the oppression and exclusion that people with learning difficulties face, and providing support (that they are in control of) to address this, seems to be a wholly appropriate way of

applying the social model of disability to supporting the self-empowerment of people with learning difficulties.

From the literature on the subject it seems that, in relation to 'normalisation', there is a need for those supporting the self-empowerment of people with learning difficulties to follow one particular interpretation of the word and work away from another. An interpretation of 'normalisation' that involves supporters setting normative agendas to modify the behaviours of people with learning difficulties is not compatible with the social model of disability. However an interpretation of 'normalisation' that involves supporting people to have the same 'ordinary' or 'normal' rights and choices as non-disabled people in society is compatible with the social model of disability.

Supporting people to be 'independent' is a common aim within social care policy for people with learning difficulties. However it seems from the literature that, like 'normalisation', people supporting the self-empowerment of people with learning difficulties need to choose one interpretation of this word over another. It can be unhelpful to understand 'independent' as meaning doing a task without support. People with learning difficulties may need support to lead the lives they choose. An interpretation of 'independent' that includes 'having control over the nature of received support' is more helpful to use when working to support the self-empowerment of people with learning difficulties. This interpretation of the word is also compatible with the principles of access inherent within the social model of disability.

Interpretations of both 'self-advocacy' and 'self-advocacy support' vary. Some authors seem to interpret the meaning of 'self-advocacy' as individuals with learning difficulties developing the skills to speak up for themselves. Other authors interpret self-advocacy as a movement and/or define self-advocacy as the collective empowerment of people with learning difficulties. These two interpretations need not be incompatible with each other, as self-advocacy groups can support both individual self-development and the collective empowerment of people with learning difficulties simultaneously.

In relation to supporting the self-empowerment of people with learning difficulties it seems that the most effective stance to take as a self-advocacy group supporter is to support people with learning difficulties to be in control of their own group and the support they receive. Analysis of the literature on self-advocacy and self-advocacy support has led me to conclude that this is not the approach taken by all self-advocacy group supporters. Much of the literature suggests that supporters set the agenda of the group and teach 'self-advocacy' skills.

A minority of the literature on self-advocacy promotes the idea of people with learning difficulties being in control of the group and the support they receive. However, how the supporter could best behave to provide effective support for service users to be in control in this way, and the challenges inherent within this support role, have not been the subject of previous research. My own research focuses on issues connected to supporting people with learning difficulties to be in control of their own agenda and group. Therefore my

research has the potential to make a positive contribution towards the literature on self-advocacy support as well as the literature on supporting people with learning difficulties to undertake their own research.

Current Department of Health policy (2005) (2001) on social care and social care in relation to people with learning difficulties directs service providers to involve service users in the management and development of social care services. While in principle this is compatible with the self-empowerment of service users, in practice it may not be. While the balance of power rests with service providers, service user involvement can be tokenistic and do little or nothing to give more power and control to service users around determining the nature of the services they receive.

In order to counteract this situation and redress the balance of power, service user researchers have promoted the idea of disabled people organising themselves to address their disempowerment and develop social care policy and practice. In relation to research this principle has been developed into user controlled research, which has its roots in emancipatory disability research and survivor research.

Very little research that claims to be user-controlled has been undertaken by people with learning difficulties and what has, has been discussed within this chapter. The majority of research that people with learning difficulties have taken an active part in falls into the category of 'inclusive research'. Even in relation to inclusive research, very little has been written about how to support

people with learning difficulties to hold control of research processes. Williams (2002) has undertaken the most extensive research into this subject and has illustrated that people with learning difficulties can take an active role across a range of research processes. However, despite noticing within her research how threatening and infantalising support can be, Williams does not address the issue of power and control within her own research (about the research she *shared* with people with learning difficulties). This issue is also not addressed within that shared research itself.

Within all of the research where a claim is made that the research has been controlled or led by people with learning difficulties, very little has been written about how the researchers were supported to gain and maintain control of the research. Upon closer inspection it appears that, on all but one project discussed in this chapter, the research had been shared by researchers with and without learning difficulties. There was very little discussion around how the balance of power was played out in these shared research relationships. On one project (The Learning Difficulties Research Team with assistance from Bewley and McCulloch, 2006; 8) a claim was made that the research was controlled by people with learning difficulties. However the writers explained in the text that the researchers with learning difficulties decided that everyone working on the research project was an equal part of the team.

Only in Hart et al. (2007) is a claim made that the research was chosen by, and the work of, a group of people with learning difficulties exclusively. This research was written up by an academic without learning difficulties and

(although the research supporter Buchanan has explained that it was approved by researchers with learning difficulties and subsequently altered) it reads as such. The research supporter on this project claims to have avoided controlling the researchers by not being involved directly in their research meetings. However other supporters were present at meetings, and how they supported people with learning difficulties to gain and maintain control of the research project is not made clear. Buchanan has only written a small amount about his role as a user-controlled research supporter and not addressed the processes of supporting researchers with learning difficulties to be in control of their own research project in any real depth. Therefore I can assertively claim that the subject of supporting people with learning difficulties to be in control of their own research is under-researched and my own research will be developing relevant new knowledge.

Chapter 3: Methodology

Introduction

As stated in the introduction, while working on this project, I aimed to find the most effective ways of supporting people with learning difficulties to be in control of a research group*. I also needed to develop appropriate ways of collecting data and writing about what happened during the time we worked together. Both of these aims affected how the methodology for this project was developed. The challenge facing me at the onset of this project was how to reconcile my emancipatory research aim of supporting people with learning difficulties to undertake their own research with the other aim I had of constructing qualitative research of my own. This chapter outlines the methodology I eventually developed for this project.

In this Chapter I discuss the importance of adopting an appropriate philosophical stance to research. Then there is an explanation of what emancipatory disability research is and discussion on the subject of research as 'production' and the current political climate in relation to emancipatory disability research. Then I explain how I reconciled an ethnographic approach with emancipatory disability research on this project. Critical ethnography is discussed here in relation to my research, along with the importance of adopting a reflexive narrative approach to research and shifting from observing research 'participants' to observing the process of participation. The challenge of employing an active voice in research is also discussed here,

along with reasons for revealing uncertainty within my own research process.

Developing a philosophical stance

Within the field of qualitative social research differing research paradigms
allow researchers to approach discussions from particular perspectives
(Bridges, 1998). These perspectives differ radically both in their
epistemologies and ontologies, forcing informed researchers to adopt a
particular philosophical stance in order to be consistent in their approach
(Crotty, 1998). When developing this methodology there was a need to make
decisions about the philosophical stance that would underpin my research.
Crotty (1998) has commented that often researchers 'throw' together
incompatible methodologies, methods and theoretical perspectives and I
aimed to avoid this situation.

Usher (1996) has discussed the meaning of and the relationship between
'epistemology' and 'ontology'. He claims epistemology has traditionally been
concerned with distinguishing what is and is not knowledge and differentiating
between different types of knowledge claims. He asserts that, on the other
hand, ontology traditionally has been about what exists and what can be
construed as reality. Usher (1996) states that ontology and epistemology are
related for the following reason. When making claims about the existence of
phenomena there may also be a need to demonstrate how it is known that the
phenomena exist. Usher also claims that often the underling epistemology of
a piece of research is taken for granted because an assumption may be made

that it is unproblematic because it is positivist/empiricist in its nature; and as such constructed on the basis of the existence of meaningful reality without the operation of any consciousness. Taking this view allows positivists to view their research as free of individual subjectivity and bias (Denzin and Lincoln, 2000). Because of the credibility and power afforded to this particular philosophical conception within, for example, areas of psychiatric and other clinical research, researchers working with the backing of particular institutions that take this approach for granted may have little, if any, pressure placed upon them to justify their philosophical stance (Turner, 1995).

While pointing out that any definitions of qualitative research have to work within a 'complex historical field', Denzin and Lincoln (2000; 3) have offered the following generic definition of qualitative research:

> Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible.

Researchers who draw upon openly interpretive epistemologies such as constructivism, where there is no meaning without a mind and meaning is not discovered but constructed and subjectivism, where meaning is imposed on the object by the subject (Crotty,1998) are not claiming complete objectivity. By definition, their research results cannot be totally separated from their personal interpretations as their research is *openly* a construction that has been influenced by who they are. Denzin and Lincoln (2000) have claimed that within all qualitative research, the practice of interpreting findings and making sense of them is both political and artistic. As such qualitative

researchers may be required to justify the validity of their research as knowledge as opposed to, for example, mere anecdote. Certainly as a PhD student undertaking interpretive qualitative research there was a need for me to do this.

Engaging with an emancipatory paradigm

I mentioned in Chapter 1 that finding out about emancipatory disability research while undertaking an MA in disability studies led me to want to support people with learning difficulties to undertake their own research. This next section explains what this emancipatory paradigm is and how I set about relating it to my broader aims on this project and my own research.

It has been argued that emancipatory approaches are part of a separate research paradigm. Oliver (1992) has postulated that there are three main research paradigms: 1. positivist, 2. interpretive and critical enquiry and 3. praxis or emancipatory research. He stated that while a great deal of harm has been done to disabled people in the name of objectivist/positivist research, the interpretive alternative has not been of much use in actually changing policy or improving the lives of disabled people. He has pointed out that interpretive researchers have benefited by rendering faithful accounts of disability but when the research is over, they move on and the disabled research participants can remain in the same position. He challenged the

producers of disability research to engage in research that would make a real difference to the quality of disabled people's daily lives, claiming that the social relations of research should be changed. He urged researchers to struggle together with disabled people to (a) challenge the oppression they experience in their daily lives and (b) to support disabled people to control the direction of the research. Barnes (1992; 123) takes a similar position on the above issue. While recognising that interpretive or qualitative research techniques can be fundamental to emancipatory research, he argues that:

> …their usefulness depends ultimately on the integrity of the researcher and their willingness to challenge the institutions that control disability research.

I would argue that not all interpretive researchers working outside of an emancipatory paradigm have made little difference to policy. For example Rolph and Atkinson (2006) have discussed how the work of Oswin (1971; 1978), who put her career at stake to illustrate what was happening to children with learning difficulties within long-stay hospitals, profoundly influenced the move towards the deinstitutionalisation of people with learning difficulties. However when I started this project I wanted to combine working towards a PhD with a project which aimed to be of tangible and practical benefit to a specific group of people with learning difficulties. I looked initially towards supporting user controlled research, as I could see that working in this way would allow me not only to construct my own research but simultaneously to support people with learning difficulties to define and undertake a research project of their own.

At points in this dissertation I refer to the research project I supported as being user controlled. Turner and Beresford (2005) have pointed out that fundamentally the aims of 'emancipatory disability' and 'user controlled' research are the same, and that the historical starting point of user controlled research is emancipatory disability research. However, a major focus of user controlled research has been the demystification of research processes for service users and the development of practical ways of enabling a wide range of service users (including people with learning difficulties who have been previously largely excluded from the disability movement) to access and control research projects.

Shakespeare (1997) has argued that there may be little point in producing emancipatory research as it may be rejected by the media and government as being less balanced and independent because of the ideological or prejudiced stance that underpins it. However, as I mentioned in chapter 2, there has been a marked increase of interest in the views of service users in recent years, and in the idea of service users shaping policy and practice within social care. The next section explains how emacipatory disability research is relevant in relation to the current political and social climate.

Writing on the subject of the difference a decade had made to emancipatory disability research, Barnes (2003) attributed this change to more than the critiques of disability research that have been made by the disabled people's movement. He pointed out that there were several other factors that had

influenced the growth in the participation, if not control, of service users in research. He claimed that the growing focus on market forces within research institutions and universities had perhaps the biggest influence on this process. He pointed out that there is an increased use of research data by policy makers, politicians and the media, and that the funders of disability research had in the main changed, from 1993 to 2003, away from government agencies who held traditional views of disability and research towards charitable agencies and trusts who prioritise user-led initiatives. He also pointed out that there is an increasing emphasis on user participation within the various National Health Services funded research councils, including Consumers in NHS Research Support Unit (now Involve) and The Social Care Institute for Excellence. In August 2008 I searched 'user participation' on Social Care Online and got 4038 results. This increased interest in service user participation is reflected in current Department of Health policy (2001; 2005).

In relation to the Department of Health's focus on supporting the inclusion and empowerment of people with learning difficulties, supporting people with learning difficulties to be in control of their own research has the potential to provide data that best reflects the interests and needs of people with learning difficulties, as they see it. This way of working also has the potential to further develop the inclusion of people with learning difficulties within the field of research. Finally, working in this way also has the potential to reveal support dilemmas that may impede people with learning difficulties from exercising

control over a project and also provide discussion about how these dilemmas may be overcome. Barnes (2003; 12) has pointed out that, over time, the rationale of emancipatory research has not changed. This is how he put it:

> The rationale of the emancipatory disability research paradigm is the production of research that has some meaningful practical outcome for disabled people. After all, emancipation is about empowerment.

However, what has changed is the position or status of emancipatory disability research, from an earlier 'utopian' perspective (Barnes, 2003; 6), to a fully viable (although still not without dilemmas for those who aim put it into practice) and effective way of practically approaching disability research projects.

The danger of adopting an individual model of disability and observing fragments of 'research subjects'

Often authors of research *on* people with learning difficulties are working with an individual model of disability. This is an ontological view or stance on who or what disabled people, including people with learning difficulties, are and how they can be responded to. The following quote by Oliver (1996; 32) describes the fundamental points that are present within this model:

> There are two fundamental points that need to be made about the individual model of disability. Firstly, it locates the 'problem' of disability within the individual and secondly it sees the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability. These two points are underpinned by what might be called 'the personal tragedy theory of disability' which

suggests that disability is some terrible chance event which occurs at random to unfortunate individuals. Of course nothing could be further from the truth.

Researchers who adopt an individual model of disability may not feel the need to reflect on how the physical and social environment can influence the behaviour of 'their' research 'subjects', choosing instead to address a specific and small part of the picture, e.g. the 'behaviour' of the research subject/s with learning difficulties.

While developing this methodology I came across a framework for 'anti-exclusionary research', that was developed by a range of people involved in different research situations that they defined as either 'emancipatory' or 'anti-discriminatory (Humphries et. al., 2000). I found it useful in the development of my methodology. Essentially Humphries et al. (2000) claimed that if research was to be anti-exclusionary the following components needed to be in place. The research should be linked to wider questions of social justice and equality. The research also needed to address issues of politics and power in relation to empowerment. Tensions within the research process (and how they were resolved, or not) should be made explicit. The political, social and institutional 'self' should be located within the research process.

The focus of my research was on how the social environment and my own responses impacted upon, or had the potential to impact upon, the levels of control people with learning difficulties had over their own research group. Therefore it was important that I was sensitive to, and that my research took

into account and addressed, the impact of the political and social environment in which this project took place.

Situating emancipatory research

Emancipatory research is linked to a tradition of participatory action research known as PAR or participatory research. PAR has been particularly influenced by the work of Friere (for example,1970) and is concerned with supporting oppressed people to achieve their aims (Thomas, 1993).

While acknowledging that participatory research and emancipatory research overlap and share certain characteristics, French and Swain (1997) have delineated distinctions between the two approaches. They state that while participatory research has grown from qualitative research methodologies and philosophical discussion about the nature of social reality, and in the case of research with people with learning difficulties, normalisation and community care policies, emancipatory research has grown out of the disabled people's movement redefining disability as a socially created phenomena.

They argue that while participatory research methodologies seek to reflect the views and opinions of research participants and ideally involve them in the evaluation, conduct and design of the research, emancipatory research methodologies aim to place research participants in a position of control over the entire research process in order that they may challenge, as they see fit,

the oppression they experience within society. They also argue that the difference between emancipatory and participatory research is that while participatory research is a research methodology, emancipatory research is not as such. They claim that emancipatory research is part of disabled people's struggle to have control over the decision making processes that impact upon their own lives.

Barnes (1992; 122) has succinctly defined the essence of emancipatory research with disabled people. The following statement by him demonstrates how this paradigm is inextricably linked with the social model of disability:

> Emancipatory research is about the systematic demystification of the structures and processes which create disability, and the establishment of a workable 'dialogue' between the research community and disabled people in order to facilitate the latter's empowerment. To do this researchers must learn how to put their knowledge and skills at the disposal of disabled people.

This project was emancipatory rather than participatory in so far as (as a supporter) I was putting my skills as a researcher at the disposal of people with learning difficulties and aiming to support them to be in control. My own research into issues connected to supporting people with learning difficulties to be in control within their own research project was not emancipatory in this sense. However it did have a broader emancipatory focus as I aimed to draw attention to issues that both impeded and supported people with learning difficulties to exercise control within an environment and over a research project. As such my research had the potential to make a contribution towards knowledge about supporting the self-empowerment of people with learning

difficulties. It also had the potential to contribute towards the demystification of certain structures that create disability for people with learning difficulties.

Research as production

Criticising Colin Barnes' discussions around emancipatory disability research Shakespeare (1997) has written about the reservations he had around whether research can be emancipatory, in as much as he was 'cynical' about any research being able to bring about major change. Shakespeare argues that if research is defined as a form of investigation that basically reveals what is happening (and may *incidentally* or *additionally* inspire or challenge people) then, in relation to any emancipatory ambitions the researcher may have, the best that she or he can hope for is that their research has the potential to contribute towards, or lend weight to, the arguments of those who are taking direct action to counteract the oppression of disabled people.

However Oliver (1999, 183) has argued for the creation of what he has defined as 'a new discourse which is based upon the idea of research as production' and states that framing research as production is vital in the construction of an emancipatory research paradigm. He outlines research as production in the following way:

> We do not merely deconstruct and reconstruct discourses about our world. Research as production requires us to engage with the world, not distance ourselves from it, ultimately we are responsible for the product of our labours and as such must struggle to produce a world in which we can all live as human beings'. (1999, 189)

However he states how difficult and threatening it is for researchers to reframe research in this way when he writes:

> It is very difficult to undertake research based upon the discourse of production not simply for operational or careerist reasons but also because of the intellectual backlash it is likely to provoke. (1999, 188)

This idea of research as production challenges the nature of what research is and is not. As Oliver has put it:

> The dominant discourse of social research for as long as it has been recognised as an appropriate means of knowledge production has been that of research as investigation. (1999, 183)

Godley and Moore (2000) have argued that there is currently a divide between research that appears to be valued by or valid within the academy, and research that is valued by the disability movement. In relation to supporting the resilience and self-organisation of people with learning difficulties, they have argued that there is a need to bridge the gap between activism and the academy and create room for inclusive research that fits into both camps.

I would argue that to some extent this research towards a PhD is viewed as a project that is broader than the critical analysis that is contained in this dissertation. This is because this project, as a whole, has been constructed in a way that has made it not only about investigation. A crucial element of this project was my role in actively supporting people with learning difficulties to undertake research on their own terms and be part of a broader research

community. Therefore, irrespective of my investigative research aims, supporting the researchers with learning difficulties *to achieve their aims* was, for me, an important part of, and a major responsibility within, this project as a whole.

However, purely in relation to this critical analysis that I have been calling 'my *own* research', I would not have been able to enquire into the subject of interpersonal support in the way I planned to without actively supporting people with learning difficulties to construct their own agendas and achieve their self-defined aims. Throughout the course of this entire project I have been aware that producing research towards a PhD and supporting people with learning difficulties to undertake research are separate aims. However, while these two aims are undoubtedly different, in relation to this project as a whole they are inextricably interconnected.

Supporting others in the process of emancipating themselves

Emancipatory research has been criticised as arrogant; as Kincheloe and McLaren (2000; 282) have put it in relation to critical emancipation (a specific variant of critical theory):

> …many have questioned the arrogance that may accompany efforts to emancipate "others".

It is important to note that other marginalised or oppressed people i.e. Black people, women, disabled people and gay and lesbian people have organised themselves to challenge dominant political hierarchies and normative views

that excluded or devalued them (Gamson, 2000). However I am not aware of any situations where people with learning difficulties work together to implement change strategically or raise awareness of their oppression and exclusion without needing some sort of support from people without learning difficulties somewhere within that process.

I would like to say that in relation to my support role on this project and what I have written about it, I have not been aiming to emancipate others. I have provided support to people who are involved in the ongoing process of further emancipating themselves and have written about it in the hope that it may be useful to others who share an interest in this subject.

Reconciling ethnography with emancipatory disability research

Discussions about the nature of emancipatory disability research e.g. Barnes (1992 and 2003) and Oliver (1992) outline ways that researchers can interact with disabled people to counteract the power that researchers have, or have had, over disabled research 'subjects' or participants, and state that research should be controlled by disabled people. However, they tend not to include discussion around rigorous ways of collecting, processing, analysing and presenting data**.** They leave it open to the researcher to define how they will do this. The following comments by Barnes (2001, 12) explain why:

> …all data collection strategies have their strengths and weaknesses. It is not the research strategies themselves that are the problem it is the uses to which they are put.

In addition none of the comparatively rare accounts of emancipatory disability research in practice, for example (Priestley,1999) and (Barnes,1991), were sufficiently similar to my own work to be able to offer me much guidance in their methodology. It is important to bear in mind that when I started this project in 2000, there was no research involving people with learning difficulties that claimed to be user controlled or to be an example of emanciptory disability research.

It became clear to me that the research methodologies and methods I would need to use could be rooted within paradigms that were not specifically aiming to be emancipatory. Therefore before I could begin data collection in earnest I needed to know that any methodologies or methods I chose to employ were wholly compatible with new paradigm emancipatory disability research.

I was seeking, right from the start of this project, to record as fully as possible in relation to my research questions, significant experiences that impacted upon the Research Group members and myself as their supporter, as well as my own reflections on the possible or actual consequences of these experiences, and how they might be responded to. Ethnography seemed to offer me a creditable way of working with this data. Tedlock (2000, 455) has summarised what ethnography involves in the following way:

> Ethnography involves an ongoing attempt to place specific encounters, events and understandings into a fuller, more meaningful context. It is not

simply the production of new information or research data, but rather the way in which such information or data are transformed into the written form.

Chambers (2000; 852) has defined what ethnography is in the following way:

I restrict my use of the term [*ethnography*] here to those varieties of enquiry that aim to describe or interpret the place of culture in human affairs. In other words, ethnography is principally defined by its subject matter, which is *ethnos* or culture, and not by its methodology, which is often but not invariably qualitative.

Davis (2000) has written about disability studies as ethnographic research with a focus on strategies and roles for supporting social change. He has drawn attention to several issues that were relevant in the construction of my own methodology. He argued that disabled people should be considered the experts on their own feelings and lives. In addition, he claimed that the reflexive process can lead to the construction of a story that represents the interaction between the ethnographer and the people they are studying (or in relation to my research, *working with*). He also claimed that in relation to disability research, ethnographers can make an important contribution by revealing the structural and cultural conditions in which self-emancipation can develop, or taken-for granted oppressive practices can flourish. All of the above points have informed how I have structured my research.

Hume and Mulcock (2004) have postulated that participant observation is the ethnographer's core methodology, and in relation to my own research on this project it was mine. However the focus I had on the people with learning difficulties I supported did not quite match up with how participant observation

is traditionally used.

In her description of the contemporary aims of ethnographic participation, O'Reilly (2002; 104) has stated that they range from spending some time in the studied community 'to full immersion in the culture of the group'. However, the purpose of participant observation has been described by Hume and Mulcock (2004; xi) in the following way:

> The rationale for this approach is that, by "being there" and actively taking part in the interactions at hand, the researcher can come close to experiencing and understanding the "insider's" point of view.

How my approach differed from the way ethnographic participant observation is more usually used was that I was not specifically studying the culture of the group of people with learning difficulties I was working with. I appreciated an 'insiders' view to empathise with them. However, my main area of study was *how I interacted* with the service user researchers, within their culture, while attempting to (a) ascertain how best to offer them support without controlling them, and (b) identify dilemmas inherent within this process.

I came to this project knowing, to some extent, all of the Research Group members. I was also familiar with the environment where we worked together as I had worked there for years as a self-advocacy supporter. As a self-advocacy supporter I aimed to support people with learning difficulties to empower themselves on their own terms, and I approached this research project with values and an ideology that was informed by my understanding of

and commitment to disability politics, and from a social model perspective. In addition I approached this project with emancipatory aims.

A classic criticism of ethnographers who are seen as getting too close to their research 'subjects' or whose views are perceived as being too biased in their subjects' favour is that they have gone 'native' (Angrosino and Mays de Perez, 2000). This term has imperialist and positivist connotations and was originally used to describe anthropologists who either lost or abandoned their academic focus when they became part of the culture they were studying, and for example, decided to live for the rest of their lives within the culture that they had originally gone to study (Tedlock, 2000).

I am aware that this accusation could be levelled at the way I have approached my research by those who think that this lack of distance could compromise my ability to be as academically rigorous and objective as possible with my data. However I would counter this by arguing that my values, ideologies and politics, coupled with my self-advocacy support role and the existing familiarity I had with my research environment and the service users I worked with have added to the validity and richness of my data.

Tedlock (2000; 467) has discussed how 'native' ethnographers (ethnographers who study the society they are part of e.g. a gay researcher studying gay "society") have contributed significantly towards producing a new ethnographic research where the boundaries between the observer and the

observed are blurred, and knowledge, experience and beliefs are integrated
into the research process:

> The observer and the observed are not entirely separate
> categories,…Knowledge and experience from outside field-work should
> be brought into ethnographic narratives; ethnographers should
> demonstrate how ideas matter to them, bridging the gap between their
> academic world and wide cultural experiences…Writing for and about the
> community in which one has grown and lived, or at least achieved some
> degree of insider status, should produce engaged writing centering on the
> ongoing dialectical political-personal relationship between self and other.

Taking this view into account, it seemed there was space within ethnography
to observe and analyse, not only the reactions of the people with learning
difficulties I supported, but also my own interactions and other forces that
impacted upon the service users and myself as their supporter in relation to
my specific aims on this project. This meant that I could represent the process
of being personally involved in what is a relatively unexplored way of working
and discuss the hurdles that the researchers with learning difficulties faced,
both in relation to gaining and maintaining control of their research group.

Shuttleworth (2004), an ethnographer who had worked for years as a
personal assistant to disabled men, and who also lived with and had friends
who were disabled, argued that while it could be seen to aid 'objectivity' to not
know or be involved with the research subjects at the onset of a project, this
could lead to a shallower level of understanding. He argued that the multiple
roles he occupied in relation to disabled people while he carried out his
studies served to bind him closer to them. This, he claimed, led to him
producing research findings that could not have been discovered without

being so intimately involved with members of the community he studied (who had requested that he produce research that advocated for them to some extent). However, he points out that critical reflexivity was an essential component of his research practice.

Shuttleworth used this process to explore quandaries inherent within the different statuses and allegiances of the multiple roles he held, as both a researcher and person in various types of relationship with disabled men that he was studying. He found that this not only led to a richer study of the subject he was focusing on (disabled men's sexuality) but also led him to question taken-for-granted assumptions within 'disability studies' and 'anthropology'.

Jaffe (1993) has written about how studying less alien cultures can intensify the ethnographer's reflexive experience because writing about people who we are closer to, and who might have an interest in our completed research, undermines any tendency that ethnographers might have to create an unproblematic self or other. Jaffe argues that this process facilitates ethnographers to recognise the political elements of anthropological practice and contributes to the goal of a cultural critique of our own society.

As a researcher who would argue against the feasibility of any ethnographic study being completely unbiased, I am not claiming that my research is. On the contrary, I am claiming that my research is inevitably biased as I would argue all social research is. However this does not mean that I planned to write down just whatever I thought. Thomas (1993; 16) has explained that as

ethnographers we should aim to be objective about the 'subjectivity of our subjects' which, in my research, included myself. However he explained that this does not mean we will be free of our own particular biases and perspectives.

Davis (2000) has explained that in the past many ethnographers falsely claimed neutrality and that currently ethnographers are expected to examine, during the course of the fieldwork, their own subjectivities and the part they play in their understanding of other people's culture. I aimed to take into account my own values and ideologies as I worked towards being as rigorous as possible about the validity of my data, by testing it and by avoiding polemical assertions. I also chose to adopt a reflexive approach towards the construction of my own research so I could examine the ways that my ideology and values influenced my research and what I chose to focus upon. I also aimed to take care not to exclude any data because it may have undermined any theory I had previously developed.

Critical ethnography

Denscombe (1995) has discussed how research that has an emancipatory agenda needs to be explicit about the principles that guide the research and be informed by critical theory. The methodology for this research can be aligned with 'critical ethnography'. This branch of ethnography is compatible with an emancipatory paradigm. Thomas (1993) has explained that critical ethnography is overtly political and that critical ethnographers do not speak *for* their subject but speak *on their behalf,* with the aim of supporting their further

empowerment. He points out that critical ethnographers aim to use knowledge for social change and that instead of aiming (within their research, as more traditional ethnographers can do) to suppress their political biases, celebrate how they can be used towards bringing about societal change.

Critical ethnography is a useful process for working with the day-to-day experiences, views and analyses of people with learning difficulties and relating them to historical, social and economic situations alongside the political observations and theories of the disability movement (and other groups who are struggling for inclusion or against oppression and prejudice). As Fontana and Frey (2000; 369) have put it, critical ethnography:

> ....relies on critical theory: it is ethnography that accounts for the historical, social and economic situations. Critical ethnographers realise the strictures caused by these situations and their value-laden agendas. Critical ethnographers see themselves as blue-collar "cultural workers" (Giroux, 1992) attempting to broaden the political dimensions of cultural work while undermining existing oppressive systems'.

By adopting a critically ethnographic approach to transforming data into text within this research, I have been able to give an account of a process of enquiry and action that I have been, and continue to be, involved in. I could set the research within a time frame and context; relating it to the development of disability politics; the self-advocacy movement; current policy; the nature of current services; research theory; and the personal, experiences, perspectives, and understandings of both research participants and myself. I envisaged a way of working that allowed the reader to become aware of the above issues, through reading what would hopefully be a

convincing written construction, which aimed to contribute in some small way towards developing the support of people with learning difficulties.

The model of reflection I was guided by on this project was critical reflection, which Fook (2004) has argued, can have transformative effects when teamed with reflexivity and critical theory. Fook has explained that the focus of critical reflection is on power, where it is held and how disempowered people can be supported to work against fatalist thinking and make steps towards further empowerment. He argues that critical reflection can also be used by practitioners who work with service users to expose how they participate in constructing power by allowing them to focus upon contradictions and conflicts (in relation to where power is situated within their area of practice) which previously have not been explored or deconstructed. This model was clearly appropriate for reflecting upon both the focus of my own research and my face-to-face practice of supporting people with learning difficulties to further empower themselves.

A reflexive narrative approach

I decided to adopt a reflexive narrative approach to this research. Alvesson and Skoldberg (2000; 39) have discussed the relevance of adopting a reflexive approach to research. They stated that:

> There is no one-way street between the researcher and the object of study; rather, the two affect each other mutually and continually in the course of the research process. A positivistic conception of research,

according to which the object is uninfluenced by the researcher and the researcher is unaffected by the object, is thus untenable.

This way of situating myself within the text would serve several purposes. It would enable me to have a way of documenting ongoing unpredictable processes and circumstances including interactions that I observed, was personally involved in or told about. In addition, this way of gathering data and constructing an account from it would not require me to take the hierarchical stance of objective 'expert', instead I would be able to document mistakes I made. I would also be able to document the emotions involved in the process, for example apprehension, confusion or frustration, not that they were interesting in themselves, instead these aspects of the research process contribute towards a more comprehensive 'realistic' picture of a particular struggle. Illuminating this process could enable the research to resonate with or be useful to others who are interested or involved in the messy and emotionally demanding process of supporting people with learning difficulties to further their emancipation.

Revealing uncertainty

Tedlock (2000; 168) has discussed the issue of researchers revealing uncertainty about ethnographic writing and fieldwork. She has presented this issue in relation to feminist ethnography:

> Over and over again, women ethnographers, be they novices or experienced researchers, reveal their uncertainty about fieldwork and about ethnographic writing…Masculine ethnographic and

autobiographical intentions, on the other hand are often powered by the desire to unify a work by concentrating on one period of a life or a single characteristic of a personality.

Tedlock states that the reason for this difference in style is to do with the social conditioning of males and females. She argues that men write their autobiographies into self-assured progressive narratives and that women's narratives of their lives are often not progressive, more fragmentary and organised into self-contained units rather than chapters that connect through a linear chronological narrative.

While not wishing to challenge the notion of social conditioning having some influence on how male and female children grow up to be 'men' and 'women' it is important to acknowledge that feminist ethnography has challenged and improved upon certain reductionist conventions that needed to be addressed by all researchers whatever their gender. For example, it would be both unethical and reductionist to construct this thesis as 'a self-assured progressive' narrative when in reality I have struggled with uncertainty and 'not knowing' to construct it, and throughout the course of being involved with this research.

Conclusion

This chapter has described the journey of moving towards the development of a methodology that enabled this particular research to take place. It contains a discussion around philosophical and ethical dilemmas that faced me when I attempted to construct an academically rigorous critical analysis that was based around, and compatible with, supporting people with learning difficulties to be in control within their own research group.

It has been a struggle to get to this position, and I have attempted to demonstrate why it is important to be open about this struggle. All social research is a construction that is influenced by the views of the researcher. In addition, social research happens within an environment that is political and the dynamics of it are complex. Power and where it is situated is of paramount significance. It was important that as a researcher I addressed all the above issues while facing up to the responsibilities I had towards the people with learning difficulties involved in this project.

This methodology has explained how I ensured that my roles in relation to two different but interrelated research projects were philosophically and ethically compatible with each other. Over time I came to understand that the methodology that would suit this project best was to support user controlled emancipatory research with people with learning difficulties while undertaking separate research towards a PhD that drew upon critical ethnographic principles.

Supporting the self-empowerment of others is not necessarily compatible with producing research that is seen as valuable or worthy within the academy. On these two research projects my roles were different but interrelated. This chapter has explained how I ensured that they were compatible with each other and supportive of the self-empowerment of people with learning difficulties both in relation to the research project I supported and my own critical analysis towards a PhD.

In short what this methodology has done is to present one way of reconciling emancipatory user controlled research with participant observer ethnographic research. However, reaching this position was a complex process. This was because it involved unpacking and suitably reconciling aspects of different research paradigms to ensure that the theoretical, political and ethical perspectives that underpinned my own critical analysis were compatible with each other. I also needed to ensure that they were compatible with my aim of supporting user controlled emancipatory research and the further empowerment of people with learning difficulties. The next chapter explains the methods I used to put this methodology into practice.

Chapter 4: Research methods

Introduction

The methods used to undertake this project are presented in this chapter.
First the basic design of this research is outlined. There follows an
explanation of how I came into contact with the service user researchers and
supported the formation of the Research Group. Ethical issues relating to the
research methods of this project are also discussed here along with how I
separated my own research from the research I supported people with
learning difficulties to undertake. My role as a researcher is also explained,
along with aspects of my initial role as a research supporter coming into
contact with service user researchers. This chapter also includes a description
and explanation of how the research data for this dissertation were collected
and analysed.

Research design: a framework for the project

After constructing the methodology of this research I reached the position of
aiming to provide non-directive support to a single group of people with
learning difficulties to carry out and be in control of their own research. I also
aimed for this exercise to provide me with the data I needed for my own
research about the process of effectively supporting service users to be in
control of a research project.

In relation to the methods of this project I concluded that, both critical ethnography (Thomas, 1993; Soyini Madeson, 2005) and user controlled research (Evans and Fisher, 1999; Turner and Beresford, 2005) or emancipatory research (Barnes, 2001) would allow me to develop ways of supporting people with learning difficulties to be in control of research practices, while simultaneously observing this support process. In addition to observing my own responses and those of service user researchers, the above research approaches would also allow me to observe the responses of other professionals with whom the researchers and I had working relationships during the course of the project, and how we reacted to them.

Working in the above way would allow two related but very different outcomes or benefits of this project to occur. Firstly, a specific group of people with learning difficulties could benefit from participating in a range of self-directed research processes. For example, they could be supported to explore areas that interested or concerned them and to disseminate their research and act upon their findings in whatever way they chose. Secondly, a critical analysis could be developed that furthered understanding around how people with learning difficulties can be supported to be involved in user controlled research. Also, from a broader perspective, this analysis could explore how people with learning difficulties can be disempowered within face-to-face support relationships and how these processes can be counteracted.

Thomas (1993) has pointed out that critical ethnography can begin with a broad focus and be narrowed down over time as themes and interesting ways

of exploring those themes emerge. This is what happened with my research. However, the research questions and the design of this research provided an all-important framework that was fundamental to this project. This framework allowed me to focus on the overall subject (both in practice and as a subject for academic enquiry) of supporting people with learning difficulties to be in control and empower themselves, while also looking at how support can be disempowering.

Over time I was able to work with a single group of researchers with learning difficulties (there were five researchers overall but the numbers fluctuated between three and four researchers at any one time) and their research participants, within a user controlled self-advocacy organisation. I was able to support them to undertake their own research, which eventually became a book. The following is an extract from their book (published towards the end of this project) that explains who took part in the project, including both researchers and research participants:

> Twelve people with learning difficulties (including us) took part in the meetings where we talked through the questions together. Six people were black and minority ethnic. Seven were women. The youngest person was in his late twenties and the oldest was in her late fifties. Five people lived in residential homes. Five people lived in their own flats with support and two people lived with their parents. Five people were going to a day centre for people with learning difficulties. Six people were going to college courses for people with learning difficulties. Three people had paid jobs as self-advocacy workers. (Robinson et al., 2007; 24)

How the project was set up, and the researchers recruited to it, is described later on in this chapter.

The researchers with learning difficulties and I met weekly for approximately

three years and then had a break from working on the book which lasted over

a year, whilst a suitable publisher was found. We then met again (irregularly,

as and when was needed) to respond to the suggestions of the publisher and

organise aspects of the book launch. In short, we kept going until their book

was published at the end of 2007. We still work together fairly regularly as

Research Group members are sometimes asked to give presentations and

take part in other research projects or various ongoing consultation groups,

and I continue to support them. The next part of this chapter describes how

the Research Group was formed.

Supporting the formation of the Research Group

Soyini Madison (2005; 19) has suggested that when undertaking critical

ethnography it is useful to do the following:

> Start where you are. The experiences in your life both past and present,
> and who you are as a unique individual will lead to certain questions
> about the world and certain problems about why things are the way they
> are. It is important to honour your own personal history and the
> knowledge you have accumulated up to this point.

As a person who had worked and studied for a considerable number of years

with the aim of supporting the self-empowerment of people with learning

difficulties, this project was to some extent a development of both my working

practice as self-advocacy supporter and my studies. However, I had not

supported people with learning difficulties to undertake research before, and I

was not aware of any existing local research group of people with learning

difficulties. In order for this project to happen I needed to set up a situation in

which I could be in a position to support a group of people with learning difficulties to undertake their own research project.

Thomas (1993; 37) states that when a critical ethnographer is setting up a research project it is important to try to find ways to work with the people who will be in a position to provide the most appropriate data. As he puts it:

> Where and from whom we obtain data ultimately provides the meanings that shape the analysis. The task is to identify the best sources that bear most directly on the topic. It is crucial to identify the types of informants who possess an "insider's knowledge" of the research domain.

However on this project accessing the best data for my own research and providing suitable support for people with learning difficulties to undertake their own research were inextricably linked.

I came to realise that the most appropriate place to undertake the field work for my own research, and this project as a whole, was within a user controlled self-advocacy organisation. Barnes (1996; 110) has argued that those who research oppression can only be on the side of the oppressors or the oppressed and that there is no independent or middle ground. I reasoned (and also knew from personal experience) that having the research group based in a user controlled self-advocacy organisation would provide a greater likelihood of being able to side fully with the people with learning difficulties I intended to support. I also reasoned that it would allow the researchers with learning difficulties the freedom (in principle at least) to be in control of their own agenda and for me to support them to be in control of it.

As a starting point I approached the co-ordinator of People First West (a self-advocacy organisation I already had connections with and had worked in before, supporting self-advocacy groups). I explained how I wanted to support people with learning difficulties to do their own research. The co-ordinator then approved a second meeting where I met with a self-advocacy worker with learning difficulties, his supporter and the co-ordinator. The self-advocacy worker and the co-ordinator expressed an interest in the research project. In addition, the self-advocacy worker was interested in being one of the researchers.

At this early meeting it was decided that I would begin to look into funding options for the Research Group and then support researchers with learning difficulties who joined the project to make funding applications (the funding of the project is expanded upon in the findings chapters). No time limitations were placed upon the project as we were not sure how long the Research Group would need to complete their work.

Meeting interested service users

At this early stage it became clear that it would be necessary to explain fully to interested people with learning difficulties both what I was offering them and what I was aiming to get out of the project myself. There was also a need to explain my motivation for choosing to be involved in research with people with learning difficulties and my support position in relation to this project.

I had worked with people with learning difficulties within People First West for a number of years. The self-advocacy worker with learning difficulties (and all the people who subsequently became members of the Research Group) knew from personal experience something about both my way of supporting and the political views I held in relation to my support practice. However it was still important to ensure that I made clear to both the self-advocacy worker and prospective researchers what I was offering them on this project and what my political stance in relation to it was.

I drafted a statement in plain English about user controlled research and what I was able to offer people who might be interested in doing research while supported by me. This statement was intended to be accessible to the members of People First West I was meeting with. I discussed the first draft of the statement with my supervisor for this PhD, working on the wording and structure of it after our meeting. None of the people who came to the meeting had been involved in a user controlled research project before. In addition their experience of being involved in, and their understanding of, 'research' of any kind was quite limited.

If I had been writing a statement for people that did not know me so well, or with whom I had not worked before, in self-advocacy groups, there would have been a need to include more about how I support people as well as a brief CV I would have also talked at this early stage about confidentiality issues that might need to be agreed upon by the group members. Upholding confidentiality was a basic component of self-advocacy support and group

membership within People First West, and all of the interested parties had worked with confidential issues with me before. However it is important to state here that confidentiality issues were discussed and agreed upon when the Research Group started, and, were reviewed throughout the course of the project. The important issue of confidentiality is discussed in considerable depth both in their book and later in this dissertation.

The next meeting I attended in the People First Organisation was with three potentially interested people with learning difficulties. I presented a statement to them called 'Does anyone in People First want to be supported by Vic to do research?' As suggested by my supervisor I kept the statement short. However it touched on the key issues I felt I was responsible for communicating at this stage. This statement was meant to be supportive in enabling people to make an informed decision about whether or not they wanted to attend another meeting to continue finding out more about what the project could be and if they wanted to be part of it.

At the time I thought that once I had presented the statement and people had asked any questions or made any comments they wanted to, I would talk with them about how we could find out if other people wanted to consider joining the group. However the three people with learning difficulties who were at the meeting all decided that they wanted to do research together and that they did not want to invite any other people to join them. Their reasons for doing so are discussed in the findings chapters of this dissertation.

The above meeting served the purpose of providing space for people to ask

questions and air their views. It also enabled me to support people to begin

thinking about the possibilities that were open to them and the nature and

boundaries of my support. Here is the statement I presented to the people at

that meeting:

Does anyone in People First want to be supported by Vic to do research?
People do research to find something out or to prove as best as they can that something is true or not true. People who do research can be very powerful. They often write in books about the best way to do something.

For hundreds of years, doctors, psychiatrists and other 'professionals' have done research on people with learning difficulties. This means they have watched people with learning difficulties or asked people with learning difficulties questions and written books about how people with learning difficulties should be 'treated'.

Sometimes researchers have helped bad things to happen. For example up until not so long ago a lot of people with learning difficulties were stuck in hospitals. A lot of these hospitals were like prisons. Researchers who said the hospitals were a good place did not help people with learning difficulties.

Today people without learning difficulties still write about what should happen to people with learning difficulties. You might agree with some things that people write. You might disagree with other things. Most people with learning difficulties don't get to find out what is written about them in books.

I go to university to learn how to help people with learning difficulties to do research. Peter Beresford helps me to learn. He is a survivor of the mental health system. Peter and me are two of the people who believe that more people with learning difficulties should get the chance to do research and say what you find to be best for people with learning difficulties. People with learning difficulties know important things that no 'professional' without learning difficulties could know. For example people with learning difficulties know what it feels like to be a person with learning difficulties.

I want to help people with learning difficulties to do research, to find out about the things you want to find out about. You might want to write something for a book or a magazine. I want to help people with learning difficulties to try and make good things happen for people with learning

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difficulties. I will be supporting you to be in control of what you do. What you do and how you do it will be up to you. I'd like to help you to do what you want. This will be your research. I will just be there to offer help and support.

Although I am offering to help people with learning difficulties to do your own research it is important to tell you that you would be helping me by getting involved in this research. To pass my university research course I will have to write something about the work we do together. Of course I will keep things confidential but the people with learning difficulties that get involved in this project will have good ideas. If you want I will write your name next to any ideas that you have. It is up to you whether I use your name or not.

If you are interested in finding out more about doing research let me know and I will fix up a meeting and invite you to it. It would be good if you could let me know what times you are able to come to meetings. At this stage I would not expect people to know for sure if they want to get involved or not. All the interested people could get to meet each other and have a chance to ask me more questions.

Once people have decided, with my support, what they want to do research on and how they want to do it you might want to apply for money. It would be good if people with learning difficulties could get paid for this work. All I can say is that we can try and get some money. We might not be able to get any. People with learning difficulties will be in control of everything to do with the research project including what fundraising we do but I am happy to help with the less interesting jobs like writing up the funding application after people have told me what they want.

Ethical issues

The research methods developed for this project did not have to go before a

formal ethics committee as I started working on the fieldwork in 2001 prior to

Brunel University having such a committee. However, in order to protect the

well-being of the researchers with learning difficulties, the organisation that

the research took place in and all the people and organisations referred to in

both this and the service users' research, there was a need to address certain ethical issues. The ethical issues mentioned here are ones that needed to be resolved or addressed at the start of or before working with the group of researchers. As has been previously mentioned, further ethical issues in relation to supporting people with learning difficulties to undertake their own research are focused on in the findings chapters of this dissertation.

Writing on the subject of ethical issues in relation to qualitative research in health care, Goodwin (2006) has postulated that there are three 'particularly important' fundamental ethical issues that researchers need to address. These are 'anonymity', 'confidentiality' and 'informed consent'. All of these issues were addressed on this project and are discussed in this section. All the people with learning difficulties involved in this project had the capacity to give their informed consent. Although I am not entirely comfortable using clinical terms to describe the researchers, perhaps I should explain, in case there is any doubt that the researchers were capable of giving their informed consent, that all the Research Group members could be described as having 'mild' or 'moderate' learning difficulties. However, there were further ethical issues that needed to be addressed before this project could get underway. The preconditions of this research also involved ensuring that the research undertaken by people with learning difficulties was owned by them and that any potential conflict of interest I had, in relation to supporting them to research into what they wanted, in the way they wanted, was resolved before beginning to work with them. It was also important that the researchers on this project received adequate support to address their disempowerment when

they needed to, and that their support was, as Beresford (2005) has stressed (when discussing the ethics of working with service users who face difficulties and problems in their lives), sensitive to their needs and supportive of them. Ryen (2000) has identified the importance of reciprocity in relation to research and 'co-operation' with research participants. I was aware that I was going to benefit from the group (by using the work with them towards a PhD) and expected Research Group members to have their own views of the personal benefits for them of participating in the group. As such I aimed to respond to these supportively and with goodwill.

Informed consent

There was a need to ensure that people with learning difficulties were not pressurised to become or remain researchers on this project and that they could ask me questions at any time about my role in the research project. At early meetings I made it clear that it was entirely up to them if they chose to get involved in the project or not. It is important to remember that potential researchers were chosen to be invited by other people with learning difficulties and not me on this project, as were their research participants. People with learning difficulties decided which people to ask to join the research group or take part in the research as a participant. Research group members recruited and set up all of the meetings with the research participants and asked them all of the research questions that they had devised themselves. I was only there to offer support if it was needed on these occasions.

However, in relation to prospective research group members, I made every effort to support them to make an informed choice based on what being involved meant in relation to this particular project. Part of this process was to make clear to prospective researchers that I was there to support people to control all aspects of the time we spent together, and that it was equally acceptable to me if they chose to be involved or not.

I made it clear at these early meetings that I would value and support the self-directed work of people who chose to become involved as researchers. However I also made it clear then, and throughout the project, that there would be no pressure from me for them to continue to attend meetings or to stay within the room when meetings were taking place. It is important to acknowledge here that supporting people with learning difficulties to make informed decisions about what they really want to do is complex. In Chapter 5 I provide more detailed description of how I worked with this process.

Confidentiality and anonymity

There was a need to assure researchers that I would uphold confidentiality about them as individuals on this project (including within this dissertation). I did this and also asked for and obtained consent from members of the Research Group to refer to them (with their names disguised) in relation to my own research. I also explained that I would show them anything that I had written about them in my dissertation and that it would be totally acceptable for them to ask for it to be removed if they were not happy with it being there. It was helpful that I had already worked with all of the people who chose to

become Research Group members before on various self-advocacy projects. A certain amount of trust in relation to my upholding confidentiality had already been built up. I also supported Research Group members at the start of this project, and throughout the time we spent together, to make informed decisions about (a) levels of confidentiality in relation to what was talked about in their research meetings and (b) anonymity in relation to the data they produced. Again, certain aspects of how this happened are described in the findings chapters of this dissertation.

Avoiding damaging the study population

I do not wish to blame, hurt, offend or cause any damage to specific individuals or organisations that are referred to within this research. Therefore I decided to aim towards holding not only the service user researchers and participants, but all parties mentioned in this research in positive regard, or to put it another way (that has been discussed by Soyini Madison (2005;103) in relation to critical ethnography) 'with a loving, caring and responsible perception'. Soyini Madison has described this approach as 'loving perception' as opposed to 'arrogant' perception, which she has described in the following way:

> To perceive another arrogantly is to stand at a distance in opposition to an egalitarian relationship, thereby prohibiting any consideration for honest dialogue.

I also decided to disguise the identities of all individuals and organisations when writing up this dissertation. The subject of anonymity is discussed, in

relation to the research I supported the service users to undertake, in the findings chapter of this dissertation.

In relation to critical ethnography Soyini Madison (2005; 111) has pointed out that the researcher's main responsibility is towards the studied people. As she puts it:

> This responsibility *supercedes* the goal of knowledge, completion of project, and obligation to funders or sponsors. If ever there is a conflict of interest, the people studied *must come first*. In addition, researchers must make every effort to ensure that their work does not *harm the safety, dignity, or privacy* of those with whom they work.

I took this into account throughout the whole of this project and refer to times when dilemmas around the above issues and potential conflicts of interest arose, and how they were dealt with ethically throughout the findings chapters of this dissertation.

Preconditions of the project

An appropriate research agenda

Being both a *researcher* on this project (undertaking research of my own) and a *supporter* (on a user controlled research project) there was a need to avoid the risk of directing the supported group's work in order to carry out my own research effectively. This issue had to be considered when developing the

methods for this project. A starting point was to develop an agenda for my research that would not compromise or compete with any agenda the Research Group chose to develop. As my aim was to support service users to develop their own research agendas, it was also important that I came to this project with no preconceptions about the content of the research I was supporting people with learning difficulties to undertake.

The above aims, or preconditions of this research, were fundamental to this project. However they took time to develop and when I first started working on my own research I had not developed them in enough depth, or fully considered the conditions that needed to be in place, for them to occur. At this early stage I made the following false or unsuitable start to this project:

A few months before I began working with the Research Group I took on consultancy work within social services. Part of my role, as a person involved in a service development process, was supporting people with learning difficulties to give their opinions about the services they wanted.

At the time I thought that working with social services, to develop the participation of people with learning difficulties in decision-making processes might relate fairly comfortably to my research about supporting people with learning difficulties to undertake their own research. However it became clear that I needed to be in a different situation outside of working for social services if I wanted to support people with learning difficulties to have as

much control as possible over all aspects of their own research project. The next few pages explain why.

When developing the research methods for this PhD I used the social services work to reflect upon what needed to be in place in order to start supporting people with learning difficulties to be in control of a research project. These reflections are briefly presented here to illustrate research support preconditions that were essential elements of the methods of this research project as a whole.

Beresford and Evans' (1999) schema to evaluate degrees of service user involvement in research processes was useful when delineating the areas where Research Group members would need support when undertaking their own research. They have identified eight dimensions within research production. These are 'origins of research', 'benefits from research', 'accountability', 'the researcher', 'research funding', 'research design and process', 'dissemination' and 'research and action'. They have outlined the degrees to which service users can be involved in each area. Readers are invited to assess their own work against the schema. The schema focuses on the principle of service user empowerment.

Using the above schema it became clear that the work I was involved in within social services did not go far towards supporting the empowerment of service users. To begin with, while service users involved in this particular consultation process with social services, were invited to give their views on

the services they required, the idea for the research came from social services and not from the users themselves. I decided that any subsequent research I was involved in, undertaken independently of social services, should ensure that the origins of the research came from, as Beresford and Evans (1999; 674) put it: 'the users who are its participants' or 'from members of the broader user group/constituency whose members are to be included as the participants of the research'.

When working for social services in the above post I informed service users about the purpose of the research or consultation they were being invited to become involved in. However service users did not identify the benefits of the research. I decided that in future while working on this PhD, I should aim to ensure that service users were given adequate support to enable them to identify the benefits of any research they chose to undertake. This process would be inextricably interconnected with service users constructing the idea for the research.

While I and other employees of social services worked with service users to develop proposals for elements of service development, we were primarily accountable to senior managers within social services. I came to decide that I would aim to be accountable to members of the Research Group and People First West (a user controlled organisation). While service users had not been able to recruit and select their research supporter (as I had approached People First West to offer my services to them), people with learning

difficulties would be supported by me to do their own research and to be in control of all of all elements of the research process.

Also in the social services project, the final responsibility for the construction of the research findings and for any financial or other plans that were influenced by them rested firmly with social services. They were working to Department of Health directives and as such only had to demonstrate *some participation* in decision-making processes, and not concrete changes in the balance of power and control. I decided that I would focus on supporting people with learning difficulties to be in control of all aspects of the research project including analysing their own data, disseminating their research and acting upon their findings.

As I was aiming to be in a position where I could support people to criticise any services they chose to, being employed by social services would not have been helpful at that time. I needed to be outside of the 'services' to minimise conflict of interest in my role. Also being seen to be outside of 'services' could help towards people with learning difficulties feeling safer with me when telling me their views of services in confidence.

After the Research Group was set up I was offered further work with social services consulting with people with learning difficulties, including members of People First West. It felt important to turn this work down to avoid confusing members of the Research Group and/or jeopardising any trust they had in me. By working for social services at that time I would have been occupying two

conflicting roles. I would have had one role supporting people with learning difficulties to do the research of their choice, disseminate this research and, if they chose to do so, campaign in whatever way they wanted to (possibly in ways social services would not have approved of). Then I would have had another role where ultimately I would have been making directive requests as I would have been answerable to social services and expected to carry out tasks that were assigned to me by social services managers.

If I had attempted to be answerable to both People First West members and social services managers in any way I would have been in a difficult position. Freire (1970, 119) has described a person who occupies the above position in the following way, as:

> … an ambiguous being, an 'amphibian' who lives in two elements. Shuttling back and forth between the people and the dominant oligarchies, he bears the marks of both groups.

Freire was referring to populist leaders within the third world being manipulated by the elite to control the people. However, when discussing issues of control and emancipation in relation to people with learning difficulties, the above analogy and much of Freire's *Pedagogy of the Oppressed* (1970) is pertinent. In chapters 1 and 2, I have discussed, to some extent, that people with learning difficulties can be controlled within services. This subject is revisited in more depth within the findings chapters of this dissertation.

The subject of the user controlled research

I aimed to support Research Group members to choose the subject of their

research. As my supervisor at Brunel University put it at the time, the

researchers on a user controlled research project could choose to research a

subject that had no connection to 'services', such as 'motorbikes'. This non-

directive approach to the Research Group's agenda fitted well in one way with

the aims of People First West which, as already stated, was a self-advocacy

organisation. Therefore supporting people with learning difficulties to be in

charge of their own agenda within this context was not controversial as such.

However People First West had a values statement that included the

following:

> The purpose of [People First West] is to enable people with a learning
> difficulty to have a voice in society and to improve the quality of their
> lives… [People First West] works to achieve this purpose through: The
> provision of a range of services for people with a learning difficulty…
> seeking to build relationships with local government, health authorities
> and the community, through which the interests and needs of people with
> learning difficulties can be improved (People First West policy document,
> 1999; 3).

The aim of People First West was to support people with learning difficulties

to put their views across and to improve conditions for service users. It may

have been difficult, within People First West, to support people with learning

difficulties to research a subject that was unrelated to the aims of the

organisation. However, the researchers chose (with no directing from me) to

focus on what was happening in their lives and the lives of other people with

learning difficulties. This included their views on services and service workers, and recommendations for better service provision. While not being the focus of this dissertation, the Research Group's work and their findings are referred to in subsequent chapters of this dissertation in relation to research support.

Ownership issues

Part of my own research included discussing support practices for people with learning difficulties including my own. However I was supporting people with learning difficulties who were addressing support issues themselves and also relating their experiences of living as people with learning difficulties to me.

The issue of who was to own their research became clear at an early stage of this project. I was aiming to support people with learning difficulties to be in control of their own research and to keep their research separate from my own. Therefore it was a logical step to accept that their research was owned by them and People First as an organisation.

I was to own my own research, this critical ethnography, but it was important to recognise that Research Group members would inevitably influence the content of it. I expected my research findings and analysis to be informed to some extent by situations they were involved in, the issues they drew attention to, and the recommendations they made about the support they

wanted. Therefore there was a need to ensure that I correctly attributed Research Group findings to them and did not appropriate them for myself.

Data collection

From the start of this project I collected an array of complimentary data. This section explains the nature of the raw data I used and how it was collected; including what my focus was and the processes that came into play in relation to data collection. At this point I am still working periodically with members of the Research Group on various projects including publicising and disseminating their research. However, I stopped keeping my main raw data source, research diaries, three years after I began to write them *(*during the time I was developing the preconditions of this project), and twenty nine months after the first meeting with Research Group members. Also, with the exception of the interviews that I conducted towards the end of this project and the Research Group's notes towards the construction of their book, I did not collect any of the other raw data sources after this point. I stopped collecting data for two reasons: firstly because I had too much data for a dissertation of this size, and secondly because I had reached a point of saturation with the primary data and was not encountering anything significant that was new, just more of the same themes. It would be helpful at this point to list the different sources of raw data that I drew upon to develop my research.

- Reflexive/reflective diaries

- Tapes of Research Group meetings

- Minutes of Research Group meetings

- The Research Group's research notes

- Research Group correspondence and funding applications

- Minutes of meetings that the Research Group had, for example, with service managers and funders

- Interviews with researchers

The raw data I collected consisted of approximately 100,000 words of diary entries and dauntingly copious amounts of different secondary data, such as the minutes of various meetings and Research Group correspondence. In addition, I had hundreds of hours of Research Group meetings on tape from the time when we met on a weekly or near-weekly basis.

Observation techniques are often employed in ethnographic studies (Pope and Mays, 2006). I used participant observation as the main method for my research and, as I stated earlier, the research diaries I kept were my main raw data source. I used these diaries for two main purposes, to record my perceptions of what was happening in the Research Group in relation to my research focus and to reflect upon what I could do to best support Research Group members to be in charge of their own research agenda.

A fundamental aspect of ethnographic research is to work closely with people and attempt to understand their behaviour (Richardson, 2006). I endeavoured to do this and empathise with Research Group members and participants throughout the data collection process as I reported observations in my diaries.

Within my diaries I reflected on how I was being in relation to the service users I was supporting. This included both how I was reacting and how I was thinking or feeling in relation to them. I also used reflexivity throughout the data collection and analysis for this critical ethnography. Shehata (2006; 260) has discussed how reflexivity can be used by ethnographers to strengthen participant observation:

> Reflexivity further strengthens ethnography. Ethnographers need to scrutinize and analyze their interactions with the "natives" for what these interactions – additional "data points" if you will – can reveal about the "natives" and their social world.

Looking at my own interventions, and how I felt in relation to service users, contributed towards my understanding their world more. For example, questioning why I felt angry in response to the interventions of a service worker could lead to my noticing the disempowering aspects of a particular situation and to empathising further with the plight of a particular service user researcher.

Discussing the nature of critical ethnography, Soyini Madison (2005; 83) has argued that the process of examining and questioning the self is also an ethical stance:

> If as Socrates said that the unexamined life is not worth living, one of the greatest attributes of the critical ethnographer is the need for critical self-reflection in our contribution to help make life worth living for ourselves and Others. To examine one's own life and intentions – to question and observe the self – in the process of questioning and interacting with Others is an ethical stance, because it requires consistent self-evaluation and monitoring relative to our integrity, effectiveness, and political commitment toward the end of helping life more worth living.

The significance of this type of ethical reflection in relation to user controlled research support is discussed in the findings chapters of this dissertation.

I practised reflexivity around how this critical ethnography could best contribute towards the literature on supporting the empowerment of people with learning difficulties. However, because of the emancipatory nature of this research there was also an additional use for reflexivity on this project. I used it in an attempt to notice, constructively act upon and record ways of working that either were or could possibly be supportive of the further self-empowerment of Research Group members and their participants.

Wolcot (1994; 157) has written the following about aiming, as an ethnographer, to be objective while recognising that this is impossible to achieve:

> We discussed objectivity and invariably decided in its favour – that is, to strive for it, at the same time acknowledging that we cannot actually attain it. But we confined the issue to objective reporting…

When gathering data in my diaries I aimed to be as objective as possible about what I was observing. For example I aimed to clear my observations of any subtle attempts on my part to dramatise a situation, overemphasise a particular aspect of an event, or come to any rash conclusions.

In an attempt to be as clear as possible I wrote diary entries as soon as possible after Research Group meetings or related events. Within the research diaries I was able to record what Shehata (2006; 260) has called 'thick culture'. This is the meaning she places on the term:

> …ethnography is best suited to explore what cannot be seen (or easily measured or counted): culture (meaning, ideas, categories, concepts, narratives, discourse and so forth). And I mean here "thick culture," not the "thin culture" of values, attitudes, and opinions that much survey research measures.

I not only used the research diaries to report my observations of what happened in meetings with the Research Group I also made separate diary entries to explore concepts in relation to my observations as and when they arose. On average I wrote in the diaries once or twice a week during the time I kept them. I recorded my observations of the weekly meetings in the diaries aiming to include as much detail as possible.

The other sources of data mentioned above all came into play when analysing the data and writing up the drafts of research notes that over time became the chapters of this dissertation. The minutes of meetings were useful for the dates and times particular subjects were discussed and for discerning the focus and agenda of particular Research Group meetings. Analysis of the

tapes provided further illustrations of issues arising in my reflexive diaries and minutes of meetings, as well as providing independent corroboration of how members of the group were responding to my interventions. The Research Group's research was useful for discerning what was important to Research Group members and their research participants, what their views were about the support they wanted and what was happening in their lives.

Data analysis

I started the process of analysing the data, from the very beginning of this project, in my diaries. In these diaries I documented and reflected upon my experience of what had happened within the Research Group and in relation to my supporting the Research Group. What I chose to focus on was initially informed by my early research proposal and then, very soon, by my developing and more final research questions.

From early on I was also able to begin the process of coding the data or grouping it into analytic units and working on describing findings. Throughout the course of this whole project this was never a linear process. Anatola Robinson (1994; 41) has described how, when generating ethnographic theory analysing data, collecting data and formulating questions overlap. As she puts it:

> In an ethnographic study the formulation of questions, gathering of data and analysing of data all overlap...I find myself working like a quilt maker, putting pieces together to support all sides while keeping in mind a general but constantly shifting sense of the overall colour scheme and design.

The analysis of the data and the collection of it were also interrelated. Thomas (1993) has explained that the process of collecting data can lead to the project's focus becoming clearer as the critical ethnographer begins to develop a better understanding of the cultural nuances that are being observed. Thomas (1993; 43) also describes the process of defamiliarisation that critical ethnographers need to go through to analyse their data. As he puts it:

> Interpretation of data is the defamiliarization process in which we revise what we have seen and translate it into something new. We bring the tentative insights we have gained back to the centre of our attention… Defamiliarization is a way of distancing ourselves from the taken-for-granted aspect of what we see and allowing us to view what we have seen more critically.

When I was working face to face with Research Group members I became increasingly sensitised to the research area. This was at times a problem for me as sometimes I became stressed by, or angry about, what I observed and felt in relation to it. This issue is documented in further detail in the findings chapters.

Anatola Robinson (1994; 58) has explained how the interdependent stages of ethnographic study and analysis can be confusing. She maintains that the way not to get lost in the sheer amount of detail is to keep focused on a research goal. As she puts it:

> …interdependence is perhaps the most exciting as well as the most frustrating and confusing element in undertaking an ethnographic study. The amount and variety of data requires that an overarching goal be kept in mind otherwise you can drown in the sea of details, with no land in sight. However, the authenticity of an ethnography arises out of the difficult dialectic between this sort of structure and openness to the details

and to the flow of the material – between planning and flexibility, or between a clearly defined pathway and a willingness to deviate from that path when the data demand a detour.

Throughout the course of this project I retained a committed interest in the ways that people with learning difficulties can be controlled and what I could do to both not control them and support their empowerment. My interest in that subject, in relation to my research questions, was the overarching goal that kept me focussed in my analysis and motivated to keep going through the difficult and complex process of analysing my data and writing up this dissertation.

Although the research diaries were my main source of raw data, from early on they felt like *my* interpretations, *my* observations. This is why the other forms of data that are mentioned in this chapter were also important in this analysis**.** It was particularly important that my observations about support for the self-empowerment of people with learning difficulties or the ways that people with learning difficulties are disempowered were consistent with what people with learning difficulties involved in this project said, or how they behaved.

I have already mentioned the importance of triangulation in relation to my research. However in practice, on this project, triangulation was not only a useful tool to convince others that the argument that I was developing through my data analysis was valid, it also served the purpose of informing and deepening the analysis that I was developing in my descriptions of the data. In other words, the more corroborating and convincing strands there were to an argument, the more I became convinced of the validity of it.

As a whole my research enquiry was iterative (Richardson, 2006). In other words I collected data, analysed it and then collected more data to strengthen or test a finding or argument. The conceptual framework my analysis was based upon was what I encountered in relation to my research questions. These questions became clearer as the project progressed but I remained concerned with the same issues.

From very early on I started drafting and refining the analysis of the project, and trying to group analysis into themes and then chapters (which were arranged and rearranged as the analysis became clearer and I reached conclusions). As I worked towards the final stages of my analysis I was able to continue drawing upon these drafts, my diaries, the Research Group's research notes, minutes of Research Group meetings, tapes of their meetings, and Research Group correspondence as basis for triangulation. Through constantly comparing the different sources of data I was able to ensure that my final analysis was as rigorous as possible. In order to corroborate or validate certain emergent themes about what the service users appeared to want from me as a supporter, I asked them questions and interviewed them on the subject. In addition I asked other supporters how they might feel in specific support situations that I felt, for example, emotionally uncomfortable in, to see if they too would find the situation difficult or stressful, and why.

Throughout the course of this research I made every effort to ensure that I did not omit important data or avoid confronting conflicting ideas. I also tried to be as transparent as possible about how themes emerged and why they were included in this research. This transparency has allowed me to show throughout the course of this dissertation how my analysis was developed in relation to the research environment and the views and responses of the service users who had a part to play in this project.

Conclusion

This chapter has described the methods employed in this research. In it the basic structure or framework of the project as a whole is explained, along with the separate aims of the two different research projects and the methods of my research towards a PhD, including the iterative process of data collection and analysis that was used. Constructing the methods of this research involved the bringing together of both ethical and functional aspects of supporting self-advocacy - with an emancipatory disability research focus and a critical ethnographic research practice.

Within this chapter I have documented ethical issues that needed to be addressed during and before coming into contact with the researchers with learning difficulties. I have explained how I supported potential researchers within a self-advocacy organisation to make an informed decision about whether or not they wanted to think about becoming involved in a research

project. I only approached one person with learning difficulties, and he approached the other people who decided they wanted to join what became known as the Research Group.

However, I needed to ensure that researchers were making an informed decision to be supported by me on this project and that issues of ownership (of their research) and anonymity were addressed. I also needed to explain my research to them and ensure that they were making an informed decision about their involvement in that. On this project, as part of supporting people to make an informed decision about their involvement, I explained in plain English the nature and politics behind user controlled research and what my role would be in essence. I also explained that there was no pressure from me to either get involved or stay involved, and that my role was to support them, and not direct them, through any research project they developed. There was also a need on this project to aim towards ensuring that conflicts of interest between my needs as a researcher and the needs of the service user researchers were eliminated. A starting point on this project was developing an agenda for my own research that would not compromise or compete with any agendas that service user researchers chose.

In relation to my own research, this critical ethnography, I chose to work with a wide variety of data. Reflexive diaries were one of my main sources of data. However I also used minutes of Research Group meetings and notes. In addition I used tapes of meetings and interviews. All of the above additional data sources were used to provide independent corroboration of how

members of the Research Group were responding to my interventions, and to

further identify dilemmas, and how I responded to them within my support

role.

Chapter 5

Findings 1: The complexity of support

Introduction

The findings in this chapter have grown out of a process of critically reflecting upon dilemmas that came to light when actively supporting service users to be in control of their own research group. Drawing upon a variety of data, including field diaries, Research Group notes and minutes and interviews, this chapter sets out what this ethnographic research revealed about challenges that complicated the process of supporting people with learning difficulties to be in control of their own agenda in this context. This chapter also documents what analysis of this research implied about ways that user controlled research supporters might constructively behave, think and represent themselves when interacting with service user researchers.

Chapter 2 explained that the subject of supporting people with learning difficulties to be in control of their own agenda (whether or not the focus is on supporting research) is under-researched. However, supporting people with learning difficulties to be in control of their own agenda (and in particular a research agenda) remains complex. Within this chapter an attempt is made to

unpack a support process that has not been well documented or taken seriously as a subject for research before, and which in this case has been informed and shaped by the ongoing development of this critical ethnography. The names of all the people (with the exception of myself) and place names mentioned here have been changed to ensure confidentiality.

The findings in this chapter are presented within the context of my non-directive approach to research support that aimed to be compatible with the social model of disability. To explain further, this chapter presents what I found out about the effects of being a user controlled research supporter in practice as I reflected upon dilemmas within the support process and adjusted my role accordingly. This process was developed in response to both the reactions and requests of the researchers with learning difficulties within the Research Group, and their accounts of what they had to deal with outside of it, and reflecting upon the emerging findings of my own research.

The findings in this chapter all focus on data that, upon reflection and analysis, furthered my understanding of how the user controlled research supporter can behave and think to support people with learning difficulties interactively to be in control of their own meetings and agenda. Over time it became clear that these findings could be grouped into two sections, under two main headings. Both sections are about the user controlled research supporter's stance in relation to face to face work with people with learning difficulties.

The first of the headings is '**Non-authoritarian support'**. This first section presents what I discovered about the process of, and strategies for, avoiding imposing authority over researchers with learning difficulties. Throughout the course of this project, Research Group members often discussed authoritarian interpersonal 'support' responses in their lives outside of the group. This had implications for how I, as a person without learning difficulties in a professional support role, needed to respond within the Research Group. Findings about the nature and effects of authoritarian 'support' in the lives of Research Group members and their participants are explained in this section. These are presented alongside implications for ways of interacting with people with learning difficulties that may be supportive of them counteracting their disempowerment to some extent. Examples of support practices I adopted (reflexively) in an attempt to counteract being in a position of authority over the group or to support the service users to be in control of the group, are also presented here.

This section draws upon four main data sources. Tapes of Research Group meetings have been analysed for two main purposes: to present what service users said about authoritarian 'support' responses in their lives, and to demonstrate (in relation to potential non-authoritarian and non-directive support) how Research Group members and myself worked together at times. Analysis of notes from Research Group meetings also illustrates what Research Group members and their participants focused upon in their meetings, both in relation to the authoritarian support they received and the support they appreciated and wanted. This section also draws upon analysis

of diary entries, that focus on support dilemmas and concerns, and analysis of interviews with Research Group members undertaken later on in the research process to clarify and add depth to findings.

The second heading in this chapter is '**Non-directive support in practice'**. The findings in this section all relate to the subject of reconciling non-directive support with offering information to support people with learning difficulties to make informed choices within the Research Group. They focus on the following two issues: identifying the areas of influence I had as a research supporter who was aiming to work in a non-directive way within an emancipatory framework, and identifying the ethical reasons for responding in particular ways that had the potential to have some influence upon the agenda of the Research Group.

This section draws upon the analysis of two data sources: (a) tapes of discourse between myself and Research Group members from Research Group meetings and (b) diary entries. The tapes revealed how and why I could potentially influence the agenda of the group. The diary entries led me to conclude that, in certain circumstances, it was ethically important to behave in ways that had the potential to influence the Research Group's agenda, despite maintaining a non-directive person centred philosophy.

The following table lays out the main themes and subheadings within this chapter:

Non-authoritarian support
- The researchers' experience of authoritarian support   - An imbalance of power between researchers and those who support them   - Making it safe to confront or disagree with the supporter   - Humour and friendliness in research support   - Research support and miscommunication   - Research support and open-ended questions   - Trust, confidentiality and research support
Non-directive support in practice
- Support and interpreting information   - Support for informed choice   - The supporter's influence: offering opinions

Non-authoritarian support

The researchers' experience of authoritarian support

Throughout the course of this project all of the Research Group members had direct experience of social care and educational services and projects outside of the time they spent in the Research Group. For example, four people had contact with social workers during the time, and two were students on college

courses specifically aimed at people with learning difficulties. One person attended a day centre. Three people had counselling from a psychologist (who worked specifically with people with learning difficulties). One person lived in a residential home and three people received domiciliary support.

The Research Group members had also all used a range of services for people with learning difficulties in the past. Two of the people who had their own flats had lived in residential homes. Two of the people who no longer attended a day centre for people with learning difficulties had done so in the past. Another two had lived in residential colleges for people with learning difficulties.

During the course of the project all of the Research Group members chose to talk about how they felt they were (or had been) controlled or mistreated by social care staff and also (for two researchers) by family members. This subject became a major focus of their research and is discussed at length within it. They all recounted incidents from their past 'support' that they felt were unjust. Some of these were very abusive, like the following example given by a Research Group member who used to live in a children's home with her younger brother:

> Mary: My brother and myself, we used to get locked in the cellar for two days, with no food, just bread and just dry bread and water and they used to treat us as we were, treat us very nasty in those days. My brother and I didn't do anything wrong. They just picked on us and other children. There was about six children and us locked in the cellar and there was all rats and things in there and I was really treated badly and while I remained there. And when I was twelve I had a social worker and when I got out of there, and if I didn't get out of there I'd be in an institution now,

and my sister was really upset and I was upset. And then I went into foster care. (Interview 13.2.08)

During the course of this project I heard other accounts of Research Group members being abused in the past. All of the women researchers in the group recounted being raped (two of them during childhood). Also two research Group members recounted being hit by support staff.

Research Group members also talked about how much control social care staff had over their lives in the past. Here is an example:

Pearl: I was living in the convent. Em when I used to live in the convent the staff used to treat us very strictly. We wasn't allowed to go out or anything like we do now, independently. We had to tell people, tell em um the nuns where we was going but we wasn't allowed no men there because it was for the girls who. We wasn't allowed to have any boyfriends going back to the convents with us or staying with us for the night. (Interview 13.2.08)

They talked about the controlling aspect of their 'support' in the present as well. In the following example Bill is explaining how he felt controlled within the college he attended:

Vic: Do you feel like you do what you want there at college?
Bill: No, never do what I want at college, always do what they want.
Vic: What do they want you to do?
Bill: Sit there like, sit there being good student. Not causing trouble.
Vic: Not causing trouble.
Bill: No…
Vic: What do they say to make you feel like that, or do?
Bill: Um, they feel they're in control of my life. (interview 13.2.08)

The themes of feeling out of control of their own lives, and experiencing controlling forms of support, resurfaced often in Research Group meetings

and were a key focus of their research. Here is another example. One participant who was interviewed by Research Group members said that she was woken up in the morning by care staff shouting at her to get out of bed:

Get up and go to work, don't like it. Get up and have your breakfast.

She went on to say the following:

My carer boss me about and the centre boss me around (Research Group interview).

The person with learning difficulties who made the above comments had high support needs. She lived in a residential home and attended a day centre. Her use of language was limited, in relation to the Research Group members. None the less the above comments make clear that she was aware that she was being controlled (or as she put it, 'bossed about') and that she didn't like it. One implication of this strong and recurring theme in the data collected in Research Group meetings and interviews with service users was that effective research supporters would need to avoid such manipulation.

The above examples illustrate just a few of the ways that service users on this project experienced routine control in their lives; whereby they were expected to fit in with rules, routines or programmes of education that were set out for them by others. A large percentage of the people who attended People First West attended college courses for people with learning difficulties. This was one of the few options that were open to many people with learning difficulties

in the borough who needed support during the day. When I asked Bill why he went to college this is what he said:

> Vic: Why do you go to college?
> Bill: Nothing else to do in London you know.
> Vic: Would you rather go somewhere else?
> Bill: Somewhere else if possible but there is nothing else to suit me. (interview, 18.2.08).

Research Group members did not claim that all their support and social care, both in the present and the past, was oppressive or unsatisfactory. They all had social care or support staff in their lives that they liked and seemed to appreciate. For example, Pearl told me that she phoned up an old social worker that she liked when she had problems and that she liked her domiciliary care worker. Bill talked about staff he liked at the local Mencap office. During the time I worked on this project I went to several birthday parties of Rudy's to which he had invited a few support staff (who used to work with him in the past). During the course of this project Chantelle chose to go out to dinner and go on holiday, several times, with an ex-foster carer of hers, and Mary told me she had a foster carer that she liked and kept in touch with. Mary also had the following to say about her current domiciliary care:

> Mary: Some people are like are very, at the moment I've got really nice support and they are really friendly and they talk with you and have a laugh…Like my support worker is very nice and they listen to you and understanding you. I've got the most really nice people. (interview, 13.2.08)

Pearl explained that, while there are friendly 'staff', some 'staff' are not friendly and can be rude or have an attitude that is unsupportive:

Pearl: Some staff can be really really friendly sometimes, but not all of them, but sometimes I get on. The ones that is rude to me I don't talk to them… It depends what their attitude is towards me, Vic. (Interview, 13.2.08)

There were times during the course of this project when Research Group members and their participants said they felt pressured to do what social care and education workers wanted. From time to time I also witnessed this first-hand. Here is an example from my diary of one such situation:

Chantelle was upset because she wanted to go to a [a national service user controlled research organisation] meeting but it fell on a 'college day'. She had recently told college that she no longer wanted to go there. Next her college lecturer had phoned up her home [Pine Lodge] and spoken to staff (not to Chantelle directly). Pine Lodge staff then 'called Chantelle into the office' (Chantelle hates this and said she had tried to run away when this happened). Chantelle said Pine Lodge staff had told her college staff had said she had made a commitment to her course at college and if she didn't attend without any days off till the end of the academic year there was no point her doing her exams.

…I spoke to Lesley, Chantelle's… key worker in front of Chantelle and she said Chantelle was over reacting because Chantelle only had to attend every Monday and Thursday till sometime in July. Lesley had completely missed the point. We knew Chantelle's college days. I explained about the money Chantelle would be earning… and that Chantelle wanted to go there anyway.

Lesley had completely bought into the value of this vocational course at college and the authority of the lecturer who phoned from there. I said I didn't see why they couldn't be more flexible in the college. Lesley was so convinced [and said] "but there is no point in Chantelle going to college if she hasn't attended enough to pass the exams".

I thought, why is everyone except Chantelle and me (Chantelle doesn't care about the college course, she told me) taking this [exam] so seriously. I felt really angry about this. Accredited courses came in because they were the only ones the colleges could easily get large and consistent amounts of funding for. How many people are the college supporting to get into 'proper' reasonably paid work? Janet [a member of People First West] has done similar courses and she is at [a work training scheme] now and thinks it's no good and paid peanuts, and Gloria [another member of People First West] went down that dead end road for years and is now out of [the same work training scheme] without a proper job. I remember at the start of college [for Chantelle], Chantelle had

talked about getting a job, from going to college and she wanted a 'proper' job. How they delude people with learning difficulties and how people like Pine Lodge's staff buy into [what]... they offer. …I know these Pre-entry NVQ courses that lead to another course and another, and the whole cyclical nature of college.

Chantelle wants to go to [the national service user controlled research organisation]… but she will not go to [the national service user controlled research organisation] meetings on College days, "Because they will call me into the office again"… I had so much to lose if Research Group members chose not to attend or leave the Research Group but I never placed pressure on them to attend… This is just control ultimately. (Research Diary 3. 5.03)

My own experience of Chantelle was that she could be assertive (see Chapters 5 and 6). However in this instance she did what the staff in the residential home wanted, to avoid having to go through the ordeal of being 'called into the office'. The above diary extract illustrates one way that people who work with people with learning difficulties can pressurise service users to do what they require. It reveals how 'staff' can use a system that is intended to support a person with learning difficulties to control them. It is one example of how people who are ostensibly there to support can coerce people with learning difficulties to conform to their idea of what their agenda should be. This is despite being told by the person with learning difficulties that they want to do something different. It also shows how difficult it was for both the person with learning difficulties and myself, advocating on their behalf, to persuade professionals to go against a timetable or routine that had been established for a service user.

Looking back at the above diary entry it seems clear to me that I was angry about how staff can make rules based around what seemed to be unrealistic expectations. At the start of her college course Chantelle told me she had

been told she was going to college to get a job. However I visited Chantelle five years later at her residential home on the 6th of February 2008 and she was not in a job; nor had she been since the time of the above diary entry. All of the Research Group members recounted how they, and many of the people with learning difficulties they knew, had been involved in vocational training schemes or college courses for people with learning difficulties in the past. It appeared this had not led to sustained paid work for any of them. Two of the Research Group members were salaried self-advocacy development workers within People First West. However attending college courses and vocational training schemes had not led to their being appointed in these posts.

> Vic: Well what I am wondering about is, do you find that all of these courses that people with learning difficulties get trained for, has it led them, do you know anyone who it has led them to an actual job.
> Mary and Pearl: No.
> Bill: Sorry no.
> Pearl: I don't think so. I don't know, not that I know of anyway.
> Vic: We know all these different people, don't you, who've been to college. Who do you know who's been to college?
> Mary: [lists five people]…
> Vic: And have any of them got any jobs?
> Mary: No…
> Mary: I mean a lot of people go to college and they do the same old thing. Like I've been to college about five years, but and drama, that didn't get me anywhere and management, management money, you know like, how to deal with money and I'm good at that em eh how to budget, how to clean.
> Vic: Yeah. You did gardening training for a few years, didn't you, and you did cookery training. Did you ever have a job in gardening or cookery?
> Mary: Erm I went to, I had a job in [name of place].
> Vic: Doing what?
> Mary: Erm I worked in [name of place] station, like, not, serving tea and coffees, erm doing dish-washing all day erm but it [the payment] was like peanuts in those days. You have to do long hours. I had to get up about half past, half past five to be at work for half past six.
> Pearl: Mma ah [a sound that indicates disapproval].
> Mary: And that's local. If people were off sick you had to do long hours.
> Vic: Yeah.
> Mary: And I only I got eighty pounds a week.
> Vic: Really!

Pearl: [angrily and loudly, speaking over Vic and Mary] They're doing that.
Vic: Was that from [the catering training scheme Mary had been on].
Mary: It came from [an employment agency for people with learning difficulties].
Vic: Were you working at [the catering training scheme Mary had been on]?
Mary: Years ago when I was at [name of residential home].
Vic: So it was before [the catering scheme Mary had been on]?…
Vic: So what do you think about people going to college and people saying to them it's for work, that they are going to get work?
Pearl: I think that, I think that is disgusting because, what's the point of going to college if you aint going to get nothing out of it.
Mary: You do the same old things, the same old course, the same old on and on, on and on and on, cause you've been working [to Vic, who worked in a college] [indistinct].
Vic: Yeah.
Mary: It's like I see loads of people I know who've been going there for years, like [a name of a person], I won't say names but like different people going there, my friends going there and them about twenty years they have been going there to college and what the point? It's supposed to help you get a job.
Bill: Yeah.
Mary: And [named person] done job skills and she hasn't got a job. [Another named person] went to work and she went to work but she had problems in her job um, they treat her really badly, so she left. (interview 25.3.08)

This particular subject was not explored in any depth by the Research Group when undertaking their own research. However it is clear from the above conversation that they felt passionately (and in Pearl's case, also angry) about the issue of people with learning difficulties training for a long time with little or nothing to show for it. It seems reasonable to infer that at least on one level, this ongoing education of people with learning difficulties can be viewed as another way in which people with learning difficulties are controlled and manipulated and, in Chantelle's case, misled.

During the course of this research, Research Group members made it clear that they could find it difficult to confront 'staff' who were trying to control or

direct them. Chantelle had the following to say about how hard she found it to stand up to staff who were trying to change her mind:

> It's very hard to stand up to staff when they are not listening to you and doing what they want. It's hard to stand up for yourself when they are trying to change your mind. Sometimes it upsets me. (Research Group notes)

People with learning difficulties can be less experienced at exercising power, and perhaps less articulate or quick, although not necessarily, within a competitive argument with a person without learning difficulties who is focusing on trying to change their mind. Barrett and Jones (1996) have written about how children with learning difficulties are less likely to have influence in negotiating and decision-making processes than children without learning difficulties. In addition, Dowson (1997) has postulated that the mundane or routine exercising of power over the self-determination or will of people with learning difficulties is a taken for granted aspect of services that are ostensibly in place to provide support.

Dowson and Whittaker (1993) have argued that professionals are likely to have had a better education, be more valued by the community and have had more opportunities to exercise their power than the people with learning difficulties they are supporting. Through immersion in the group it became clear to me that, being a person without learning difficulties, I, like other professionals, was in danger of overpowering the service users I was supporting if I argued competitively with them and tried to change their minds.

One Research Group member explained how she felt that the balance of power was weighted between her social care workers and herself: Chantelle said she felt she had some influence over how she was supported in social care, but only up to the point of conflict of opinion. This is how she put it:

> …You have a say when they don't disagree with you. When they disagree with you, you don't have a say. (Research Group meeting notes)

This comment was used in the final draft of the Research Group's research. Therefore all of the members agreed that it was their experience too. This implies that they were all familiar with the dynamic of people without learning difficulties claiming that people with learning difficulties had control in a situation and then disproving this by taking control at the point of disagreement or conflict.

Thus emerging from the earliest phase of this project were data suggesting that there was a need for me as a research supporter to resist assuming control over researchers when conflicts of interest arose between myself and them. A starting point was making an effort to ensure that any agenda of mine did not conflict with the agenda of supporting people with learning difficulties to be in control. I wrote the following in my research diaries:

> [I need to] reconcile people with learning difficulties leading, and my own explicit or non-explicit agenda. (Research Diary 7.6.00)

> I must not assume control when I come to the meeting [with prospective researchers with learning difficulties] and think of ways of not assuming control. (Research Diary 15.3.01)

Going on the past experience of the researchers, there also seemed to be a need to prove to them (by my responses towards them over time) that I would take their views and concerns seriously, and prioritise them over my own at the point of disagreement.

Using my research diaries I reflected upon the process of supporting the researchers to be in control of their own agenda as I developed my support practice. Very early on in the project I reflected on the idea of the researchers being in control of their own research meetings:

> The issue is that the people with learning difficulties must choose what to do and how to do it. (Research Diary 14.3.01)

The following diary entry shows me reflecting on the issue of researchers remaining in control during meetings. This was not the only time I did this:

> It is important that I don't grab space, turn it into 'this is what we are going to do'. (Research Diary 17.4.01)

I also reflected upon the nature of the Research Group's agenda and the content of their research in relation to them being in control of it, as the following diary enty demonstrates:

> People with learning difficulties will be in control throughout the whole process, being supported to do what they want. It will not be a conventional academic piece of research. It will grow out of the process. Their opinions and their hearts will be in it… They live it. They write it. (Research Diary 17.7.01)

Finally here is an example of me reflecting upon a development within my

support practice that came out of aiming to support the researchers to be in control of the project:

> It has taken me a year to work out my position in this research… I'm just supporting people with learning difficulties to get across what they want to. (Research Diary 18.7.01)

I have explained how Chantelle felt anxious about being 'taken in to the office' in her residential home. She was not the only Research Group member who said their social care support led to them feeling anxious and afraid at times. Mary said the following about this subject:

> Mary: I don't like being bossed around. I've been through that, it brings my panic attacks on.
> Vic: What happens if people start telling you what to do and that?
> Mary: I get into a bit of a state and my panic attacks come on… it doesn't happen here. (Interview, 13.2.08)

Chantelle told us about another time when she was frightened of staff in her residential home:

> He [a member of staff] was very angry. He came close to me and I thought he was going to hit me. I shouted back at him and now I'm scared of him.

> I've been upset and scared for over a week now at home. I don't know what he is going to do next… I daren't tell my key worker or the manager of where I live about what happened because I am worried that it is going to go back to [the man that shouted] and he will be angry again. (Research Group notes)

Clearly, some members of the Research Group could experience high levels of anxiety around professionals. Having made these observations, I did my best to communicate with service users in a gentle manner. When listening to my voice on tapes of Research Group meetings the tone is calm and gentle.

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However, there was one time when I expressed anger about the way that Chantelle was treated by social care staff, I initially thought I was being supportive by doing this. She informed me that this frightened her because it reminded her of times when 'staff' had been aggressive or violent towards her in the past. I discussed this issue with other Research Group members in an interview. This is some of what they said:

Vic: One time I was getting annoyed about one of Chantelle's staff, you know what I mean?
Bill: Mmmh.
Vic: And I started shouting a bit, I was going like erm I'll just do it for you. Like [raises voice quite a bit but not actually shouting] I don't know why they are like that. It really gets on my nerves. [voice goes back down to usual level] you know what I mean, like this thing, and Chantelle said to me that my shouting like that was upsetting her because it reminded her of when staff shouted at her in the past or maybe hit her or something.
Pearl: Mm hm.
Vic: And even though I wasn't shouting at her. I was getting angry about
Pearl: The staff…

Vic: Well I try not to shout because I remember that Chantelle got really upset when I started shouting. If I started shouting and getting angry about staff in front of you how would you feel?
Pearl: I'd say, I would say, please don't do that Vic, because I don't like it.
Vic: You wouldn't like it if I started getting angry. Why wouldn't you like it?
Pearl: Because, because it's annoying innit you know and plus you know it frightens me a little bit, when people shout.
Vic: Even if it's someone you know like me, if I started shouting it would frighten you a bit, OK?
Mary: I never hear you shout.
Vic: No but if I did. If I started to sort of show signs of anger even if it wasn't about you, do you think it could make you feel a bit nervous or not?
Mary: Yeah I do a little bit [indistinct] but I wouldn't [indistinct] because it's just imagination.
Vic: Well, you've never seen me do it.
Pearl and Mary: No no.
Vic: But if I did, I'm going to pretend to do it now, see how it makes you feel.
Ian: Mmm.
Pearl: Go on then.
Mary: Alright [indistinct].

Vic [raises voice] I'm really pissed off with that. [lowers voice] So, go on, how does that make you feel?

Mary: [laughs] A bit frightened.

Vic: [laughing] Yeah it frightened you, didn't it?

Mary and Pearl and Bill: [laughing]

Mary and Pearl: [laughing] Yeah.

Vic: So even if I just get annoyed, I can just see by looking at, so what was that like?

Mary: Horrible [laughing].

Vic: Was it?

Mary: I don't know it was a bit.

Vic: Yeah OK then [laughing].

Mary: I'm alright.

Vic: So it's made you change colour.

Pearl: [laughing] Mmm.

Mary: I'm alright [indistinct].

Vic: Yeah, so like what is it about that? Is it important that staff don't do that?

Mary: I don't know it makes me jumpy and makes me put down.

Vic: Even that, well, I wasn't talking about you.

Mary: No no, not you, but staff put me down sometimes.

Vic: So it reminds, does it remind, you see I'm not actually putting you down but.

Mary: No no no, but I've heard [named staff in residential home] shout at me.

Vic: Ah, it just reminds you of other people shouting at you by the sounds of it.

Mary: Yeah, [same named member of staff as above] used to be very shouting, used to fright be scared of [same named person].

Vic: Yeah OK.

Mary: But I've never seen you.

Vic: [laughing] No, you've never seen me do that.

Pearl: [laughing] None of us.

Vic: [laughing] I'm only doing it in acting.

Mary: [laughing] Yeah I know.

Vic: It's a role play.

Mary: It's a role play isn't it…I've always been a nervous person.

(Interview, 25.3.08)

It is important to mention that at the time of the above interview I had worked closely with all three of the above service users for many years and had built up a level of trust with them. Also what we were discussing in the above conversations were relatively subtle expressions of anger (a long way from rage and more akin to expressing annoyance). However it seems from the

above conversation that not only Chantelle but Pearl and Mary too were not comfortable around me if I expressed any anger of this nature. It seemed at the time that Bill was unmoved by my annoyed 'role play'. This sort of expression of annoyance or anger on behalf of a person that one cares about may have been supportive within a different context, for example when supporting a colleague without learning difficulties. I've used it in a supportive way myself in the past and witnessed it being used when people have been supporting me. However it was not appropriate on this project as it emerged that the history of control and aggression or impatience from staff members continued to affect Research Group members emotionally. Therefore the Research Group, and the support they were offered within it, could not be seen as isolated from other aspects of their daily life.

It seemed from the above conversation that more than half of the Research Group members would have been uncomfortable with their supporter expressing this level of anger or annoyance, because it reminded at least two of them of situations in the past where people had abusively directed anger towards them. This implies there is a need for supporters to bear in mind that a person without learning difficulties in a professional supportive role can have the power to inadvertently induce fear or anxiety in the people they are supporting.

This also implies that supporters of people with learning difficulties (including user controlled research supporters) not only need to aim to be gentle in their approach and avoid responses that stress or frighten service users. It also

suggests that supporters may need to make effort to watch for signs of people

being frightened or stressed by their responses as they might need to adapt

their manner further to suit the people they are supporting. Examples of

particular research support strategies that aim to avoid stressing or unsettling

researchers with learning difficulties are covered in subsequent sections of

this and other findings chapters of this dissertation.

An imbalance of power between researchers and those who support

them

Throughout the course of this project Research Group members made it clear

that they believed a power imbalance existed between themselves and their

'staff' (people like me, paid to be in a supportive role in their lives). For

example, one Research Group member pointed out that in her view, staff

could behave badly towards service users *without repercussions*.

> If the clients had spoke to the staff like that they would be straight into the manager's office and we would get spoken to about it by the manager. But when the staff speak to the clients like that why isn't the manager sorting them out? (Research Group notes)

The Research Group decided to include the above statement in their book.

This strongly implied that from their point of view they were in an unequal

relationship with professionals, and that the power was weighted on the side

of their staff. When Research Group members were interviewed by me on this

subject this is what one had to say:

> Mary: Erm, a lot of people just get away with it you know, treating people with learning disabilities just get away with it, not get told off, you see. Don't get like a warning, like a written warning or anything.
> Vic: They get away with it, treating people like how?

> Mary: How? Erm like telling them off and you shouldn't be doing this, you shouldn't be doing that.
> Vic: Yeah, and what if a person with learning difficulties started saying that to the staff, you shouldn't be doing this, you shouldn't be doing that?
> Mary: Well, they get a telling off, they get, the staff get away with it.
> (interview 25.3.08)

Because I was based within a self-advocacy organisation there may have been repercussions if I had responded to people with learning difficulties in the way that the above quotation mentions. However it would have been inaccurate to suppose that a power imbalance did not exist between myself and the people with learning difficulties I was supporting.

In relation to supporting people with learning difficulties to be in control of their own research project, clearly some responsibility falls on research supporters *to behave in ways that facilitate* the researchers to be in charge of their own project. However, this research suggested that in order to be in control of their project, service user researchers needed to feel safe to contradict or disagree with the supporter and experience her or him as having less power than them in deciding the direction of the project and the agendas of their research meetings.

An implication of this is that research supporters may need to set clear boundaries around their own behaviour in an attempt to redress the balance of power between themselves and service user researchers. In addition, supporters may also need to monitor their own responses to ensure that they do not resort inadvertently to being manipulative or directive towards service user researchers at stressful times.

Making it safe to confront or disagree with the supporter

As stated earlier, research findings indicated that it would be beneficial for the user controlled research supporter to develop ways of supporting that would be facilitative of researchers (a) feeling safer about confronting their supporter, and (b) doing and saying what they choose. Atkinson (1995) has discussed how some people with learning difficulties may try to work out what people without learning difficulties expect of them, and respond in ways that avoid conflict and aim to please. I decided, in response to the above implications that were learned from earlier data analysis, that it could be helpful to put the following resolve into practice, with the aim of it making it easier for researchers to confront or actively disagree with me: I would watch my behaviour to try and ensure that I never expressed personal displeasure or even subtle irritation at whatever course of action individual Research Group members chose to take, or at whatever they said to me.

Also when working with Research Group members I made it clear, by my actions and attitude, that there would be no repercussion or conflict if researchers contradicted, criticised, directed me or did something that led to me feeling uncomfortable (this is expanded upon later in this chapter). I backed this up by periodically stating that the researchers with learning difficulties had ultimate control over all aspects of the research. Here is an example:

> Vic: Not all research with people with learning difficulties, well virtually no research, well no research as far as I know, is like this one where you

have complete control. Do you know what I mean? You push the direction of this totally? What they say in (another) People First… they say a researcher comes in and they share it between them what they are doing. They share the control and the power between them… Do you share the control and power with me or have you got more control and power than me?

Bill: More.

Vic: More?

Bill: Yeah.

Vic: So that's the difference. (Research Group tapes, 11.11.02)

Research Group members initially saw the group as being mine or my supervisor's, and at first they were unsure about how to be in control of it. For example during the first few Research Group meetings the self-advocacy development worker with learning difficulties kept referring to the work of the Research Group as 'your research' or 'Peter's research' [my PhD supervisor]. I was aware that I was bringing an idea or a concept to the group and having some influence from the very beginning, as the following diary extract demonstrates:

I really sold the idea of the potential of the research. I was enthusiastic and so was everyone else. (17.4.01)

It became clear that the problem of service user researchers seeing the project as 'belonging' to, or driven by, the research supporter was complicated by my attempting to explain how I was aiming to support people to be in control of their own research. I felt that this process in itself was a form of 'pushing'. I wrote in my diary on the 17th of April 2001 that I was worried about the possibility of Research Group members feeling, 'bored or invaded' by my continuing to explain repeatedly that it was their research.

At the very first meetings of the complete Research Group, members of the
group came with literature and other information they wanted to work with, as
the following quotation from my diaries at this time demonstrates:

> ...[Chantelle] described what she had brought with her to this first meeting
> as books. They were information booklets [for example] how to make a
> complaint about a council department etc. She was concerned that these
> would be useful. (Research Diary 14.5.01)

The above researcher seemed interested in the project at this stage and was
thinking about it outside of the meeting as she was gathering information.
However it still took a while for the researchers to move towards seeing it as
their project that they were in control of.

I found it complicated to be in a position of not being in control at this stage. It
was not straightforward. During the early stage of supporting the Research
Group I struggled not to be in a position of taking the lead and reflected upon
this issue within the diaries:

> I definitely came in with a subject that exists much more in me than
> anyone else at the moment….. It is important that I don't grab space, turn
> it into this is what we are going to do…..make decisions, fix agendas.
> (17.4.01)

I noted in my diary that while I knew more about different ways of producing
research than the Research Group, I was still a fairly inexperienced
researcher. I was concerned that this lack of experience could lead to me
attempting to assume control as the following diary entry demonstrates:

> When I supported art, people who didn't know about art would support it
> in a rigid/oppressive way, not have the knowledge to know how to let go

and be confident that they could support a creative process. I fear I may be like this, nervous, rigid. (Diary 23.5.01)

It was invaluable that that I had supervision and guidance around the subject of research at this point. My supervisor was able to reassure me that the researcher's work did not have to be academic as such, and that the most important issue was that it was controlled by them and undertaken on their own terms.

My fears about Research Group members owning or taking the initiative for directing their own work were short-lived. During the course of this project I found that Research Group members were quick to start making decisions and assuming responsibility for what happened in the group, as the following examples illustrate. Very early on they decided upon the length of the meetings:

We all agreed with Rudy when he said the meeting should be 1 ½ hours long. (Research Group Minutes 23.4.01)

On the 14th of May 2001 I noted that without me 'prompting' anyone, either Rudy or Pearl read the minutes out and started the meeting. I also wrote the following in my diaries at this time:

The meeting was going well…in my opinion people were discussing what was interesting to them. (14.5.01)

My diaries record that I was excited at how involved and motivated the Research Group members were in contrast to some other meetings I had

recently participated in that involved people with learning difficulties. I wrote

the following in my diary at the time:

> Rudy said that it was a good meeting, everyone is excited and fired up and it was extremely noticeable to me that people with learning difficulties were talking away and getting on with the meeting far more and with much more conversation than…[certain other task-orientated groups, some of which were initiated by social services]. (14.5.01)

At the time I wondered why, and wrote the following about one difference

between these other task-orientated groups and the Research Group:

> I think that me not controlling the meeting and there being a lack of a series of complex issues that need to be resolved at the meeting (whether people [with learning difficulties] understand them or not) was a major difference (Research Diary 14.5.01).

I also wrote the following on the same day:

> Rudy certainly doesn't seem to think that he is helping me or Peter to do research now…Perhaps part of the success of the last meeting is my not being too keen to structure, order etc, preferring to let things come up when and how they do. I also agree with them at times and said I thought it was outrageously bad what…[the director of a national organisation for people with learning difficulties] had been reported [in the newspapers] as saying. (Research Diary 14.5.01)

Eventually Research Group members got to the stage where they did what

they wanted in Research Group time (not necessarily research) and were not

expecting me to make decisions or direct them. The following extract from my

research diaries gives one example of this. The Research Group had been

meeting on a weekly basis for one year and four months at this stage:

> Last week a large part of the meeting was spent supporting Chantelle around her college courses. She was worried that the college would say she "had" to come on Monday. The group and me explained it was

Chantelle's choice not to go to college on Mondays and I explained that many people with learning difficulties who go to college have other commitments on different days. She is very sure that she doesn't want to give up the Research Group. Last week Mary lost her mobile. She had been to visit her new flat with her social worker. Mary was emotional and tearful about the phone loss (it was probably left in the new flat) and the whole business of moving house. She needed a lot of support and was not able to focus much on writing the book. That was the morning. After lunch everyone (not me) decided they were too tired and had worked long enough on writing (It can't have been more than two hours work done all day) and decided to end the group early around 2ish. (Research Diary 9.9.02)

Putting the above situation in context, in my opinion this was not a particularly productive meeting in terms of them moving forward with their research project. At the time I was not comfortable about them going home, being worried about the timing of the project in relation to the funding. Examples have already been given of how some Research Group members chose not to risk annoying their staff over doing what *they* wanted to do. Any risk of this sort was minimised in the Research Group because I *consistently* avoided getting annoyed or defensive or taking charge. If I felt annoyed or uncomfortable in response to service users I owned and contained those feelings. Here is an example of one such situation from my diaries:

Yet again the security or future of the PhD seems jeopardised. My PhD my future, my career… The group, now only Chantelle and Pearl, were doing great today but at one point Pearl said she was thinking of stopping coming to People First West… Chantelle mentioned that she had decided she didn't want a third member of the research team…and Pearl mentioned that if that is what Chantelle wants she will go along with it…I'd said I wanted to talk about some thoughts I had on this, like when one person can't come there is only one person left and not a team or a group… I am amazed at how assertive Chantelle and Pearl have become. This week's tape records them really in control and confidently using their space… I cannot have more people coming to the group if Chantelle is saying no more people, and Pearl is saying OK if that's what Chantelle wants. It is quite possible that this research group could just stop through lack of attendance. So I got a headache when I saw *Monsoon Wedding* at [a cinema with a friend that evening]. [Another

friend had described the film as] 'feel good'. I cried heavily throughout the entire last third of the film. Admittedly I am still feeling pretty ill with a very bad chest and not my usual self at all. (Research Diary 4.2.02)

In the above example I clearly felt very worried about Chantelle and Pearl deciding that they did not want any more members in the Research Group. It felt to me that both their research project and my PhD were on the verge of collapse at that time. There clearly was a conflict of interest here between what I saw as my needs and wishes, and what the researchers were choosing to do. Despite aiming to eliminate conflicts of interest at the methods stage, I found that they arose several times on this project. They are discussed at different points within the findings chapters of this dissertation, along with how I used the process of reflection as a tool for working towards maintaining the non-directive focus of my support role at such times.

Within the later stages of the project the researchers appeared to see me as someone they could comfortably direct and even admonish, for example:

Vic writes up the minutes of our meetings. We all say if we think the minutes are alright. Pearl reads the minutes at the meetings and supports the Research Group to decide what we are going to do in a meeting and who is going to do what.

If you [Vic] put in jargon words we would't be able to understand it and you would get into trouble with us because you would have to write it all over again. (Research Group notes)

Later parts of this chapter focus on the development of a reflexive self-advocacy support role. Adopting this reflexive role enabled me to steer away from being defensive and to maintain clearer boundaries around my own behaviour. Having a clear idea of my role within the group and trusting the

process of supporting them to be in control was also helpful in this context, as the following quotation from my research diaries demonstrates:

> I've done a lot of work on not taking over. It does feel chaotic but that's OK. In this case I'm sure they will get there as [another self-advocacy group I had previously supported] did. I don't suggest breaks. I don't suggest lunch. They make all the decisions. They talk at a rate of knots. There is no passivity, no waiting for me to suggest things. I can't keep up with them when I am trying to do the minutes. … I've let go of any ideas of what I think it [their research] might be. I'm really not sure but I trust in the process. I've had plenty of practice of this… in self-advocacy groups, in person-centred psychotherapy/counselling groups. The thing is they understand the underling basis for tying to do [their] research, 'to be heard', 'to be more powerful'. (Research Diary 4.6.01)

The above diary extract mentions that I felt that having experience in person-centred group work was helpful in enabling me to feel comfortable about the researchers being in control of the group. I also felt I was able to trust the process of them being in control because, by the time the above diary entry was made, Research Group members had a clear idea of the underlying basis or rationale of their research.

I wrote the following in my diary about the attitude I held in relation to supporting the researchers to be in control:

> I think my intention or stance [to support Research Group members to be in control] is more important than any particular intervention. (Research Diary 4/6/01)

Although the group felt chaotic to me at this stage it was also possible to see that they were moving forward and taking control. I also felt that the group was positive and dynamic, as the following diary entry from the same day illustrates:

So far we get halfway or more through the meeting before the last minutes are read…It can seem like there is no focus or people are not aware that they are at a research meeting but this is not true. It seems to me that all three people have ideas about what the meeting means and what they want to do. Rudy in particular brings things from one meeting to another. What may seem unlinked or unrelated comments upon further questioning for clarity are threads that are more than connected and he really understands what potential the group has…if I ask Rudy a question for further clarity...he will say how he sees it fitting into the wider picture. You can see an example of this in today's minutes…[Rudy] sees us as working on things, developing them, moving forward and if that is how he and other people feel that's great. …I can't keep up with them when I'm trying to do the minutes…Anyway it is working somehow and it feels good…They will take things in directions I couldn't imagine and it's great to see them working together. (Research Diary 4.6.01)

If I had attempted to place a structure on the group and bring in an agenda of my own it would have been in competition with the self-directed agenda of Research Group members. However the Research Group being in control felt unnerving at times. For the greater part of the time I supported the Research Group I didn't know what direction their research would go in and if it would definitely be completed positively (by them publishing a book as they wanted). I wrote the following entry in my diary about this subject:

It's all kind of happening naturally. It's nothing like I thought it would be. No one is wanting to go around interviewing people with learning difficulties (yet) in the group. Perhaps they never will. (2.11.01)

I wrote in my diary again that I felt my person-centred psychotherapy training was helpful in this situation:

This whole uncertainty issue that is the nature of this research, you need to have had some person-centred training to deal with it. (Research Diary 2.11.01)

My experience of person-centred practice and my training helped me to sit with uncertainty and not resort to trying to direct the service user researchers.

I came to the Research Group assuming that I would have to offer the service users some research training. During the early days of the Research Group working together, I asked them if they wanted to undertake training and they said they did. They opted to use a particular training package. However when they attempted to listen to the research training tape we had bought (which had been developed specifically for people with learning difficulties) they quickly became bored with it and decided to turn it off.

No Research Group members ever brought up the issue of research training at any time during the project. An outsider might presume that giving research training would be a fundamental aspect of the user controlled research supporter's role, and I had assumed it would be. But the researchers did not seem interested in undertaking research training. I did not pursue the idea of research training any further for the following reasons: Adopting the role of a 'teacher' coming into the group with an agenda and ensuring that agenda was carried out could have been counterproductive to supporting people with learning difficulties to be in control of their own agenda and meetings. This could have been particularly true at the early stages of the group when they were getting to grips with the concept of it being their research, and their group, that they were in control of. This problem could possibly have been overcome if the group had decided at some stage to employ another person

to offer research training, but there was not enough funding on this project to consider this option seriously.

However, from early on the Research Group members grasped and took forward the idea of representing themselves through their work being published. They strove to act in ways that advanced their argument and moved towards goals they identified as being useful in their struggles to improve conditions for people with learning difficulties. These issues are explained within their own published research. I was willing to be used as a research consultant as best as I was able with the support of my supervisor, and to support the Research Group members to work with their concerns and interests within a research framework.

Humour and friendliness in research support

It became clear when working with the Research Group that they all wanted the people that supported them to be friendly and have a good sense of humour. They discussed this issue in depth on several occasions. Also expressing their own sense of humour (or as they put it, 'joking around'), and not being prevented from doing this, was important to Research Group members. The following quote from the Research Group's notes shows the importance they placed on humour and 'staff' having a good sense of humour:

> We think staff should see the funny side of things and they should not try and stop us from joking around (Research Group notes).

When interviewed on this subject, Research Group members had the following to say about what they thought being with 'staff' who would not joke

around with them and share in the humor of the group would be like:

> Mary: Oh it would be boring, boring.
> Bill: Yes.
> Mary: It would be like, be like sour milk.
> Bill: Mmh, oh yes, thanks.
> Mary: Boring, yes be no. What's the point, having staff who is just boring?
> Bill: Yes.
> Mary: What's the point of it? (Interview 25.3.08)

Research Group members seemed to often enjoy making each other and me laugh. My joking along with them was something they seemed to want from me as a person supporting the group of which they were in control. Being 'friendly' and being 'supportive' seemed to be part of the culture of the group. Here are some examples of Research Group members talking about how they saw their group as being friendly and supportive, and what that meant to them:

> Mary: We help each other.
> Pearl: We help each other. We do things together. We have meetings together. We make tea and coffees together and that stuff and we make sure that we are we are in a safe place and we are very supportive as well.
> Mary: Make sure that we have got enough support… and you [Vic] were always there for us.
> Vic: What about if you, if any of you had problems? Did we just like continue with the work or did we.
> Mary [interrupting] No we [indistinct] talk to someone. (Interview 25.3.08)

In the same interview Research Group members talked about how supportive a past Research Group member who was not at the meeting had been to them. Bill said he had supported him in the following way:

> Bill: [Rudy supported me by] saying things, nice things, support… so gentle. (Interview 25.3.08)

Mary went on to say the following about the supportive nature of the Research Group:

> Mary: It was very good supportive…very good atmos[phere]. Everyone was there for you. If you were not very happy they were still there for you. (Interview 25.3.08)

Here is an example of both the humour and friendly support that was present in the group from one of the tapes of the Research Group meetings. To put this example in context, I had been explaining triangulation in accessible language to the group and had talked for a while. Then I said "now I'm going to shut my big gob" and Chantelle had said, "Hey, can you stop that please":

> Vic: Are you telling me off because I'm not saying a nice thing about myself?
> Chantelle: Yes.
> Vic: Alright OK I know, thanks Chantelle, thanks for looking after me. Is that what you mean?
> Chantelle: Yes I don't like (pause)
> Vic: You don't like to see me put myself down?
> Chantelle: Yeah that's right.I tell, I tell, Susan [a worker from her residential home] puts herself down and I tell her off an all.
> Vic: Does she yeah, you are a lovely woman Chantelle.
> Chantelle: That's why I say (indistinct four or five words).
> Vic: It's a lovely group of people here, isn't it?
> Chantelle: Yeah.
> Vic: Well you three are.
> Bill: Yeah (laughs).
>
> Chantelle: And don't forget that pain in the neck next door.
> Vic: Do you mean the man whose name cannot be mentioned, the manager [of People First West].
> Chantelle: Yeah.
> Vic: Is he lovely?
> Chantelle: Yeah, when he's asleep! (loud laughter from everyone)
> [Chantelle liked the manager and often sought out his company].
> (Research Group meeting 4.3.02)

The above quotation is a typical example of what the mood of the Research Group was like after several months: mutually supportive, trusting and friendly

with the space for researchers to affectionately tease both each other and me. Chantelle also affectionately called her fellow Research Group members and me a 'pain in the neck' and 'trouble'. She often used these terms as a warm greeting when she arrived at the group.

In time all the Research Group members instigated socialising with each other and me outside of meetings. I still socialise, from time to time, with all of them, going for meals, afternoons and evenings out and to parties etc. When interviewing Research Group members about socialising together they had the following to say:

> Vic: …We go out together. I think that maybe, I think that might make some sort of difference. If I was the sort of person who didn't joke, didn't tell you about myself and we never went out in the evenings, we never went to the pub, I don't know if you'd see me in quite them same way.
> Bill: No.
> Vic: I mean I go out a lot with you Bill, for example.
> Mary: And [indistinct] me.
> Vic: We've all been out together. Do you think that makes a difference?
> Bill: Yeah.
> Mary: It makes a lot of difference because, it makes people not so bored. It's nice to go out and have a chat in the pub. It's nice to do things together like I have done in the past with you.
> Vic: Do you think it's helped our relationship?
> Pearl: Yeah, like a work like a work erm relationship.
> Vic: Is that helped by going out sometimes and that I know, but what do you think?
> Pearl: I think it's like good to have a working, working partner relationship, because you can get together and mingle out with other people as well.
> Vic: Yeah, mingle.
> Mary: And understanding.
> Pearl: Yeah, understanding.
> Bill: Yeah.
> Vic: Understanding in what way do you mean? If you are going out, mingling out.
> Pearl [interrupting] Cause you know, you know that you can be, you know you are in a safe environment and in a safe, in a safe atmosphere as well.
> Vic: But say like if I'd not gone out to the pub with you or if I'd never done social things with you and I, I said no I'm not coming to anything. How would that make you?

Mary [interrupting] It would make me feel upset.
Vic: Why? I know I'm being tough really by asking all these hard questions, it's just to find out what.
Mary [interrupting] It makes you feel upset and [pause] put down.
(interview 25.3.08)

Analysis of the above transcript suggests that Research Group members valued us going out together. Pearl mentioned that it helped our working relationship and that it was good to have working partner relationships because we could 'mingle' and 'get together' [socialise]. It seems like she was implying that she saw us as co-workers working together rather than me being in a 'client' and 'professional' relationship with them. The role of mutual work colleagues suggests a more equal balance of power than that of service provider and service user.

Later on in the same interview, Mary said that going out socially had made us closer. This is how she put it:

Mary: It's made me closer going to the pub with you and Bill.
Vic: Yeah, how does it help us being closer going out?
Mary: Talking after work.
Bill: Talking.
Mary: You didn't have to talk about work. You can talk about everything…
Me and Bill have a joke with you and Pearl come too [indistinct].
(Interview 25.3.08)

Being informal with each other, sharing a sense of humour and socialising together was a positive way of Research Group members and myself coming together on what was possibly more equal footing. Being and behaving this way contributed towards the relationship between us all becoming more comfortable. It enabled me, although having a clear support role within the group, to be accepted over time as part of the group in some way, and not be

perceived as a comparatively distant and less trusted 'member of staff' to them. It helped towards moving our relationship into being one of (as Pearl said in the first of the last two quotations) 'working partners', friendly colleagues rather than 'staff' and service users.

Menzies and Lyth (1990) have argued that the divide between the 'professional' and the recipient of 'support' can be a form of defence mechanism used to prevent the professional from empathising with the person with learning difficulties, causing distress to the supported person. Historically many 'caring' or 'supportive' organisations have actively promoted this particular type of distancing and continue to do so. However the use of educational or professional structures can be seen, in themselves, as a way of attempting to distance or protect professionals from uncomfortable or threatening feelings (Menzies Lyth, 1990; Sinason, 1992). Speck (1994) has argued that professionals can attempt to hold back uncomfortable feelings such as guilt or anxiety by taking a rigid task-centred approach to work. Cohn (1994) has discussed how by adopting the position of being too busy to acknowledge the importance of emotional needs, or by taking a 'stiff upper lip' approach to themselves and others the value of just being with the people with learning difficulties could be denied. This research indicated that adopting an informal and friendly approach to research support and joining in with the humour in the group was a productive way of working against an 'us' and 'them' barrier that professionals can maintain by upholding an air of 'professional distance' and authority.

Research support and miscommunication

Part of my role on this project was to explain information to Research Group

members and also to hear and understand what they were explaining to me.

Although I did what I could to use language that was accessible to them,

Research Group members did not always immediately understand what I was

saying (and did not always tell me). Here is one example of a situation where

a researcher did not understand what I was saying. I was interviewing

Research Group members on the subject of humour and support. We had

been talking for a short while on the subject and I wondered if everyone in the

group understood what the term 'a sense of humour' meant:

> Mary: Humour for me is important, the staff to have erm, what's the word?
> Vic: A sense of humour?
> Mary: A sense of humour and er don't be miserable you know. What's the
> point of working with learning disabilities if you're miserable?
> Vic: Yeah.
> Mary: It's good to have some humour, can't say it properly, sense of
> humour.
> Vic: Do you all know what sense of humour is?
> Pearl: Mmmh. Sense of humour is like being human, you know getting
> treated like a human being. Do you know what I mean?
> Vic: It's like sense of humour is when people can see jokes.
> Pearl: [interrupting] Yes, so you don't take it for granted or don't take it for
> serious. You know what I mean. They might [indistinct] [does a whining
> voice] 'oh leave me alone, don't do this, don't do that'. You know what I
> mean?
> Vic: Yeah.
> Pearl: 'Oh why are you taking the piss out me' and all this, you know?
> Vic: Yeah.
> Pearl: [laughs]
> Mary: And you're joking.
> Pearl: Yeah. (Interview 25.3.08)

In the above interview the term 'sense of humour' was outside of Pearl's

frame of reference and as such was not accessible to her. Pearl rarely said

she did not understand and generally gave an answer when asked if she

understood a term or word even if she was unsure of the meaning. She said it meant 'being a human' (humour and human sound similar). I knew she understood the word 'jokes' as it was commonly used by Research Group members, so I used this word as a way of introducing her to the concept of 'humour' or linking her understanding to what was being talked about.

Also I did not always immediately understand what the service user researchers were trying to tell me. Miscommunication between the researchers and me occurred regularly and on numerous occasions. It was a significant aspect of the dialogue that took place between us. Bearing this in mind, it seemed safe to presume that it could be useful for me as a supporter to try to find ways of reaching clarity of communication (or understanding) within the Research Group that would avoid embarrassing researchers and that would not lead to them blaming themselves for misunderstanding information. Therefore I aimed to find ways to ask Research Group members for clarity that were both supportive and non-confrontational (It has already been mentioned how difficult it can be for people with learning difficulties to confront professionals in a supportive role).

Often I could see by the expression on the faces of researchers that they might not fully understand what I was saying to them. The following example from a tape of a Research Group meeting gives an example of me noticing this and acting upon it:

> Vic: I'm not explaining this at all well … and even now while I'm saying this I can see that Chantelle looks like 'what the hell are you on about'

and I don't blame you [Chantelle]. (Tape of Research Group meeting 11.11.02)

Analysing such interventions led me to conclude that it could be useful if research supporters demonstrate that they are prepared to take responsibility for any misunderstandings between themselves and the service user researchers.

At this point it would be useful if I explained more fully how I put this in to practice. While making every attempt to present materials and discuss issues in ways that were as accessible as possible, I openly took responsibility for misunderstandings that occurred between my self and Research Group members. For example, if a statement or term was unclear to the person or persons with learning difficulties this was because I had not yet found a way of making myself understandable. In short, it was because I was not presenting information in a way that was accessible to Research Group members and it was my responsibility to change how I was communicating that information. Here is an example of me explaining this process to Research Group members while they were engaged in interviewing research participants who were not accessing the interview questions and as a consequence were remaining quite quiet:

> Vic:… if we can all think all think of ways to try and ask questions so that Rita and Jean are able to tell us a lot and understand what we are talking about (Tape of Research Group meeting 29.7.02).

Here is another example of my taking responsibility for not being as clear as possible. To explain, I was supporting the group to review a research proposal for another project. I had not said something that was inaccurate as such, but

I had presented the information in a way that was confusing for the service

user:

> Vic: When they come to do the research do you believe, do you feel
> confident that the staff will not be in control
> Chantelle: Yeah.
> Vic: I'm not saying, I know that's me, the words I'm saying are wrong
> here. I've put them in they wrong way round and it's muddled you up I
> know it is.
> Chantelle:Yeah.
> Vic: You think [Chantelle had expressed this view earlier] the staff have
> done this [a research proposal that the writers claimed was written by or
> with people with learning difficulties].
> Chantelle: Yeah.
> Vic: And that they've not involved, they've not worked together with
> people with learning difficulties, trying to get the views of people with
> learning difficulties all the way along to be part of this. You just think
> they've gone on and done it.
> Chantelle: They are not getting them involved in the research itself.
> Vic: This research proposal.
> Chantelle: Yeah.
> Vic: So this is the plan for the research so when they come to do the
> actual research will the staff get the people with learning difficulties
> involved?
> Chantelle: No. (Tape of Research Group meeting, 11.11.02)

This approach minimised embarrassment or stress around the situation of 'not

understanding' for Research Group members, because I shouldered the

responsibility. It was 'my fault', not theirs. I also applied the same principle in

reverse. When I was unable to understand the communication of a Research

Group member I took responsibility for not understanding. This way of working

supported Research Group members to communicate with me without my

responses contributing towards their fear of 'getting it wrong' or feeling judged

as inadequate in some way. It is important to mention here that people

involved in this research thought being asked questions was important. When

working on documenting their access needs for a national user controlled

organisation, two of the members of the Research Group who were part of the

organisations 'national user group' stated that being asked questions was an element of their access needs ([Service user controlled research organisation] national user group minutes).

Research support and open-ended questions

MCarthy (1998) has discussed how some people with learning difficulties can find open-ended questions difficult. I found on this project, that asking open-ended questions was an essential part of supporting people with learning difficulties to express their views. However analysis of my research data led me to conclude that at times, members of the Research Group and research participants needed support to expand upon a particular subject. Here is an example:

> Vic:...What do you think about this situation [how he said he was treated in college]?
> Bill: I am happy, no, not happy with it.
> Vic: Not happy with it, can you say any more about that like why or, why are you not happy with it? There is plenty of time, you are doing a very good job (pause).
> Bill: Rules, too many rules there?
> Vic: Too many roles there?
> Bill: Rules.
> Vic: Too many rules there.
> Bill: Yeah.
> Vic: And what are the rules?
> Bill: I don't know.
> Vic:.. too many rules, I'm sure you're right, but how does it feel like, that makes you know there's too many rules?
> Bill: I know, that all. How can I put this?
> Vic: Yeah how to put it, I mean I'm sure you can do it.
> Bill: Kindly.
> Vic: Yeah, put it however you want it… you know these things because you are in tune with it. 'I'm not happy with it, too many rules there'…explaining to the reader how you know that because of the way you feel.
> Bill: Too tight there.

> Vic: Yeah, too tight there…I know they don't say the rules, they don't tell you the rules, I know that, but what does that make you feel like when you're in there?
> Bill: A bit hurried, bit nervous, bit nervous.
> Vic: Do you feel a bit hurried and a bit nervous now?
> Bill: No.
> Vic:..do you want to say anything else, or do you want to stop now with my question and answer going on?
> Bill: One thing I sum it up, it's crap there, I want to get out of it. (Tape of Research Group meeting 7.10. 02)

In the above conversation I was not only asking open-ended questions to find out how Bill felt about how he was treated in college. I was also supporting him to deal with the process of answering them. For example I mirrored back what Bill said. I also reassured him that I thought he was able to answer the question because he understood the subject. I reassured him that I thought he was doing fine answering the questions and that he could afford to take his time and answer when he was ready. I also checked out how he was feeling and if he wanted me to stop asking him questions. When analysing the above transcript it seemed that all of these responses contributed towards facilitating Bill to say what he wanted, and worked against me (as a research supporter) pressurising him to talk. What is implied by the above interaction is that open, empathic responses combined with supportive but non-directive encouragement may contribute towards enabling certain service users to state their views. However in order to avoid pressurising service users, supporters may need to employ sensitivity around ascertaining when the service user wants any questioning or encouragement to stop.

When asking open-ended questions ,especially if people seemed as if they might be feeling nervous of answering, there were times when I emphasised

that as far as I was concerned there was no right or wrong answer to the

question and that I as the supporter was just as happy with one answer as

another. I did this in an attempt to minimise the possibility of researchers

giving answers that they thought might please me. I also reasoned that this

would help to take away any fear of getting the answer 'wrong' that the

service user may have been holding and possibly make the process of

answering the question less stressful.

There were also times when it seemed supportive to reassure researchers

that their views were valid, as the following transcript demonstrates. In this

example I was checking that I had written down what a Research Group

member wanted me to by repeating the text back to him:

> Vic: So when I go there on Thursday [college] I think oh God, not this
> place again. Do you feel that that here [People First West]? Really it's
> fine to say if you do. And you said I feel safe here, no one can get me,
> you treat me as human.
> Bill: Put it wrongly. Is it put it wrongly?
> Vic: Absolutely not, it's up to you what you want to say, absolutely good.
> (Tape of Research Group meeting 7.10. 02)

Booth and Booth (1998) have discussed how threatening it can be to people

with learning difficulties to be asked questions in an interrogating way. I

always aimed to gently ask about Research Group members' understanding

of a subject in an unthreatening and transparent manner. As the aim of a user

controlled research supporter is not to be in a position of authority it became

clear that the reasons behind asking a question needed to be made clear to

the researchers. Here is an example:

> Vic: I think I'm not explaining the question very well, I'll just explain the question to you and you don't have to answer it. It's only just to try and get your views. I am only asking you a question to try and get your views together. That's why I'm asking you a question. I'm asking you a question to find out, so I can write down for you what your views are on people having a say in what happens in day centres and residential homes….(Tape of Research Group meeting 7.10. 02)

At times throughout the course of the project, it felt necessary to check out how service users might feel about answering certain questions. The reason for this was that I was aware that they might not choose to dwell on, or further explain, a potentially painful subject. To contextualise the above statement I would like to offer the following example. I had recently been told by a Research Group member that he felt he was treated as a human at People First West (he was comparing People First West to a place where he was not treated so well). I was writing down his views:

> Vic: So this treated as humans, how are you not treated as a human some time? Can I ask you that?
> Bill: Yeah. (Tape of Research Group meeting 7.10. 02)

In relation to discussing the components of the research supporter's role, what this implies is that the supporter may need to employ sensitivity around what questions may stress or distress service users, and at times ask them if it is acceptable to ask particular questions.

It also emerged from this research that there were times when it seemed supportive to make clear that it was entirely up to the service user researcher how much information they chose to divulge, if any. Here is one example of my doing this:

> Vic:...you don't have to say anything you don't want and you don't have to answer these questions if you don't want (Tape of Research Group meeting 29.7.02).

This type of intervention was done in an attempt to avoid, or minimise, service users feeling obliged to answer questions. It was also used to work against putting any pressure on service user researchers to focus on or answer questions related to subjects that they would rather not discuss because, for example, they found the subject too painful or stressful.

Trust, confidentiality and research support

There were times during the course of this project when researchers wanted reassurance that what they said to me or wrote down would not get back to certain other people in their lives:

> Bill: [to Vic]… Teachers, you ain't going to say it to teachers?
> Vic: Me, no. Let me just make it plain, does anyone believe I would go out of here and say anything to the teachers or the staff?
> Chantelle: No.
> Pearl: No.
> Bill: No.
> Vic: I won't I really won't, but it [what Bill did not want me to say to the teachers] is in the book; you can take it out if you want. They won't know it's you. We won't put your name on it.
> Chantelle: I don't give a monkey's because to be honest, people with learning difficulties should be treated equally and they should be treated right.
> Bill: Yeah. (Tape of Research Group meeting 7.10.02)

The following quotation from the Research Group's notes demonstrates how breaking confidentiality can make service users feel vulnerable and how it destroys trust. The Research Group member who is talking here had thought that the particularly intimate disclosures she had made to her social worker

were confidential. However her social worker revealed what she had said to the manager of her residential home.

> It's come to that stage where it is not safe for me to be there. But if I speak to [a social worker] it will go back to [the manager of my residential home] won't it? ….The social workers, anything that I tell them, they would tell [the manager of my residential home] and then what? You know the rest. …anything you say should be confidential and shouldn't be going out unless your consent [is given]...I just feel that I don't trust nobody at [her residential home] nobody. The only thing I can do now is ring up and talk to the people [where social workers are based] and tell them if I tell you something I don't want it going back to [my residential home]. I want it confidential, private… I told something confidential and it was broken and [a worker in the residential home] got to find out and I was called in [to the office in the residential home]. (Research Group notes)

The above quotation demonstrates how people with learning difficulties can experience 'staff' as being in league with each other, talking between themselves about intimate aspects of service users' lives. In order to talk about what really mattered to them in their lives openly (this was a fundamental aspect of the Research Group's research) Research Group members needed to be able to trust me and each other not to break confidentiality. As I mentioned earlier in this dissertation, all the Research Group members had been supported by me in one context or another before the formation of the Research Group. Some members knew me considerably better than others. A certain level of trust, for at least some of the people with learning difficulties, had already been gained. This may have helped in the early stages to make the process of communication more comfortable and consensual for the people with learning difficulties involved.

Over time, Research Group members discussed more intimate and potentially contentious information in my presence. For example, they talked about past abuse and what they thought about the behaviour of support and education workers that they did not feel strong enough to confront, people they were afraid of. During the course of this research it became apparent that maintaining confidentiality is a crucial aspect of developing a support relationship where service users are in control and feel comfortable enough to say what they want to.

Research Group members had aimed from the earliest meetings to make a difference in the lives of people with learning difficulties and to get their 'voices' heard nationally. The following section of the minutes of one of the earliest Research Group meetings clearly shows their intent (we were talking about the purpose or function of the Research Group):

> Vic asked what jobs are people doing in the Research Group. Chantelle had said the Research Group was her job. Vic also asked what makes the Research Group different to any other group that people are in. Chantelle said she can say what she wants, and swear if she likes. Pearl said we are sorting out racism and bullying and going round the borough asking people how long the bullying has been going on, and what it is like.
>
> Chantelle said "management are not allowed to pull up clients" and that the Research Group is a place where we can talk about professionals and work out how we can do research in the future. Rudy said the group is a chance for people with learning difficulties to do research and to stop people like [the manager of a large organisation for people with learning difficulties who had been quoted in the newspapers as saying something that seemed to be against self-advocacy] getting away with it. Pearl said that the real difference is getting our voices heard across the country.
>
> Vic said thanks for answering his question because it will help him to support the group better because he knows what people want the group for. (Research Group minutes 5.11.01)

They soon were clear that they wanted to publish their research as a book and even at this early stage (bearing in mind what their completed research was like) they were also clear about the focus of their research:

> Pearl and Chantelle want to write a book about their experiences and those of other people with learning difficulties and about what the research team did to help. Chantelle and Pearl want to write about making life better for people with learning difficulties using their own thoughts and those of other people with learning difficulties. Chantelle and Pearl said the point of the research is to talk about whether people with learning difficulties are happy or not in day centres and residential homes and what we can do about it. (Research Group minutes: meeting about funding 30.1.02)

However their research documented certain situations that they had been in, or were still involved in. At times, despite all attempts to render individual service users anonymous, these documented situations contained personal and other information that could identify them to their own service staff. I found it was necessary to check what researchers wanted to leave in and take out, while explaining the possible consequences. The following quote from research tapes documents one such situation out of many:

> Vic: I'm worried, wondering, about this book because there are some quite personal things in here of yours. Do you know what I mean? And you did say you wanted them in at the time but with this rape, with you being raped, you do say you want it in, but you are like, in a way saying there are some things wrong with [your residential home], something wrong with the way you were supported.
> Chantelle: Yeah.
> Vic: And you are saying that there is something wrong with the way you are still stuck there. So if people work out who you are even though you are called [another name] in the book they will know what you think. Do you mind if they know what you think?
> Chantelle: I suppose not. I suppose not.
> Vic: So you don't really mind?
> Chantelle: I don't give a shit at the moment (laughs). (Tape of Research Group meeting, 28 .11. 02)

An implication of this research is that research supporters working with people with learning difficulties need to be as clear as possible that the people they are supporting understand the consequences of publishing personal information and that they make an informed decision about whether or not to publish any personal information about them that is in the text. Even if names have been changed, to some people (for example their 'staff') the data will not be totally confidential because they might be able to work out who the person is from the situations described in the text.

Non-directive support in practice

As has already been explained in the methods chapter of this dissertation I was aiming to provide non-directive support to the researchers on this project. However, during the course of working face to face with Research Group members, several sources of data revealed that practising non-directive support in this context was not straightforward. It also became clear that the user controlled research supporter, unavoidably, has some influence on both the researchers and their research for the following reasons. The way in which the supporter presents, interprets, or excludes information has some bearing on what service users understand about a subject. Also, in order to support researchers to make informed decisions the supporter needs to divulge potentially influential information. In addition there are times when the supporter needs to give his or her potentially influential views to researchers, for example, when supporting them to counteract disabling, abusive or disempowering situations in their lives.

Support and interpreting information

The researchers with learning difficulties on this project needed support to understand and access information. However, it was not always possible to provide adequate support of this nature. The following quotation documents a time when I felt a piece of written information that the Research Group had been asked to work on was so detailed, confusing and complex that I could find no ethical way of interpreting it to make it more accessible to service users:

> Vic: There are so many things in here and it is so complicated to try and explain I'm not sure I'm giving you a chance to understand everything, but what, what I sum it up to be isn't going to be the whole picture because there are so many things involved in this.
> Bill: Like what?
> Vic: Well, Derek [the director of a research organisation] has asked me to explain it to you and all I can do is pick out bits and pieces to explain to you. …I don't think we can do it. I don't think we can do it. I don't think we can go through all this information and work out whether it's a good thing or not, where you really have say whether it's a good thing or not because there are so many things to talk about and work out because it is such a complicated proposal.
> Pearl: It's nice to ask us though isn't it, to do it.
> Vic:... I can't explain everything in it because… it could take a long, long time… Derek perhaps thinks I can explain it all to you but I feel that I'll be manipulating you in some way. Manipulating is not the right word. I feel I won't be able to explain it enough for you to have a real say over what you think about it, one way or the other.
> (Tape of Research Group meeting 11.11.02)

However, interpreting information was a significant part of the role of research supporter on this project. Here are some examples: At times there was a need to explain the roles of professionals that members of the Research Group were in contact with. Also I was called upon to interpret relatively inaccessible written information from different organisations, or to explain

words or concepts, that researchers came into contact with but did not understand.

The following transcript from a tape of a Research Group meeting shows me working to interpret information from the same research proposal as above. Research Group members were being employed to assess it. However, at this point I was not supporting them to try to understand the wording of the research proposal itself. Instead they were trying to ascertain the degree of involvement of people with learning difficulties in the development of the research proposal and the research. This is just one example of my needing to interpret information out of many I could have chosen:

> Vic: What they are saying the purpose of their research is, is to use the skills and the things they have at [a different People First organisation] to help develop self-advocacy and inclusion, which means people with learning difficulties being involved in things, being included. Do you know what included means?
> Chantelle: No.
> Vic: Joined in, part of things.
> Bill: Hmm.
> Vic: (pause) And they say they want people with learning difficulties to bring the experiences they have to the research project and to be more involved, more part of things, more joined into the way the research goes, have more control over the way, well they don't actually say that, just to be more part of the research and then somebody with learning difficulties, Brenda here, says…(Tape of Research Group meeting,11.11.02).

When summarising relatively inaccessible information it was clear to me that words or terms can be interpreted in a variety of ways. I found I was in a position to choose whether to use expansive descriptions with examples of related words or terms, or to keep my descriptions shorter, but risk being reductionist. I was also in a position to choose whether to put issues into a

broader political context or not. I came to realise that even when striving wholeheartedly not to have any influence over the agenda, the way that information was explained by me had an impact upon the service users' understanding of a subject. User controlled research supporters who work with people with learning difficulties are in the powerful position of being influential through the way they interpret and present information.

Support for informed choice

This research also highlighted that there was a need to support researchers with learning difficulties to make *informed* decisions. The following extract from my research diaries shows this. It also gives one example of how my involvement in the wider context of the researchers' lives impacted upon my role as a research supporter (in ways that might not have happened in a different research setting). The researcher mentioned was trying to decide whether to move to a woman's refuge after being raped in her own home. I was supporting her to identify the advantages, disadvantages and unknown quantities so she could make up her mind about what to do:

> From 3pm to 4pm I supported Chantelle to make an informed decision about moving to a women's refuge or staying at Grassacre [the residential home she was living in]. I said the sort of things I would want to find out before I would make a move. She knows nothing about the refuge or the staff or how long she could stay there or if it is in the borough or out of it, or where she would go after the refuge. Would it be to another temporary place or would it be the permanent place she is waiting for at Grassacre. I told her that she could ask to see the place and meet the staff before she made a decision. I helped her to be aware that there is no specialist refuge for women with learning difficulties within the borough. She might not get the amount of support she gets at Grassacre out of the borough in

a refuge for women with learning difficulties, everything and everyone would be new, with people she didn't know completely.

It seemed like going to a refuge was a big unknown, a risk that could go either way and Chantelle wasn't uncomfortable enough to take that risk and decided to stay at Grassacre. The man who raped her has been removed from Grassacre. He could not get past security it seemed. The door to the street can only be opened by staff at Grassacre and they would not let him in. Chantelle has moved downstairs and is surrounded by staff and she likes and feels supported by the majority of them, and really likes the manager. Chantelle, however is not happy with her key worker who has questioned her, asking if she is telling the truth about the rape. I didn't mention that Chantelle could ask to have her key worker changed if she wants. Chantelle has never really got on with her, to put it nicely, right from the start of their relationship. Perhaps I should mention this to Chantelle if she remains uncomfortable and dissatisfied with the service the support worker is offering. (Research Diary, 17.4.02)

Supporting Research Group members to deal with difficult personal problems and situations emerged as a significant part of my role on this project and more is written on this subject later on in this dissertation. However within the context of this section of this chapter it is enough to state that the above quotation gives an example of offering information to support a researcher to make a crucial decision in her life. The following is an example of a situation where Research Group members *reversed* a decision they had made when they were given the information to make an informed choice:

Janet [a manager of an organisation for disabled people] wanted [a well known research organisation] to have People First's [the Research Group's] 'Training Notes' and 'Presentation to Social Services Notes', and a copy for herself. When I asked her what she wanted them for, she said that it was unlikely that she would publish from them. At first I had let this go forward [without saying anything], she had asked Pearl and Chantelle if this was OK and they had said it was, but the consequences had not been explained to them. I explained later that they could either use them [the notes Janet wanted] for their [the Research Group's] book or give them to [a well-known research organisation who may possibly use them] for their book, and Chantelle and Pearl chose to not give the info. to [a well-known research organisation]. (Research Diary, 30.4.02)

It is clear that in both of the above situations, by taking care to support service users to understand information as fully as possible, and by pointing out the negative and positive consequences of courses of action as I saw them, as a research supporter I was an influential party in both Chantelle's, and Pearl's decision-making process.

Not sharing information that could contribute towards service users making an informed decision may reduce the research supporter's potential to influence researchers. However, the more researchers with learning difficulties understood the consequences of particular choices, the better equipped they were to make informed decisions. By offering information to support informed choice, as a research supporter, I was taking a necessary active role in supporting the self-empowerment of people with learning difficulties – and supporting the researchers' self-empowerment was a fundamental precondition for the effective operation of the Research Group.

The supporter's influence: offering opinions

This section looks at the subject of research supporters offering opinions to researchers, in relation to non-directive support and my experience of supporting researchers on this project. The following quotation is taken from my research diaries. At the time I was struggling with what seemed like a tension or contradiction between non-directive support and sharing partisan views and opinions with Research Group members.

I am not impartial. I am angry…about the injustices people with learning difficulties face… Surely I can have feelings and concerns that I can express and people with learning difficulties can be in control of the project. Why am I coming to them? Why do I want to do research? All this needs to be explained. [I need to] move away from services and approach them [Research Group members] as a human being. Human being to human being… The denial of feelings is a professional approach. I am anti-professional in as much as distance and denial of feelings is concerned. I am working with people with learning difficulties, not studying them. When people work together they discuss their enthusiasms, passions, concerns etc. It is possible to share feelings and interests without taking over. I am worried about this whole subject of taking over. (Research Diary, 15.3.01)

The following quotation from the Research Group's notes explains how they thought it was important that 'staff' believed in the rights of people with learning difficulties:

If they don't believe in the rights of people with learning disability what's the point? They can speak to us nicely but if they don't believe in our rights what's the point? (Research Group's notes)

The following extracts from tapes of Research Group meetings show me as a research supporter agreeing with service users and backing up their views.

Chantelle: We shouldn't be treated like that.
Vic: That's true.
(Tape of Research Group meeting, 4.3.02)

Chantelle: Yeah, it was Steve [a member of staff at the day centre Chantelle attended], yeah. Do you agree with that, Vic?
Vic: Yeah.
Chantelle: It was Steve that was making it difficult wasn't it?
Vic: It was, yeah. (Tape of Research Group meeting, 7.10.02)

As previously stated, research supporters aiming to be non-directive will influence the direction that researchers with learning difficulties take to some extent through the way that they interpret information and through the

information they offer to support informed choice. However, the influence of the research supporter is most obvious when offering observations or opinions. Research Group members often asked my opinion, and at times it felt like it would have been unsupportive not to offer a view. The following is an example of one such situation. The researcher saw the behaviour of a member of staff as being rude. I expanded upon that by saying that the member of staff was not only rude, but expecting behaviour from the service user that she had no right to expect:

> Chantelle: I was going to the emergency unit upstairs and I wanted to go back upstairs because I because I live up there. Because sometimes I spend some of my time downstairs, she erm, I wanted to go up and she said to me why don't you stay in one place, see that's being rude, isn't it?
> Vic: Yeah, she shouldn't tell you to stay in one place and not move around.
> Chantelle: You've got to move around, you can't stay in one place, my leg will seize up.
> Vic: Well, you shouldn't have to stay in one place anyway, you should be able to move around. You shouldn't be told to stay still and that you can't do this and can't do that. (Tape of Research Group meeting, 4.3.02)

During the course of this research I felt it would have been unethical to withhold particular information from people with learning difficulties, for example on issues concerning the oppression of people with learning difficulties and potential approaches to dealing with it. For example, by the time I first started working with the Research Group, current directives from the Department of Health stated that people with learning difficulties and their carers should have control over what happens to them within their own support services. They stated that should there be a disagreement between carers and people with learning difficulties the choices or decisions of people with learning difficulties should be given priority (Department of Health, 2001).

I concluded that part of my research supporter role was to inform people with learning difficulties of the Department of Health's directives in relation to their rights. I found Research Group members wanted to know this, and they were keen to discuss the areas in which they were controlled with a view to working towards furthering their empowerment. During the course of this project members of the Research Group chose to take part in several Department of Health-funded research projects on service user views around social care policy and practice. Here is an example from tapes of a Research Group meeting where researchers are discussing a Department of Health white paper. Stuart was one of the Research Group's participants. He too had learning difficulties:

Vic: The white paper says people with learning difficulties are going to be in control of their lives, now the new rules are the people with learning difficulties will be in control of their own lives.

Pearl: I don't want the government telling me what, telling me that I mustn't go anywhere on my own like I can't go out to a night club to socialize with people and things like that, you know what I mean. It's not right.

Vic: Would it be the government or social services?

Pearl: I think it's everything, social services more than the council…

…I want to enjoy my freedom before I get married.

Vic: Will that stop when you get married?

Stuart: What's that to do with the white paper?

Pearl: No, I don't want people to control my life for me, I want to control it myself.

Bill: Yeah yeah yeah, I see what you mean you don't want social services and all that. They are a pain in the.

Pearl: That's what I'm trying to say. I don't want social services to control my life…

Vic…Have you had a person centred plan made, Bill, to help you enjoy yourself more and go out and do what you want more?

Bill: Someone take me out.

Vic: And that never used to happen before.

Bill: Not happen again.
Vic: What it stopped?
Bill: Yeah.
Vic: Oh, that's terrible.
Bill: Last summer.
Vic: You had someone taking you out and now they've stopped?
Bill: Since last summer stopped it.
Vic: Why have they stopped it?
Bill: I don't know, nobody take me out.
Vic: It says you should be going out more, getting a job, going to college, having a great time. All the carers should be doing what you want them to do. They shouldn't be bossing you about. You should get good health care. You should be able to have control over where you live, how you live.
Bill: Now I am stuck in with no one to go out to with take me round the shops.
Vic: Well that's no good, is it? They say that, well basically everything you want, the government say they are going to try and do. You name it: you have control, you have a job, you have money, you go out, you go to clubs, you have a great time. They say that the government is going to work together to help you do that.
Bill: Oh yeah like what, next Christmas! I don't think so!... Liars, all liars.
Pearl: All liars.
Vic: Who're all liars?
Bill: Council. Say, they say they'll do this do that, never do. You see em on telly, they say make this world a better place, never do. (tape of Research Group meeting 21.12.02)

In the above transcript I was supporting Research Group members to understand aspects of the government's white paper Valuing People (Department of Health, 2001). I was drawing attention to how the directives in this white paper might relate to the lived experience of individual researchers if they were put into practice. This approach of relating local or national policy to their lives was one I often took to support researchers to understand both what a piece of policy meant (presenting policy in this concrete way made the meaning of it more accessible to researchers) and how their current experience related to it (which supported researchers to develop opinions about how effective current policy was in their own lives and those of their research participants).

In the above transcript, Pearl was focussing on an issue that she chose to discuss a lot during the group's research: how controlling services could be in her life and the lives of other people with learning difficulties. The directives in Valuing People were in stark contrast to Bill's lived experience. He only had his retired parents to support him to go out (he could not cross main roads on his own safely) and the little professional support to go out, that he and his parents had pushed to obtain, had been withdrawn. He clearly felt disillusioned about government policy for people with learning difficulties and because of what was happening in his life it is not surprising that he felt lied to.

As a supporter I was required to walk a fine line between not being directive and offering views and suggestions. However I discovered a constructive way of viewing this dilemma in relation to supporting the researchers to have the power over what happened in the group. I wrote the following in my diaries after I had been working on the project for over six months and had been meeting with the researchers in person for two months:

> I am not their teacher. I am more of a consultant who comes in, is
> employed by people. I try and think of myself like that. I am their [the
> Research Group's] consultant and they are my employer. (Research
> Diary 4.6.01)

Through reflecting upon the power balance between myself and the researchers and how I could view my role in relation to offering opinions, it eventually emerged in this research that viewing myself as consultant directly

employed by them (and consequently with the power to provide only the service that *they* wanted) was helpful.

Conclusion

Within this chapter I have presented dilemmas I encountered, within the context of Research Group meetings, when supporting people with learning difficulties to be in control of their own agenda. I have drawn attention to some of the barriers that this research indicated can prevent people with learning difficulties from exercising control with their own research group. I have also addressed, within the context of my interpersonal support role on this project, the ways that I worked towards supporting people with learning difficulties to exercise control over their own agenda.

It emerged in the initial stages of supporting the Research Group that the members all had experience of being routinely disempowered, and in some instances abused within organisations for people with learning difficulties. These experiences were part of the history of individual Research Group members and to some extent part of their current experience as service users.

Although they appreciated and valued some of the support they currently received, Research Group members made it clear that in their opinion, people with learning difficulties were afforded less power within their services and organisations than social care professionals. They claimed that at best they

were only afforded power to make decisions up to the point where 'staff' disagreed with them. They also made it clear that they found it hard to stand up to people who were (like me) employed to support them, when they were being pressured to change their opinions or decisions.

Thus emerging from the earliest phase of this project were data suggesting that user controlled research supporters need to work against being in, and/or being perceived as being in, a position of authority over researchers. An implication of this finding is that *user controlled* research supporters need to avoid directing or assuming control over Research Group members, particularly during times when they disagree with researchers' decisions, and/or when there is a conflict of interest between the supporter's and researchers' needs.

In response to the above I aimed to minimise conflict of interest by attempting to ensure that any agenda of mine (as both a research supporter and a researcher in my own right) did not conflict with my aim of providing support for the members of the Research Group to be in control of their own project. I also aimed to set clear boundaries around my own behaviour to avoid getting into conflict with the researchers. In order to do this I found there was a need to practise a vigilant and reflexive self-awareness around my own interactions with Research Group members.

It became clear in this research that supporting Research Group members to feel comfortable to confront or disagree with me as their research supporter

tied in with supporting them to be in control of their own project. One strategy I used was to often inform them that they, and not me, were in control of the group. Another strategy I used was aiming to ensure that I did not express subtle irritation or disapproval at decisions they made even when they went against what I perceived as my own best interests. I also sought to make clear by my actions that there would be no repercussions on my part, or conflict in response to, whatever course of action Research Group members chose to take. On this project I also needed to be especially gentle in my manner, as some of the Research Group members (because of past trauma) could experience high levels of anxiety around professionals.

It appeared that Research Group members did get more assertive and confident over time about setting the pace of their meetings and being in control of their own agenda. At times, they also appeared to comfortably make decisions to work in ways that I didn't always agree with. In time, Research Group members seemed confident enough to mildly admonish or correct me (albeit in a humorous and good-natured way).

On this project the Research Group members were very supportive and friendly towards each other and me. They clearly placed value on being informal and friendly and sharing a sense of humour in their meetings. They also made clear that they thought it important that people who supported them had a sense of humour.

The researchers invited me to socialise with them outside of the group, which I did. They made it clear that they valued this time and claimed that it helped the quality of our working relationship. On this project, sharing a sense of humour and socialising with the researchers appeared to facilitate them to be more comfortable with me, and to work against my being perceived as being in a position of authority over the group.

It also was revealed in the early stages of this research that miscommunication (my not understanding what Research Group members were aiming to convey at times, and them not always understanding each other and me) was to be a fundamental and enduring dilemma on this project. This research implied that there was a need for a support strategy to work with miscommunication, that the researchers would feel comfortable with, and that would not embarrass or place unnecessary responsibility on them for what was, in effect, an access issue.

During the course of this project a way of working towards reaching understanding on both sides without placing responsibility on the researcher with learning difficulties was developed. In essence, as a research supporter, I took responsibility for not making myself clear when I was misunderstood and for not understanding when I was unclear about what a researcher was trying to communicate.

 It became clear early on in this project that asking open-ended questions, was a fundamental aspect of supporting Research Group members to

express their views. However as MCarthy (1998) has pointed out, some people with learning difficulties can find answering open-ended questions difficult. During the course of this research I found that certain strategies could be used to support researchers with learning difficulties to feel more comfortable and confident about answering open ended questions. The following could be helpful: being transparent about the purpose of asking the question, making it clear that they could take as much time as they need to answer the question, mirroring back what people were saying, reassuring them that they had the capacity to answer the question (if I had evidence of this), reassuring the researchers that their views were valid and that there was no right or wrong answer (and therefore nothing to get wrong in understanding the question). In relation to the ethics of asking open-ended questions it was also revealed in this research that the supporter could stress that there was no pressure on researchers to choose to answer the question, and that it was up to them when they stopped talking, and how much and what they chose to talk about.

It became clear during the course of this research that in order to feel comfortable to express certain views, Research Group members needed to trust both, me as their supporter, and each other, to maintain confidentiality. There were also times during this project when researchers wanted to be reassured that what they said would not get back to certain persons. Research Group members explained that they had experienced support staff breaking confidence. They also discussed how it could seem that 'staff' were all in league with each other. Although all of the researchers knew me to

some extent before this research (and had no experience of my breaking confidence) it seemed that in this research they trusted me more over time. It became clear that supporting people to understand the consequence of publishing research that had personal information in it, even when names and places had been changed, was a fundamental part of the role of research supporter on this project.

This research has focused on dilemmas relating to the issue of aiming to provide *non-directive* user controlled research support to people with learning difficulties. However it was revealed during the course of this research that providing *non-directive* support was not straightforward on this project. The researchers with learning difficulties needed support to access information, and interpreting information was a significant part of my role as a supporter. It became clear that how much data I gave them when interpreting information, and the focus I gave my interpretation, inadvertently gave me some power or influence over the agenda of the researchers.

This research highlighted that supporting researchers with learning difficulties to make *informed* decisions was also a significant part of the user controlled research supporter role. By taking care to support service users to understand the choices that I understood were available to them, and by pointing out potential negative and positive consequences of particular courses of action (as I understood them) I was, at times, an influential party in the decision-making processes of Research Group members. However, it became clear on this project that by offering information to support informed choice I was taking

a necessary active role in supporting the self-empowerment of people with learning difficulties.

On this project researchers often asked for my opinion. It became clear during the course of this research that the influence of the research supporter is most obvious when offering observations or opinions. It also became clear that at times, it would have been unethical and unsupportive not to offer my opinion. For example, I felt I needed to offer opinions about potential approaches to dealing with oppression and make my views, about the behaviour of professionals who treated Research Group members disrespectfully or unprofessionally, clear. I also concluded, during this research, that at times it can be part of the user controlled research supporter's role to inform service users of their rights in relation to current social care policy.

It became clear during this project that the user controlled research supporter is required to walk a fine ethical line between not being directive and offering views and opinions. However, this research revealed that the user controlled research supporter needs to focus upon supporting service user researchers to be in control. As a research supporter I found it helpful (in relation to my offering views and opinions) to view myself as being directly employed by the service user researchers, as a consultant for them, providing the service they wanted.

Chapter 6

Findings 2: The impact of the wider organisational setting upon supporting user controlled research

Introduction

This chapter sets out findings related to the issue of supporting and practising user controlled research both, *within* the specific context of People First West and while coming into contact with *other* organisations. A deep understanding of the research supporter role for people with learning difficulties cannot be obtained without consideration of this wider organisational context. Therefore this chapter builds on the findings presented in Chapter 5 by opening the research focus out to look at how projects and organisations that were not the Research Group impacted upon service user researchers (and myself as their supporter) during the course of this research. The findings presented here document how Research Group members and myself interacted with these different projects and organisations to keep the Research Group's project *user-controlled*. The findings in this chapter are divided into four sections under four main headings.

The first of these headings is '**Funding**'. From early on in this research it became apparent that I was required to become involved in the fundraising process for the Research Group's project. This section lays out the issues and dilemmas, revealed in this research, around the subject of *providing user-controlled research support* during the fundraising process. In addition findings related to the issue of actually *obtaining funding* for the Research Group's project are also presented here. This section draws upon several data sources. Diary entries are used to focus on stages of the fundraising process (and my reactions to them as a research supporter). Minutes of Research Group meetings and Research Group notes have been drawn upon, in relation to the researchers' views around payment and an access issue that was part of the group's fundraising experience.

The second heading in this chapter is '**Recruitment, contracts and benefits**'. When undertaking this research several dilemmas arose in relation to providing user controlled research support and recruiting and paying service users to practise research within People First West. These dilemmas and issues are presented in this section in relation to the development and maintenance of this research supporter's practice of providing support for researchers to be in control of their own project. Two data sources are drawn upon in this section. Interviews are used to ascertain the views of Research Group members about their recruitment process. Diary entries are used in relation to how researcher employment issues impacted upon my support role on this project.

The third heading in this chapter is **'Supporting research for, and within, an organisation'**. There were times during this research when dilemmas relating to the funding and management of People First West directly threatened, or had potential to influence, the way Research Group members organised themselves. There were also times when the interventions of other workers in People First West had the potential to interrupt the self-directed nature of the Research Group's project. This section explains what these situations were and how I (in my role as user controlled research supporter) responded to or learned from them. This section draws upon two data sources: interviews that focus on opinions held by Research Group members about the nature of their support, and diary entries that record, and reflexively discuss, the interpersonal and organisational issues connected to supporting user controlled research in People First West.

The final heading in this chapter is '**Supporting researchers when they confused their Research Group aims with those of other projects'.** This final section documents some of the situations where confusion arose for Research Group members (and at times myself, as their supporter) within the Research Group, around the nature and structure of their working relationships with other projects, both within People First West and outside of it. This section also presents what this research revealed about the role of the user controlled research supporter in addressing this confusion. This section uses a variety of data sources. My research diaries are drawn upon to present

how I experienced, and addressed, supporting confusion within the Research Group. Research Group minutes are used here to explain (to some extent) the researchers' agendas, the range of issues they could choose to address in a meeting and how confusion could arise.

The following table lays out the main themes and subheadings within this chapter:

Funding
- Pressure to learn about processes connected to funding   - Inaccessible and inappropriate funding processes   - A need to seek advice   - Fundraising and a conflict of interests
Recruitment, contracts and benefits
- Recruitment issues   - Employment contracts   - Payment and benefits
Supporting user-controlled research for, and within, an organisation
- Responding to those who hold power in or over the organisation   - Internal organisational politics   - Managers attempting to define the agenda of the Research Group   - Unequal support and ground rules
Supporting researchers when they confused their Research Group aims with those of other projects

Funding

Pressure to learn about processes connected to funding

When embarking on this project I knew little about fundraising and issues connected to service user researchers being paid for their work. However it became clear early on in this project that (although I was not skilled at fundraising) I was going to have to take a large part in the fundraising process for the Research Group's research. This initially involved working with the co-ordinator of People First West. At the start of this process I felt somewhat daunted by the complications of fundraising and issues connected to the payment of members of the Research Group, as the following diary entry shows:

> Then I had to go in and speak to Dave [the first Co-ordinator of People First West that I worked with] about funding. Dave said that we needed more time. We arranged an appointment in a couple of weeks. I had invited Rudy [the first Research Group member] into the meeting. Only Dave and me talked. I felt anxious but it was stuff that did need to be questioned.
> - Who is leading this project. Who is in charge officially? (People First is officially in charge as an organisation. This is what I think I said).
> - There is a problem with benefits for some people around payment (Not for Rudy though he [Dave] pointed out).
> - Also Pearl is on the Management Committee and she could not get paid he said…
> - There are equality of opportunity issues and recruitment issues around people getting wages…
> …I left feeling a bit despondent about the complications [around funding and Research Group members getting paid]. I feel good now [reassured that] Dave is taking it seriously [the idea of a research group that I had initiated by saying I could provide support for one in People First West] and identifying potential problems… I had told him at the last meeting that I was no good with money and administration really.
> Why is everything so uncertain? Because I am doing something new… Today I realised that relaxing and letting go is an important

point… I have to learn to see this as part of the process. (Research Diary 17.4.01)

While fundraising was not an area I felt confident about, I had not even considered the other issues that Dave drew attention to, such as the payment of researchers on benefits and equality of opportunity policy in relation to the recruitment of researchers. However, in my role as research supporter on this project, aiming to overcome these dilemmas became part of my responsibility. I left the meeting not knowing how to resolve the dilemmas and anxious about being in this position. However I also realised that I had to have a strategy to deal with being in an uncertain and unfamiliar position.

As a research supporter undertaking tasks I was not experienced in, I found it difficult to be confident that my responses would be *as helpful* to service user researchers as they were intended to be. This was because supportive responses around tasks I was inexperienced in were untested. Here is an example from my diaries:

> I am feeling very inadequate not being able to fill in the form [The National Lottery research funding application form] with where we are at the moment. [The Co-ordinator of People First West] was right, it is very academic and perhaps not suitable. I said I'm sure we can do it. Now I don't think we can. (Research Diary 10.7.2001)

What emerged in this research is that part of the support researcher's role on projects such as this one (where there is no funding in place initially and the research is developed over time by a group of people with learning difficulties with support) may be to support service user researchers to access suitable funding for their project. It also became apparent that unless the research

supporter or service users are experienced in, and skilled at, fundraising at the onset of the project, or someone else has the skills and is in position to fundraise for them, there will be a need for the research supporter to learn about aspects of fundraising and about the issues related to the payment of service user researchers.

As has been previously stated in this dissertation, the aim of the service user controlled research supporter is to provide whatever appropriate support the service user researchers require to be in control of their own project (what is and is not appropriate support is discussed throughout the course of this dissertation). Fundraising was just one of several subjects that this research supporter was required to *learn* about to support the Research Group to move forward with their project. There were several more occasions when I as a research supporter needed to learn about a specific subject under pressure to provide adequate support. These situations are documented throughout this dissertation.

The ethnographic approach adopted in this research has revealed that the *reactive* aspect inherent in the support researcher's role can lead to supporters having to learn new and complex skills (urgently at times) in reaction to the needs of researchers and in order to support researchers effectively. This subject is not discussed within the literature on supporting people with learning difficulties to be actively involved in research production or a self-advocacy project.

Inaccessible and inappropriate funding processes

When attempting to get funding for the Research Group's project the research

funding forms we sent off for were not appropriate for the Research Group

members, or their project. The following extract from my research diaries

discusses a National Lottery form in particular, but it documents barriers we

encountered in relation to all of the academic research funding forms we

looked at:

> It is really difficult [the form is complex and written in language that was inaccessible to members of the Research Group] and would force us to hurry everything (faster than the Research Group members are doing it) on. People with learning difficulties don't think like the forms. They got really bored with the form when I tried to do it [work on it together with the Research Group]. It seems unsuitable…They [the Research Group] have not solidified what they are doing and the form requests that people are very defined about everything. (Research Diary 10.7.2001)

As the above diary entry mentions, parts of applying for funding were

relatively inaccessible for members of the Research Group. I found there was

a need for myself as a research supporter to act as both an interpreter and

scribe for the group in this situation. In order to support Research Group

members to make their own decisions when applying for funding, I

endeavoured to explain the content of the forms to them in relation to the

decisions that needed to be made in response to it. However, I found some of

the forms very difficult to explain to the Research Group, as the following

extract from the Research Group's minutes makes clear:

> When Vic tried to help people to understand the National lottery funding form people got very bored and Vic could not make it accessible and interesting really even though he tried. Vic said that trying to get money from the National Lottery might not be such a good idea because they

want us to be really clear about things the research team have not sorted out yet and the research team will need time to sort things out in their own way. (minutes of Research Group meeting 9.7.01)

We found that the research funders we approached required a clear research proposal outlining the content, management and timescale of the research project in detail. This was problematic on a user controlled project such as this one for the following reasons. Research Group members were inexperienced in research. Also they didn't know, at the start of their project, the exact nature of the research they wanted to undertake and how they planned to do it. The Toronto Group (2005) have stated that it is not usually possible for service users to obtain funding to prepare research proposals. They identified this as one of the barriers to empowering service users within mainstream and traditional research.

We also found that research funders wanted more information than the Research Group were able to give. The Research Group did eventually obtain funding, but not from a research funder (this is explained later). This research found that applying to organisations that *specifically fund research* was not productive. Turner and Beresford (2005) argue that user controlled research is not really valued by many research funders, politicians and people who run services. They claim that research that has a medical approach is valued much more highly currently, and that service users report it is harder to get funding for user controlled research than other types of research.

As I have already stated, the forms we looked at were written in academic language that was completely inaccessible to the researchers with learning

difficulties, and asked for highly detailed academic research proposals –

thereby excluding people with learning difficulties. An implication of this is that

supporters working ostensibly to support people with learning difficulties to

undertake research could feel pressured to take over and write and design

research proposals themselves. This could result in supporters obtaining

funding for a project that researchers with learning difficulties had not really

decided to undertake. During the course of this research I saw what appeared

to be an example of this.

Members of the Research Group were asked to review, for the Department of

Health, a research proposal for a large amount of money that was reportedly

written by people with learning difficulties. They clearly did not believe that

people with learning difficulties had written the proposal. Among other

comments they said the following in the report I supported them to write on

the subject (except for Pearl they chose to withhold their names on this

report):

> We don't understand the proposal.
> "I don't believe that it's done by people with learning difficulties. It's been done by the support worker" (Research Group member, name withheld).
> "I think it's all the support workers work and not people with learning difficulties. That a person with learning difficulties has not been involved in putting it together" (Pearl).
> "We think it's wrong that the staff have done it" (Research Group member, name withheld).
> … "We think that the people with learning difficulties would have liked to have done the research proposal but they are not getting their voices heard" (Pearl).
>
> From looking at this proposal this is what we think about the research:
> "Staff will have the power..." (Research Group member, name withheld).
> "The staff will take over people with learning difficulties" (Pearl).
> (18.11.02)

The Research Group members thought that the supporters involved in the above proposal had significantly disempowered the researchers with learning difficulties and that consequently their behaviour was unethical.

A need to seek advice

As we were having no success with being funded we asked for advice from a research centre that had a history of supporting people with learning difficulties to actively participate in research. I supported the Research Group to write in their own words to the Norah Fry Centre. This centre had worked in conjunction with people with learning difficulties on research projects in the past. They advised the Research Group to write to the Joseph Rowntree Foundation and ask them for funding, suggesting that the Research Group let them know 'what the research is about'. I supported the Research Group to do this.

The Joseph Rowntree Foundation explained that they could not justify funding us because they had recently decided to fund another group of people with learning difficulties in our borough to undertake a video project within a self-advocacy group. However, they gave us a list of funders we could choose to approach. With my support the Research Group wrote to them all in their own words.

Trust for London replied to one of the letters. They were very supportive of the project. They came to meet with the Research Group, myself and the co-

ordinator of People First West to guide people through the funding process. They accepted the process that the Research Group were going through. Although Trust for London was not primarily a funder of research, the Research Group's project fitted in with their aim of supporting the further empowerment of marginalised people (both in the process and content of the group's research). We worked with the co-ordinator of People First West to put forward an application to Trust for London. They decided to fund the Research Group's project.

Therefore it became clear during the course of this research that contacting other people in the field of researching with people with learning difficulties and asking their advice could be useful, as advice gathered in this way led to us finding a suitable funder. As I have already stated, a major problem we encountered was the inaccessibility of academic funding processes for inexperienced self-directed researchers with learning difficulties. Therefore in order to support them to maintain control at this important stage within their research project there was a need to move away from more traditional research funders and *find viable alternatives*. Supporting service users to network in the above way was part of this process.

Fundraising and a conflict of interest

At the start of the project People First West had agreed to meet the basic costs needed to undertake the Research Group's research until they managed to raise funds. This *temporary* funding did not include money to pay researchers with learning difficulties or myself for our time. However it

became apparent that the service users involved in this project felt strongly from very early on that they should be paid for their time. The following quotes from Research Group notes and minutes of the Research Group meetings demonstrate their views:

> Although we wanted to be in the Research Group even if we didn't get paid Pearl said right from the beginning that: "it wasn't right that people with learning difficulties only do voluntary work and not get paid". Chantelle said: "I felt hurt that I wasn't getting money for the job I was doing". (Research Group notes)

> Dave [the first co-ordinator of People First West] had said that he could not see a way for Pearl and Chantelle to get any money for working on the research project because they are both volunteers… Pearl and Chantelle said this was very unfair. They both said that they should get paid for doing the research and any other work they did for People First. Rudy explained how pissed off he felt when he wasn't being paid when he was a volunteer at [another] People First [organisation]… Pearl said that she feels that she is being used by People First because she is not getting any pay. Chantelle said that she feels pissed off because her and Pearl have done lots of work and they are not getting paid. (Minutes of Research Group meeting 30.7.01)

Clearly Research Group members felt strongly that they should have been getting paid for their work. As people with learning difficulties they had extensive experience of doing voluntary work. They felt that by not being paid they were being devalued and they were angry about this. The issue of Pearl and Chantelle receiving pay was complicated by them both having been members of People First West's management committee. A new co-ordinator was appointed to People First West several weeks after I started working with the researchers. Not long after he was appointed, this second co-ordinator liaised with the Charity Commission, who agreed to Chantelle and Pearl receiving pay. However I was afraid that Research Group members would

give up on the project if fundraising was unsuccessful. I wrote the following in my diary on the subject:

> I am worried a lot about funding now. My project could disappear and my PhD if I don't get funding. (Research Diary 2.10.01)

The above statement shows that as a research supporter I had vested interests in the Research Group succeeding in obtaining funding. My PhD was based around supporting a group of people with learning difficulties to undertake research and without funding the whole project may have failed. Therefore it emerged from this research that despite efforts made to separate the needs and ambitions of this research supporter from the agenda of the Research Group, this was not completely possible in relation to supporting the Research Group to fundraise.

An implication of the above finding is that when a user controlled research supporter has something to lose if funding is not obtained (for example their post as a research supporter or some status as a research supporter who supports service users to successfully achieve their goals) the supporter may have a vested interest in the researchers achieving funding. This could place pressure on them to attempt to try and make the project fit into a funder's requirements and compromise how much control the researchers have over their research project.

Oliver (1999) has discussed how emancipatory disability research paradigms require that the researcher actively sides with the disabled people they are

supporting to undertake research, or researching, with and supports them to get what they want from the research project. That was the stance that I took as a research supporter. Consequently the role entailed doing what I could to support the group to achieve and maintain the funding they wanted.

Taking the above stance into account, an implication of this research is that there may be another reason why the research supporter could have a vested interest in obtaining funding for a supported group's project. The research supporter may feel some *responsibility* for a project collapsing through lack of funding. It can be argued that ultimately the supporter holds no responsibility in this area. However the ethics of the supporter adopting a stance where they do not do the best they can to support the group to get funding (in the face of it being a difficult task) could be dubious.

This dissertation contains numerous examples of the exclusion and marginalisation of people with learning difficulties. If, for example, the project I had supported had failed through lack of funding it would have been yet another example of people with learning difficulties being excluded (in this case from being self-directed researchers).

Recruitment, contracts and benefits

Prior to the Research Group being funded, People First West, as an organisation, had no experience of paying members for working in any type of group. At the time the only person with learning difficulties being paid by

People First West was one *salaried* self-advocacy worker. After the Research

Group obtained funding it became apparent that issues needed to be resolved

in relation to administering payment to service user researchers.

Recruitment issues

Previous chapters of this dissertation have documented both, the way

Research Group members were selected to be invited to join the group, and

the reasons behind the Research Group's selection process. It has already

been mentioned that *knowing* and *trusting* the people they invited to work with

them were two elements of the Research Group's informal selection criteria.

However, this is what a Research Group member had to say when the group

was interviewed about this subject:

> Vic : The [the Research Group's] book says the Research Group chose
> people for the group and why.
> Pearl: We wanted, we wanted a good a good atmosphere and we wanted
> erm people that we could get on with and to be trusted and to you know
> talk about, about private things you know. Like in the book we wanted it to
> be, our people first, we wanted it to be confidential and we wanted a good
> atmosphere around people in the group we did. (interview 8.4.08)

Speaking on behalf of the Research Group, Pearl outlined their views on what

they required from new members. They wanted people that they could work in

harmony with and trust not to break confidentiality. Their way of ensuring that

they got this from new members was to invite people they knew to join the

group, that they felt (from personal experience), would meet these criteria.

The first example of an issue to be resolved in relation to payment of service

user researchers came when the first co-ordinator of People First West was

concerned about 'recruitment' to the Research Group, in relation to the

organisation's 'equal opportunities' policy. He felt that because payment of

money was involved, the 'posts' should be advertised publicly to give as many

people as possible the opportunity to apply to join the Research Group. He

proposed that those people who best fitted the criteria of the 'post' be given

the work. No official criteria for joining the group had been drawn up by

Research Group members. I expressed concern about implementing an equal

opportunities recruitment process because of the way membership to the

Research Group had been developed up until that point. This did not prevent

the co-ordinator from insisting that a formal 'equal opportunities' recruitment

process should take place. I was not sure what pressures were on him to

ensure that recruitment took this form.

However, that particular co-ordinator left People First West very soon after

giving the above directive. What transpired was that the Research Group

never addressed 'equal opportunities' in relation to recruitment; neither they or

the next co-ordinator brought up the issue. However, when the second co-

ordinator, 'Thomas' [not his real name], read this dissertation he had the

following to say about this subject:

> I took the view that this group was in fact a reflection of the diverse
> background of the organisation at the time and that as a self-selecting
> group there was no need to impose a largely tokenistic and unnecessary
> equal opportunities recruitment on the group (note to me from Thomas,
> 25.9.08).

Although it never happened, the Research Group's self directed way of

selecting new members was *about* to be overridden before the first co-

ordinator left. However, a finding of this research is that the autonomy of a self-directed research group *can* be compromised by the policies and funding requirements of the organisation they are working within (and, how those policies are implemented by managers within the organisation). During the course of this research it also became apparent that non-directive research support can be rendered more complex and stressful when a powerful person outside of the group wants or needs, as an organisational or funding requirement, specific procedures to be followed, especially when they run contrary to the way that service user researchers are choosing to manage themselves.

Employment contracts

Another example of an issue that needed to be resolved in relation to payment of service user researchers (after funding was in place) came into play when Thomas (the second co-ordinator of People First West) needed, as an organisational requirement, the Research Group members to have contracts. The co-ordinator drafted sample contracts then asked me what I thought of them. In effect we then worked on them together to make the contracts as flexible as possible. This is what I wrote in my diary about the subject:

> [Thomas] asked me to comment on the contracts (more power than I want here, but I didn't have the foresight to suggest anything else and the contracts could be improved upon to give more flexibility to the Research Team I thought). He put in all the changes I recommended (i.e. 'for about one day' rather than from 10.30 till 3.30 and got rid of the bit that said people can't have time away from the group without producing a sickness certificate to 'people can be paid if they are sick'. (Research Diary 12.6.08)

While I realised that constructing the contracts with the co-ordinator placed me in a powerful position that did not sit comfortably with my user controlled research supporter role, at the time neither of us considered how we could involve Research Group members in this process.

Upon reflection I experienced this power as a dilemma within my support role. There were times when various professionals I came in to contact with appeared to interact with me as if I was a spokesperson for, or co-ordinator of, the Research Group (one example is mentioned later on in this chapter). This was not surprising as at times I acted as an advocate for researchers, I had also initiated the project and could not expect others to understand the role I had constructed for myself when it had not been explained to them. However, what can be inferred from this dilemma is that when interacting with other professionals who are also in place to provide a supportive service of some sort for people with learning difficulties, user controlled research supporters can be presented with a conflict of power in relation to their role.

In relation to service users having control of their own project it would ideally have been preferable if the researchers themselves had been fully involved in the process of structuring their contracts. However, the contracts the Research Group were eventually issued with allowed members to decide the following: when they wanted the group to meet or not, how long they wanted to work on given days and when to have time away from the group. It was crucial that members could have periods of time away from the group when they needed to, as at times being involved in the Research Group could be

very stressful for individual members.

During the course of this research it became clear that contracts issued by the organisation employing service user researchers could also have *the potential* to compromise the autonomy of the self directed research group. For example, if the co-ordinator had taken a different approach and decided to issue less flexible contracts, Research Group members would have had considerably less control over the terms and conditions of their involvement in their research than they did in this instance.

Payment and benefits

It became apparent there was another issue that needed to be addressed in relation to the payment of service user researchers. Members of the Research Group, the co-ordinator of People First West and myself as a research supporter were concerned that any payment made to Research Group members who were in receipt of benefits should not put those benefits at risk.

One Research Group member on benefits expressed serious concern about her benefits being stopped or put on hold. The rest of the Research Group were supportive of this member's concerns, and the general consensus within the group was that no risks should be taken in this area. I supported Research Group members to discuss the situation and to talk personally with an expert on law and benefits. He worked in the same building as People First West and was known to the members of the Research Group. The researchers agreed to go ahead with whatever he recommended.

In the short time it took the expert in benefits to prepare a statement advising us to take a particular course of action there was a change in the amount of money people on benefits could legally receive. The following extract from my diary explains this:

> After speaking with [the expert in law and benefits] on Monday and Tuesday I have told [the co-ordinator of People First West] to backdate the Research Group's pay only till 8th April. They may have got around three to four weeks more if we hadn't but [the expert in law and benefits] advised this because the law changed then from 'therapeutic earnings' where you have to see a doctor to 'permitted earnings' where you don't have to see a doctor. [The expert in law and benefits] said it would have been very complex if not impossible to sort out and because of the backdated nature possibly cause the benefits of Research Team members to be stopped. We can never risk that. (Research Diary 14.5.02).

In this research we found that it was beneficial to ask an expert in law and benefits to advise us about how payment to service user researchers on benefits could be safely made. We chose to work with an expert in the field because it became apparent that the subject is complex and that the criteria for benefit eligibility changes, and these changes need to be kept up with.

It has already been discussed in chapters 1 and 2 that people with learning difficulties can be disabled by and excluded within society. As such many people with learning difficulties are unemployed and in receipt of benefits. This research has indicated that part of the research supporter's role can be to ensure that any payment made to researchers will not compromise these benefits. This may involve liaising with benefits advice experts or supporting individuals with learning difficulties to do so.

Supporting user-controlled research for, and within, an organisation

Findings related to the issue of providing user controlled research support to a group that is *part of an organisation* are presented in this section. This section also sets out how the funders of People First West had the potential to impact upon the work of the Research Group.

Responding to those who hold power in or over the organisation

On this project both Research Group members and myself, as their supporter, were employees of People First West. Different self-advocacy groups within the organisation were funded by a range of organisations. However the funder that gave the largest amount of money (by far) to People First West was the local social services. Their funding paid for the use of the building, the full-time co-ordinator's post and a part-time self-advocacy development post for a person with learning difficulties (with a supporter). In time, social services also funded another full-time worker in People First West to support the involvement of people with learning difficulties in local Partnership Board meetings (that in principle informed decisions social and other services made around service delivery and development in the borough).

As has been already stated, the Research Group was not funded directly by social services. However, I was aware that people in power within social

services could feel threatened by the content of the Research Group's research. I wrote the following in my diary:

> While I am fairly confident that the people with learning difficulties [within People First West] will not mind what I write [on behalf of the Research Group] and wholeheartedly approve it… I am not so sure that [the co-ordinator of People First West] will… Pressure may be put on [him by social services] to complain about what [is]… written. (Research Diary 7.12.01)

There was good reason for me to be concerned about the response of social services to the content of the Research Group's research. At one point social services managers did get upset about something that the Research Group did. The Research Group had written (with my support) on a website that both social services and People First West did not know what to do about racism between service users in a day centre. They also had requested examples of good practice. Assuming that the problem we were discussing was not just a local one we had not realised that social services managers would be concerned about what was written. However they were. The following extract from my diary recounts what happened the day after we posted the email on the forum:

> [The co-ordinator of People First, Thomas] phoned me this morning. He had received a phone call from Alice [the manager of a team of Social Workers] (Thomas thinks she is standing in for Michael as he is on leave at the moment) about the 'What can we do about Racism' email that we posted on [a website] yesterday. Alice had responded immediately…she had already spoken to Tony [the manager of the day centre]. Thomas told me that they were concerned about a part of the email that stated we had spoken to social services managers and they, as well as us, didn't know what to do about racist name-calling from service users. Thomas told me that Tony had said it wasn't quite like that. Alice wanted to arrange a meeting about the email. Thomas asked her to write to the Research Group. I said to Thomas that I feel nervous but this is just the start really. If you support people to say what they want and they say things that social services don't like or feel exposed, or misrepresented by, they could respond in ways that will make us feel very uncomfortable. Thomas said he is not going to back down. He understands the dynamic and also admitted to feeling nervous. We know that what we are doing is

supporting people with learning difficulties to say what they want.
(Research Diary 24.10.2001)

Tony [the manager of a local day centre] questioned Chantelle in the day centre, on her own, about the email. Chantelle told members of the Research Group and me about it. Being questioned like this had upset Chantelle. The co-ordinator of People First West phoned Tony up to relay to him that People First West did not want him to approach Chantelle on her own again about the subject. This is what I wrote at the time in my research diary:

> Thomas phoned Tony on Thursday because Chantelle had said that Tony [the Manager of the Day Centre she attended] had "pulled her up" about the email. People in the Research Group think it is wrong for Tony to get Chantelle to one side outside of the Research Group…Chantelle was upset about Tony speaking to her about the group and felt as if she couldn't cope. Rudy said "We are in a war against racism" and we will stand together. (Research Diary 29.10.2001)

A short while later, Thomas explained to the Research Group and me what had happened when he phoned Tony. It seemed that Tony felt that the email made him and Michael look as if they were incompetent and uncaring. Rudy decided to speak to Michael about the issue to explain and find out what Michael's views were on the subject. At this point I was feeling nervous myself about being involved in such a contentious issue with social services, the main funder of People First West. I wrote the following in my research diary:

> …Thomas phoned Tony up to say that people at People First didn't think it was a good idea to get Chantelle to one side outside of the Research Group to question her about things to do with it. Tony had said at some point, according to Thomas, that the email made them look like 'incompetents who don't give a shit'. Thomas said he didn't think the email did this and that was not his impression of it and that he should get in touch with the Research Team.…Tony is a powerful manager. Chantelle sometimes calls him "my manager" and he was questioning the validity of the email with Chantelle on her own while holding a very aggrieved response to it. Rudy… decided to phone Michael [a manager of Social Services for people with learning difficulties in the borough] about it. Michael did not question the validity of the email. Michael said he would talk to Tony on Wednesday. Rudy felt Michael was supportive…I hope Michael understands what [I think] the limitations to his post are…[and

that this issue is] not some failing of his…My heart is pounding. I am scared. (Research Diary 1.11.2001)

The Research Group minutes for the 5th of November 2001 contain the following statement about the result of Rudy's talk with Michael. It is interesting to note that Tony, the manager of the day centre, was claiming that racism happened only three or four times a year in the day centre and that service users disagreed with this analysis:

> Rudy talked to Michael about Tony getting Chantelle to one side outside of the research meetings. Rudy told Michael this was wrong and that if anyone has an issue to talk to the Research Group about they should contact the group to arrange a time to time to speak to the group. Michael said he would speak with Tony about this issue. Rudy arranged a meeting with Michael and Tony for the 20th of November….Although Tony has said racism only happens 3 or 4 times a year in Nicholas Street people [Research Group members] thought it happens more than that.

The Research Group had their meeting with Tony and Michael. The atmosphere was very tense. Michael and Tony did not want the issue of the content of the email put on the agenda. I wrote the following in my diary at the time:

> They [Michael and Tony] have hidden agendas that they don't want putting on the agenda. They say they have nothing to add to the agenda and then they hijack the meeting to get their point across, that they had obviously had a meeting about.…They obviously wanted to talk about disagreeing with the email and feeling vulnerable but nothing is above board ("scratch it off the minutes" and "don't minute this" etc.). (Research Diary 21.11.2001)

However, the social services managers eventually came out and said that we had potentially damaged their image, which they needed to protect because of how they were monitored. There was a lot of tension and some anger (on their part) prior to this disclosure. Members of the Research Group and I were stressed by their response.

Reflecting on how difficult the meeting had been and my own behaviour in relation to it, I wrote the following in my diary on the 20th of November 2001:

> Am I...trying to attack those with more power than me? I hope that nothing or very little of this is true. However I will have to watch out for it and avoid any feelings of superiority or anger. This work is so emotionally challenging…The meeting with Tony and Michael was scary and difficult. It was difficult to get agenda items addressed.

I was aware that the Research Group's research contained numerous examples of active criticism of social services' interventions and as such had the potential, when published, to threaten them even more than the question posed by the Research Group on the website. Carl Rogers (1978) has discussed how challenging it can be for the individual who supports people to be in control of their own agenda, and how aggressive those in 'authority' can be towards those who give non-directive support. In a description of how he brought the client-centred approach to a Summer Workshop for children, which he states went very well, in both his and the children's view, he was sacked because he was seen by those who had employed him as not exercising 'discipline'. Those people in charge were so angry, outraged and disturbed by his way of working that they ganged up on him in an underhand way, as the following quotation describes:

> I walked into Mr. Barnes' upstairs office on Monday morning on the fourth week of camp and found Mr. Smith there along with Mr. Barnes and some other people I didn't recognize. I was told that *everyone* was not there yet… "What!" I thought. "This was supposed to be a meeting between three people!"…I walked into a room full of about eight people. This I learned, was most of the executive board of the Community House. The executive director of the board was a sixty-six year old woman…..,who was a nice person, and who had, in her way, given a lot of time to doing things for the community - but in a kind of …liberal way, which was absolutely unresponsive. She knew what people should have and what should be done and nobody should rock her boat and nobody should challenge her because she was an awfully nice lady. And she was. She really was…I learned later that by this time there were some fantastic rumours going around about me: I was a homosexual and was assaulting men on the staff; I was seducing the women and was caught making love with one of them in the sandbox; I was part of a Communist conspiracy, trained in a camp in Canada to take over this community, starting with the kids – that last one came directly from Mr. Barnes, according to three

people. I was seen sort of like a conspiratorial Pied Piper. (Rogers, 1978; 195-196)

It would be easy to state that circumstances were more difficult in 1978 and that people would not be attacked now for supporting people to be in control of their own agendas especially as Valuing People (2001) advocates that people with learning difficulties have more control over what happens in their lives. However, it still remains difficult, complex and at times frightening to side in a non-controlling way with people with learning difficulties and engage with those in authority. In relation to advocating on behalf of people with learning difficulties (which can also be an aspect of supporting self-advocacy) Henderson and Pochin (2001; 25-26) have made the following comments:

> Even within structurally independent schemes, the temptation for advocates to collude with service systems rather than remain loyal to their partners is all too real…advocates may find themselves seduced by the camaraderie that often exists within large service provider organisations, or lured by the trappings of professionalism. This is a failing of the advocacy movement as much as of the individual advocate. Speaking up for disempowered individuals, often within a hostile environment is a high-stress activity.

An implication of the above findings is that there may be a need for the research supporter to be aware of who holds power within or over the organisation that employs service user researchers and their supporters. The research supporter may also need to be aware of how that power could be exercised to control or compromise the work of the service user researchers and respond appropriately to this information.

Internal organisational politics

At certain points while supporting the Research Group at People First West I was drawn into office politics and interpersonal tensions within the

organisation. Here is an example, also connected to social services funding work in People First West. One of the workers with learning difficulties and her supporter felt at a particular time that the co-ordinator of People First West was too close to managers in social services and other managers that she felt had been personally disempowering towards her. Some of these managers came in to People First West to see the co-ordinator and had meetings with him alone. I got the impression that the worker with learning difficulties and her supporter wanted to know where I stood in relation to this isssue. I made my position and views as clear as I felt I could. I wrote the following in my diary:

> I felt very uncomfortable talking about [the co-ordinator of People First West]… [The worker with learning difficulties] said that… People First West is too manager-led…I couldn't disagree [at that time] with [the worker with learning difficulties and her supporter] and why would I? It is not possible for me to just be outside of this. [The worker with learning difficulties and her supporter] asked directly for my views. (Research Diary 13.4.02)

There was a high level of emotion involved in the above situation. It was certainly made clear in this research that the role of user-controlled research supporter be can emotionally demanding and far from that of an 'objective' academic. I was reticent about getting involved in the above dispute because at the time I felt it had the potential to impact on the Research Group in some way. However I did get involved, albeit tentatively. In the end I was an active party in the disputes going on in the team at People First West at that time.

I did my best to be helpful and supportive to the worker with learning difficulties and her supporter. It was clear that the worker with learning

difficulties was feeling comparatively powerless in relation to the co-ordinator who did not have learning difficulties. In the end, thanks mostly to the worker with learning difficulties and her supporter, the tensions were aired openly and the co-ordinator was told about the concerns staff had about the balance of power in the organisation.

I wrote the following in my diary after a People First West meeting where a lot of the tensions had been openly aired:

> We had a good team meeting and spent quite a lot of time chatting as a group today. The atmosphere has changed. It seems like [the worker with learning difficulties and her supporter] are more relaxed. [The co-ordinator of People First West] was very much going on about how he valued working with us all and how pleased and lucky he is to be working with us. We all said something about how pleased we were to be working with each other. I said that People First has been quite the same in structure for a long time, well before when [the current co-ordinator of People First West] arrived as 'manager' and now things were very dynamic and starting to change for the better. People agreed. We worked in a way that seemed very constructive to me on [a conference we all worked on] and there was a good team feeling today. (Research Diary 17.4.02)

The above happened at a time when there was tension within the team of paid workers at People First West. Responding to such tensions can be part of the role of people who support user-controlled Research Groups. Managing power dynamics and dealing constructively with the feelings of comparative powerlessness felt by people with learning difficulties can also be part of the role.

However it also became clear during the course of this research that being part of the workforce of an organisation can help to develop the work of the

research supporter. There were times when I, as a research supporter, was grateful to be working in People First West and felt supported by others working there, including the co-ordinator, as the following diary entry demonstrates:

> After the Research Group [the co-ordinator of People First West] suggested we chat about "how are things going" etc. We talked a bit about People First's/Research Group's book and how it is going... [The co-ordinator] seems very enthusiastic about it and what it will achieve. He is actually very good at helping me to develop my ideas about what I am able to do in the whole process. (Research Diary 1.4.02)

I found that as a research supporter working on a user led research project, there was often a need to become involved with other workers and people who were also part of the organisation. Consequently I found that on this project different interpersonal, political and organisational issues continued to be present throughout the entire time I worked at People First West. Researchers using more detached methods (for example, observation or questionnaires), who do not need to spend so much time within the research environment or get so involved within it, may have a better chance of avoiding this. However an implication of this research is that, when working in a supportive role within an organisation for people with learning difficulties, there may be times when attempting to be impartial in order to avoid any involvement in conflict or tensions within the organisation could be unethical. I found that dealing with interpersonal and organisational tensions was yet another time-consuming, emotionally demanding and potentially stressful aspect of the role of user controlled research supporter.

Managers attempting to define the agenda of the Research Group

Throughout the course of this research I supported Research Group members to meet with a variety of different managers of services and organisations. At times these managers appeared to have their own views on the function of the Research Group. Here is an example from my research diaries. This situation happened at the time when the Research Group attempted to work with social services on counteracting racism in the local day centre. When we met with a manager for services for people with learning difficulties he had his own ideas about the role of the Research Group:

> [A social services manager of services for people with learning difficulties] did ask what the role of the Research Group was at the start of the meeting. He added it as an agenda item. I asked him what his motivation was in asking. He said that People First had to be involved in the construction of social services policy. I explained that it was… the level and the way or place that people become involved that was in question rather than people being involved, and explained that the Research Group had a specific role and a limited amount of time to do it in, and again that it would fall to the management committee [of People First West] to decide how People First West would become involved in the development of policy within social services. [The social services manager] talks about People First's involvement as if I or the Research Group were making the decisions about what happens in People First. (Research Diary 9.2.02)

At this meeting I had to be assertive and confident to challenge the views of this social services manager, who was powerful within the organisation that was the main funder of People First West. It seemed to me at the time that his approach to the Research Group initially was that they were there to provide some sort of service for social services. This 'misconception' had to be

discussed before we could effectively proceed with the meeting. Therefore during the course of this research, I found that the research supporter may be called upon to stand up to, or contradict, powerful people who feel they have a right to define the agenda of service user researchers.

An uneasy relationship between the local social services and People First West members and workers contributed towards stresses and tensions in People First West. These impacted upon the Research Group and me as their supporter. Because much of the work in People First West was funded by social services, at times it felt like there was a certain amount of pressure from them to work in ways they approved of and that suited their needs. A problem I did not take into account when starting to work with People First West, an organisation that was ostensibly 'user controlled', was how much power those that fund a project have. The post of co-ordinator of People First West presented whoever took on the role with an essential conflict of interest. To fulfill the requirements of the funders to an extent where funding is continued, and to support the further empowerment of people with learning difficulties, are two aims which at the point of conflict do not share an equal balance of power.

Carr (2004) argues that despite there being a marked 'theoretical' movement away from paternalistic approaches to service users and a movement towards a 'partnership' approach, dilemmas surrounding historical power relations have not been resolved. The following quotation explains this situation further:

> …exclusionary structures, institutional practices and attitudes can still affect the extent to which service users can influence change. It appears that power sharing can be difficult within established mainstream structures, formal consultation mechanisms and traditional ideologies. (Carr, 2004; 14)

The co-ordinator of People First West read the final draft of the Research Group's book before it went to the publishers and did not try and change any of its content. He was initially unsure whether it was a good idea to be published under the real name of People First West, as I was, but he did not try to stop the real name going on the Research Group's published research. However, like me, he was nervous about how social services would respond to the publication and launch of the research. We both talked about how we felt about the situation. Therefore, while ultimately the work of the Research Group was not compromised there were still difficulties connected to social services providing the core funding for People First West.

Unequal support and ground rules

Two other workers within People First West brought to my attention that they were concerned that some members of the Research Group were being supported less than others at a time when a certain Research Group member was spending a considerable amount of time dealing with problems, and expressing distress, during Research Group meetings. I was asked what the Research Group's ground rules were. However the group had not made any ground rules. One member of staff made clear that she thought this was not good practice on my part, and that I should get the group to establish some ground rules. I wrote the following in my diary about this situation:

> I feel threatened about being challenged around ground rules as people may think I am just lax not to have got everyone to talk about them at the beginning of the group. I have discussed with [the co-ordinator of People First West] why I have not done this. I don't want to start the group by controlling the agenda (i.e. the development of the ground rules). If conflicts arise (which has never happened in the Research Group…) part of supporting the group may involve suggesting the development of ground rules. I know about ground rules… I have been challenged [by staff] for not setting ground rules before [when supporting a self-advocacy group in a mental health services drop in centre]… It seems that some people think [establishing] ground rules is a necessary part of supporting a [self-advocacy] group and anyone who doesn't ensure they are set at the start of a new group is behaving unprofessionally. (Research Diary 15.5.02)

I felt threatened by another worker saying I should ensure that the group had ground rules. I had been strongly criticised in the past in a different organisation for not *ensuring* that a group I supported had ground rules. The above diary extract also explains how I felt that, by aiming to put ground rules in place (especially at the beginning of the group) I would have given a message that I was directing the Research Group.

I told Research Group members about what had been said to me to see what they thought about adopting ground rules. They decided that they didn't want them. It is important to bear in mind however, before going any further, that Research Group members chose each other and knew each other well. This has not been the case with other groups I have supported who have opted to devise ground rules for their meetings, often to avoid or deal with conflict. There was no serious conflict between Research Group members during the entire time we met. They knew about ground rules. They had been in other groups that had them. When interviewed at a later date, Research Group

members had the following to say about why they didn't want ground rules in

their group:

> Vic: We didn't have any ground rules in the Research Group.
> Bill: No.
> Vic: Now you've written about this in your book.
> Bill: Yeah.
> Vic: But I just wonder if in your own words why? We didn't have any rules. Often we have ground rules for meetings but you lot decided not to have ground rules in your group. I think there were reasons for that. Why did you not want ground rules?
> Pearl: Because we had we had too many rules in our life already.
> Bill: Yeah, too many rules in my life always.
> Mary: Too much in our lives.
> Bill: I know I don't like rules.
> Mary: I don't like rules. I know we go to meetings, but that's why we decided because I've had loads of rules in my life (indistinct). It's best not, when we are doing the research not to have rules. I know we do in meetings (indistinct)…
> Vic: …You did all get on very well though. I don't remember a single argument between one of you, you know. When you think of some of the groups.
> Mary: [interrupting] Oh please, the [named group in People First West] God. One time I had to like split Rodger [People First West member], you [Vic] had to have Rodger, I had to have Rose [People First West member] (Mary makes a choking sound) you know.
> Vic: Yeah, What's that (makes the same choking sound as Mary), because you won't be able to see that on the tape.
> Mary: Because he got hold of her neck, didn't he…
> Vic:.. But why, why didn't you argue then?
> Mary: Because I get on well with Pearl. I get on well with Bill.
> Pearl: Because we didn't, we didn't feel like to have an argument all the time. Especially in work, cause you know what I mean?
> Vic: Yeah.
> Pearl: Because everybody gets on with everybody in People First West. There's no to have an argument in meetings or training (indistinct) and that's it.
> Vic: You all kind of knew each other as well.
> Mary: I've known Pearl a long time and Bill as well.
> Bill: Yeah.
> Vic: You all picked each other as well.
> Pearl: That's why we decided that we didn't want no more ground rules in our life.
> Mary: There's too many.
> Bill: Yeah. (interview 25.3.08)

Taking into account the views expressed above by the researchers, it seems safe to state that it is not the research supporter's responsibility to *ensure* that service user researchers establish ground rules in their meetings or even to assume that explicit or implicit ground rules should be in place.

It has been mentioned in previous chapters that the role of the user controlled research supporter involves aiming at all times *not* to control or be in a position of authority over group members. Putting this into practice as a research supporter meant not chairing, being in charge of, or being responsible for the nature of, Research Group meetings. However this research revealed that adopting this stance may not always sit well with co-workers within the organisation where user controlled research is being developed.

I did not mention to Research Group members at the time about the issue of my being challenged about not offering more equal levels of support at one time. However, I brought up this issue at a later point when interviewing them. They had the following to say about 'unequal' support:

> Vic: Now when I was doing these meetings with you. I never told you this but some people in the building… said some people in the group get more support than others…let me just explain she was saying Chantelle was getting more support than Bill say, at that time and she [Chantelle] was very upset. It seemed to me that you, you didn't want like, to just share all the support out equally but just give support to people who needed it at the time.
> Bill: Yes.
> Vic: Now Chantelle had, that was the time when Chantelle had only just been raped very recently.
> Bill: Yeah.
> Vic: Do you think we should have been giving everybody equal support at that time or more support to Chantelle at that time?

Mary: People should have support. I know [named member of staff] supports Chantelle a lot.
Vic: What do you think?
Mary: She should have more support. I had support like that [in the past].
Vic: And were you happy to have less support yourself from me?
Mary [interrupting] (emphatically) Mmm, Yeah, I was ok. What about you Bill?
Bill: I was OK. I feel sorry for Chantelle.
Vic: Yeah.
Bill: You know.
Vic: I do know… Can I just say this: [another member of People First's staff] was concerned at one time that Bill wasn't getting enough support at the time when Chantelle was raped and I was starting to wonder whether I should be giving like, equal support to people… What do you think…?
Mary: You supported her a lot, Chantelle.
Vic: but should I have done that?
Bill: Yeah.
Mary: Yeah.
Pearl: Yeah.
Vic: Why?
Mary: Because she needed it.
Bill: Yes.
Mary: (stridently) She was attacked…She needed support because I know what it's like. I've had a lot of problems and I've like been attacked when I was a kid, and in those days you didn't get a lot of support and I know what she was going through.
Vic: That's er.
Pearl: (interrupting) She needed it. (25.3.08)

What emerged in this research is that it can be unhelpful to *assume* that the role of the research supporter involves aiming to allocate support as equally as possible to service user researchers in the group. It became apparent during this research, that taking this stance could possibly lead to the supporter not providing the support that the researchers want. Adopting the stance of offering 'equal' support could be used as another way for the supporter to assume some control over what happens in the group. Supporters working in this way could perhaps underestimate any capacity that researchers have to empathise with each other's distress. To explain further, it is clear from the above interview transcript that the Research Group

members, unlike the small children that they sometimes got treated like, were not egocentric. They had the capacity to be empathic and reflect upon Chantelle's needs, and were choosing to support her because she was distressed at that time. Also at the time, they were not indicating they wanted support for themselves. Research Group members never complained about feeling pressured to support Chantelle. To all intents and purposes they appeared to want to support her during this difficult time and for me to support her also.

Supporting researchers when they confused their Research Group aims with those of other projects

During the course of their research, members of the Research Group (and myself as their supporter) worked on a variety of subjects related to their concerns, both inside and outside of People First West. For example, in just one not untypical Research Group meeting the following wide range of issues was discussed:

> [Subject 1] Rudy explained about the meeting he had arranged with [local social services managers] on racism…
> [Subject 2] Chantelle said she was upset on the phone the other day because she wanted to come to the [Research Group] meeting and because she had made a decision at that time to leave the management committee because one of the members of the [People First West's management] committee was being racist. Rudy explained how that member has been suspended from People First… [Chantelle] said she will come back [to the Research Group] as long as the suspended person stays away…

[Subject 3] Chantelle said one of the drivers called her a 'spoilt brat' the other day… everyone agreed that it is really out of order for a member of staff to call a service user names like that…

[Subject 4] …Chantelle applied for a counselor not so long ago… Chantelle does want to chase this up…

[Subject 5]… Pearl said, and Rudy and Chantelle agreed, that Vic should thank [the chair of a research organisation] for inviting the research team to [the research organisation's] conference…

[Subject 6] Rudy asked Vic if he had given [his PhD supervisor] the petitions [for a campaign Rudy was involved in with another People First organisation and as it eventually transpired with another group within People First West who saw themselves as co-ordinating the campaign]…

[Subject 7]… Rudy said we could check out the email [to see if a potential funder had got back to us]…

[Subject 8]… Rudy talked about people complaining about him laughing when he went to see French and Saunders at the theatre… Rudy wants to make a complaint to the theatre…

[Subject 9]… Rudy, Chantelle and Pearl talked about the way that people stare at them on the street. Pearl said "They look at you like you're nothing, and it's wrong to do that"…

[Subject 10]… Chantelle talked about how she hates making complaints. How [a complaint against a service she was involved with] is "eating her up inside"…[the group members discussed taking the complaint to a higher level]…Chantelle said she wants to do nothing [about taking the complaint further] for now. (Research Group minutes 10.9.01)

Clearly Research Group members could address a broad range of issues within their meetings. However, at times, it seemed like the boundaries between the Research Group's work and other projects, both within People First West and outside of it, had been blurred. Sometimes the subjects Research Group members focused on in their meetings (which they were also working on elsewhere) seemed to merge into one another or overlap.

For example, ongoing campaigns and projects, that were of concern to individual Research Group members, were brought into the Research Group to be developed further or worked on. However at times Research Group members were working with other service users and supporters on these issues in different groups they were part of.

Here is a description from my research diaries of one such situation: A member of the Research Group, Rudy, was involved in a campaign that had been initiated by another People First organisation that he was a member of. The campaign involved sending off petitions to complain about the director of a well known organisation for people with learning difficulties, who appeared to have made comments during an interview with a newspaper that went against the ethos of self-advocacy and user led projects:

> Joe's [the campaign manager of another People First organisation] involvement in this campaign or his support and our support, mine and [the co-ordinator of People First West's] doesn't seem to be coming together and between us we are serving to confuse people with learning difficulties. Rudy cannot see the full picture as I have explained it to him, or rather I have not explained it in a way that he either can or wants to grasp… Is it enough for Rudy to discuss this strategy without me being there [at the meetings in another People First organisation to understand the campaign strategy] if I am going to support him to carry out the campaign at People First West? I do not understand what Joe's role is in all of this. For example why didn't he support a campaign from his office? How much and in what way is he supporting People First [West]'s campaign. All this is unclear and I am left feeling that people with learning difficulties feel their campaign has been undermined…
>
> [The co-ordinator of People First West] was equally involved in saying the campaign as it was could not be endorsed by People First [West] and must be Rudy's private campaign because [the group in People First West that had made their own response to the newspaper report independent of the other People First organisation's response] had got a letter back from [the name of the organisation whose chair had been reported in the newspaper as making comments against self-advocacy] management committee [and] a proper campaign had not been constructed yet [by the group in People First West that was dealing with this situation.… [Rudy was annoyed and felt that his efforts to campaign against the man who had possibly made comments that were against self-advocacy where being 'stopped']. Rudy seems to be blaming [people working in a particular disability advice organisation] for not signing the petition (not me). Anyway Rudy is being told by Joe that he is being blocked. I feel pissed off with Joe but realise that he may be just as confused as [the co-ordinator of People First West] and me in this dynamic. I feel scared because people [in the Research Group] may think I blocked the campaign. (Research Diary 9.11.01)

The above diary extract documents a situation involving three individuals in a supportive role, of sorts, in Rudy's life and two different campaign groups (excluding the Research Group) that were focusing on the same campaign. As a non-directive research supporter I was working with what the group members brought to the meetings. Rudy had brought up the subject of the campaign and expressed the desire to develop it within the Research Group. Discussions about how to progress this campaign occurred during several Research Group meetings. However in relation to this particular campaign Rudy seemed to be operating independently within People First West (who already had a group in place to focus on this issue and respond in People First West's name). As work on this project was going on in other groups both within and outside of People First West (initially unbeknownst to us, and without effective co-ordination between the groups) this led to confusion.

Also, as research group members were involved in developing their interests and concerns in other groups *within* People First West, I found it difficult myself, as a supporter, to understand how I should view the Research Group in relation to the rest of what was happening in People First West. I wrote:

> It is all so confusing…The Research Group just doesn't stop at 3pm on Mondays they go on and into People First. What happens in People First comes into the Research Group. (Research Diary: 4.10.01)

 As well as discussing this issue with the Research Group I felt the need to discuss it with the co-ordinator of People First West. I wrote the following in my diary on the subject after meeting with him:

> [The co-ordinator of People First West] and me have discussed this.
> [After talking it seemed as if] the Research Group are now part of the
> fabric of People First, and within People First all of the things that happen
> outside of the Research Group are part of the fabric of the Research
> Group. (Research Diary 18.10.01)

Research Group members had said the following about how their work tied

into People First West in an earlier Research Group meeting:

> Rudy said the research is part of People First West. It is a People First
> West Project. (Research Group minutes 24.4.2001)

Having some idea of how the work of the Research Group fitted into People

First West (albeit not a totally clear idea) was helpful. However it is clear from

the above statements (particularly the first one) that the work of the Research

Group could certainly be expansive.

It emerged from this research that working *within* a self-advocacy organisation

on a user controlled research project (and on a variety of other projects) led to

both researchers with learning difficulties and myself as their supporter

experiencing a certain amount of confusion. Emancipatory research prioritises

production or concrete change over enquiry (Oliver, 1999). The nature of the

Research Group's proactive research combined with their active involvement

in other self-advocacy projects contributed to the confusion. It became

apparent that recognising and constructively addressing areas of confusion

was part of this research supporter's role.

During the course of this research I found that supporting researchers to

understand and differentiate between the aims, objectives, contexts and

approaches of different projects was an essential aspect of the research supporter's role. At times, all of the Research Group members needed support to differentiate effectively between the above categories in relation to their own project, other self-advocacy projects, campaigns and (eventually) other research they were involved in, both inside and outside of People First West.

Conclusion

As has already been stated, the role of the user controlled research supporter is to provide support for service users to be in control of their own research project. The previous chapter presented findings relating to the development of a specific non-authoritarian and non-directive research support role that was a part of this process. This chapter has illustrated that there is another layer to the user-controlled research supporter's role that can contribute towards its complexity. I found that as a user controlled research supporter I was required to react to a variety of complex situations and dilemmas that were (or stemmed from) outside of the Research Group and 'research' as such. However, they were related directly to the work of the Research Group and to supporting the researchers to finance and organise their project while staying in control of it.

To begin with, I came to this project understanding little about fundraising and issues connected to paying service user researchers. However I was required to support service users who were inexperienced in this area to address the

above issues. In order to do this I had to work in conjunction with the co-ordinator at People First West and employees of other organisations.

It has been revealed in this research that user controlled research support for people with learning difficulties, is largely about responding to the needs and requirements of service user researchers. Giving the support service users both wanted and needed (in relation to funding and employment issues) meant that, as a supporter, I had to learn about the subjects of fundraising and service user payment, and work with the co-ordinator of People First West as well as Research Group members while I went through this process. In relation to this, I found my role had a broader span of responsibility than I had anticipated and that I was under no small amount of pressure to 'get it right', as the project might have collapsed if funding could not be found, and it would have been very distressing for researchers if their benefits were stopped because of them being paid for undertaking research. On this project, the researchers and I found that expert legal advice was needed to ensure that researchers did not put themselves at risk of losing their benefits when being paid for their work.

The researchers certainly did not know how to fundraise or ensure that their benefits were not compromised. Despite being there to 'support' the researchers to achieve what they wanted, the responsibility fell (at least in part) on me to ensure that funding was obtained and that dilemmas in relation to service user payment and benefits were resolved.

An implication of this finding is that reflexive user controlled research supporters may be required to learn about any relevant subject that will enable them to provide the type of support that service users want from them. They also may be required to learn quickly, under no small amount of pressure, and take on responsibility for resolving administrative dilemmas urgently in relation to the service user researchers' project. Also these levels of responsibility, and the pressure and stress that come with them, throw into question (along with other findings in this dissertation) the current low professional status of the role of research supporter with people with learning difficulties. This subject will be discussed further in Chapter 8 of this dissertation.

It became clear when supporting the Research Group to apply for funding, that all of the organisations we looked into that specifically funded research did not have application processes that were appropriate for people with learning difficulties undertaking user-controlled research. The application forms were worded in a way that was not accessible to Research Group members, and they also requested detailed 'academic' research proposals that Research Group members were not in a position to give at the early developmental stage of their research. Basically these research application processes, despite paying lip service to inclusion, were aimed at more 'conventional' or 'academic' projects, and as such excluded people with learning difficulties involved in user controlled research projects.

On this project, getting advice (from organisations that had involved people with learning difficulties in research) about what organisations to approach for funding resulted in us getting in contact with an appropriate, supportive funder. This funder did not usually finance research but they were interested in supporting the further inclusion of people with learning difficulties into society. This implies that when applying for funding for user controlled research it may be useful to look for alternative sources of funding, from organisations that do not mainly fund research.

On this project effort was made to separate my needs, as a supporter and researcher, and the needs and interests of the researchers with learning difficulties. However, in relation to funding, this was not completely possible as it would have almost certainly impacted negatively upon my own research if the Research Group had not received funding. An implication of this finding is that if user controlled research supporters have any vested interest in service user researchers obtaining funding, for example to stay in employment themselves, their own needs may be involved in the funding process. This risks them needing or wanting to exercise a certain amount of control in this area in order to get their own needs met, which would compromise their role of supporting people with learning difficulties to be in control of their own project.

On this project, it seemed initially that pressure may have been put on this research supporter to facilitate service user researchers to go through specific recruitment procedures. In addition there was also an organisational need for

researchers to be issued with contracts of employment. In this case both the recruitment procedure and the conditions of the employment contract had at least the potential to compromise how much control the service user researchers had in relation to recruitment to the Research Group and the responsibilities of Research Group members.

The researchers claimed they needed to know and trust their co-researchers in order to speak openly and write about their experiences of services. They also claimed they needed flexibility around when they met and for how long, because at times they found the research both stressful and psychologically distressing. Both of these needs would not have been met if they had been directed to recruit their co-researchers in line with equality of opportunities policy and to sign a contract that stated when they had to meet and for how long. Therefore an implication of this research is that unexamined assumptions about the ways that organisations should run (with an equal opportunities policy and contracts of employment) may disempower researchers with learning difficulties and prevent them defining their own access needs in relation to undertaking meaningful user-controlled research.

Also if I (as a user controlled research supporter) had attempted, for example, to implement an equal opportunities strategy around employing researchers, I might have risked going against the role of supporting service users to be in control of their own project. In relation to user-controlled research support this would present a conflict of power.

I was aware, as a research supporter, that the content of the Research Group's research had the potential to upset managers within local social services. On this project this situation was of particular significance because social services provided the core funding for People First West. I found that being aware of who held power, both within People First West and over it, and at times finding ways to respond suitably to these parties, was part of my role as a research supporter. User controlled research supporters on other projects may have to deal with similar or related situations with powerful people and organisations.

I found that as a research supporter I could not always remain outside of the politics and conflicts that existed within the workforce of People First West. This was another time consuming and potentially stressful aspect of being a user controlled research supporter working within an organisation for people with learning difficulties.

On this project, despite being based in what was ostensibly a user controlled organisation, there was a time when two co-workers without learning difficulties thought I should direct the focus of the Research Group in a couple of areas. They recommended that I adopt two strategies that would have been against what Research Group members wanted and required. One was to ensure that the group set up ground rules and another was to ensure that the focus of my support was allocated more equally to all the members of the group. An implication of this finding is that in order to provide the support that service users want and to avoid directing service users, user controlled

research supporters may need to look to the supported group for guidance, particularly when ascertaining if they want support that may impact upon the structure of their meetings. Another implication of the above finding is that when user controlled ways of working are challenged by co-workers it may be necessary for the supporter to defend their non-directive user controlled stance.

In relation to protecting the self-directed nature of the Research Group's work there were times during the course of this research when it was necessary, as a research supporter, to stand up to powerful people without learning difficulties. An implication of this finding is that research supporters (as well as being gentle and supportive with service user researchers) may need to be strong and assertive around such powerful people, to work towards preventing them exercising some element of control over service user researchers. Again, this emphasises the variety of interpersonal skills that can be involved in supporting people with learning difficulties on a user-controlled research project.

The Research Group's project took place in an environment that was in effect particularly supportive of people with learning difficulties being in control of their own agenda. However, even in this near-perfect environment for supporting user controlled research, organisational pressures and the interventions of other professionals that had working relationships with either myself or the Research Group still had the potential to minimise, in some way, the self-directed nature of Research Group members' meetings.

In opening up previously hidden contextual issues about supporting people with learning difficulties, the ethnographic approach adopted in this research has revealed the following finding: when focusing on supporting people with learning difficulties to be in control of research and their own lives there is a need to consider more than just what takes place within the relationships between the supporter and service user researchers.

Issues relating to the impact of professionals, working within organisations that have potential or actual power to influence the way that the researchers organise their own agenda, have not been discussed in the literature on the subjects of self-advocacy and/or supporting people with learning difficulties to be involved in research processes before. However, the relationship between the supporter and researchers does not exist in isolation. This research has made clear that recognising and responding effectively to external pressures that threaten to minimize the control that researchers have over their working methods, and the way that they choose to organise themselves, can be a fundamental aspect of supporting user controlled-research with people with learning difficulties.

This research has also revealed that part of the user controlled research supporter's role can be to support researchers with learning difficulties to differentiate between the aims and focus of different groups and projects that they may be involved in. It became part of my role on this project because the researchers brought issues they were working on in other groups into the

Research Group and sometimes became confused between the aims of different groups. At times, in order to avoid confusion or duplication of work, I found that it was necessary to liaise with other groups to support researchers effectively.

Chapter 7

Findings 3: A reflective approach to personal attitudes and values

Introduction

This chapter presents what I discovered about, and out of, the process of being reflective about personal attitudes and values in relation to the research support role. The findings in this chapter focus on situations where user-controlled research supporters could find offering non-directive support psychologically difficult or personally stressful.

During the course of this research there were times when it was more difficult to adhere to the commitments and boundaries I set myself as a user-controlled research supporter. It became clear, that to stay on track and develop my support practice, reflection was an essential part of the user controlled research supporter's role. The findings here focus upon how reflection was used to develop and maintain my support role on this project.

This chapter uses only one data source, my research diaries. The reason for this is they demonstrate times when I used reflection to ensure that I dealt

with situations I found difficult in a way that was compatible with my commitments as a user controlled research supporter.

The following table lays out the main subheadings within this chapter:

A reflective approach to personal attitudes and values
- Reflection and user controlled research support   - Support and distressed service users   - Reflection and supporter anger   - Reflectivity and conflicts of interest   - Lack of status in the research support role

Reflection and user controlled research support

Brechin and Swain have stated that self-advocacy supporters need to monitor their communication (1988). Williams and Shoultz (1982) have argued that self-advocacy supporters cannot assume, because they have good intentions, there is no need to go through this process. They claim supporters have to be prepared to go through the difficult process of change. Throughout this project, I found that there was a need for me (as a research supporter) to monitor my own interventions with the service users I was supporting. However, I also found there was a need to be reflective about the values, attitudes, motives and feelings that underpinned these interventions.

I have already explained that as a user-controlled research supporter I needed to set boundaries on my own behaviour in order to best support the self-empowerment of Research Group members. However, I found there were times when it felt more difficult to stay within these boundaries. For example, it was more difficult when there was a conflict of interest between my own needs and motivations and those of Research Group members. It was also more difficult when the behaviour of Research Group members elicited feelings within me that were psychologically uncomfortable. In order to prevent damaging the support relationship I needed to acknowledge what it was that was making it feel difficult to keep offering non-directive user controlled support, and find ways to move forward constructively that did not compromise the quality of my support.

This chapter does not contain an exhaustive list of situations where I found I needed to be reflective about my responses in relation to the service users I supported. Also, what I found psychologically uncomfortable and what I needed/need to work on will not be exactly the same for another person. However, a range of key examples that were pertinent to this research are presented here. These examples demonstrate the need for ongoing reflection in relation to the user controlled research supporter's interactions with researchers with learning difficulties.

This level of sensitivity to and reflection about emotions and personal boundaries may not be such a significant part of research support in other circumstances. However this research has clearly demonstrated that user

controlled research with people with learning difficulties can involve offering

support for researchers to deal with intimate, relatively personal and

emotionally charged subjects as well as academic and administrative ones.

Support and distressed service users

During the course of this research I found that recognising and constructively

addressing defensive, unsupportive, or unconstructive reactions in response

to distressed service users, and continuing to develop self-awareness in this

area, was part of the user controlled research supporter's role. While working

with the Research Group there were times when one or another of the

members was considerably distressed. Here is an example of one such

situation from my diaries:

> [A Research Group member] ran from the room in tears. I caught up with
> her straight away as she slowed down to open the door to the toilets. I
> can't remember what I said but remember she said "I want my mum" and
> she put her head on me and I hugged her as she cried. (Research Diary
> 15.5.02)

The following quotation from my research diary shows me being reflective

about how I needed to respond in another situation in order to carry on being

supportive during a time when a service user was extremely distressed:

> [A Research Group member] didn't know whether to focus on the
> Research Group or talk about thoughts connected to her being raped
> recently. It feels funny writing it down 'raped' and just continuing to type
> but I have to and I have to be strong to help [this Research Group
> member] and other people as well as myself and write the PhD. My
> meditation is helping a lot recently. [A friend] phoned very distressed
> tonight. Usually other people's distress hurts me somehow and while I
> was able to support her I remained calm and composed myself [after
> listening to her]. Great, I need to be like this if I am to be useful [for the
> Research Group member and other people in the Research Group]. I

can't crumple and get so upset about the distress of others and the pain in the world. I need to be concerned and care without burning up or out. (Research Diary 17.4.02)

Obholzer and Roberts (1994) have discussed how professionals who work with people with learning difficulties can be in close proximity to people who are in a great deal of emotional pain and consciously or unconsciously seek to protect themselves from empathising fully with them. Although this does not appear to have been documented before in relation to supporting people with learning difficulties to undertake research, avoiding being supportively empathic towards service users in emotional pain can hurt them. I witnessed this happening several times during the course of this project outside of the Research Group. Here is a particularly clear example. A Research Group member had recently been raped in her residential home and was distressed about it. She approached a supporter to talk about the subject and the supporter turned away from her and did not respond. This resulted in the Research Group member getting even more distressed. I wrote the following in my diary about why the supporter had behaved in this way.

[Sarah, the supporter who refused to listen to the Research Group member] said [to me later that] it was difficult for her to listen to [the Research Group member] talking about this painful subject… as it could bring up feelings in her and perhaps really upset her and keep her awake at night. (Research Diary 15.5.02)

The reasons why the supporter felt she could not listen had not been explained to the Research Group member. It is not suggested anywhere within this research that supporters carry out their practice in ways that risk substantially damaging their own health or psychological well-being.

However, with the advantage of hindsight, it is possible to see that in such situations supporters can protect their own psychological well-being and offer support at the same time. For example, a supporter could explain that they could not cope with hearing about a particular situation for personal reasons and offer to find someone who can.

One of the times when it was most difficult for me to hold onto my stance of not attempting to control the group was when a Research Group member cried for considerable periods of time at Research Group meeting over a period of several consecutive weeks. I could not always comprehend why she was so distressed. I wrote the following in my diaries on the about how I felt about this situation: 'I feel 'despairing' and 'powerless' (Research Diaries, 2.10.01). These were difficult feelings to acknowledge and stay with.

Reflection and supporter anger

There were times during the course of this research when I felt angry about the actions of a member of the Research Group, particularly when I felt vulnerable in some way in response to their actions. I found that as a research supporter I needed to deal with these situations reflectively. Here is an example from my research diaries. One member of the Research Group repeatedly made the decision to leave the group but kept reversing her decision and returning:

> FRIDAY Chantelle rang me at home and said that she was not going to come in for 2 weeks until 25th when Alan [the regular minibus driver] is back. She also said that she didn't want Adrian [another service user] to join the Research Group…[earlier on in the week Chantelle and Pearl had decided to ask Adrian to join the Research Group]. I know I felt annoyed

or unnerved by Chantelle. She… was very assertive... She said she wanted a holiday and didn't want to be doing too much travelling and that is why she is having two weeks off. I said I didn't know what to do [about the Research Group now only having two members]. She said neither did she but if Adrian comes she can always leave. That she can leave or will leave if Adrian comes. I know at some point that I said that recently she has been saying she will leave every week. I told her I would phone Adrian and I did telling him that Chantelle is off for two weeks and doesn't want him to come and that Chantelle and Pearl might decide that they want an Afro Caribbean person after all. Adrian will go in to hospital… very soon so after Monday he wouldn't have been able to come in for a while anyway.

I phoned Chantelle back and in a friendly manner told her that Adrian had been told not to come to the group. Again Chantelle said she needed a holiday and that she thought it would be a good idea if I had a holiday. I laughed. At one point after phoning Chantelle I asked her if she was going to stick with coming to the Research Group now that was sorted out. She said she would decide this when she came back. Chantelle seemed quite relaxed really at this point. After the phone call I was very wound up. I feel so out of control of this project. Chantelle won't allow other people to come into the group and then often says she is going.

This week is too much altogether. I was very wound up and restless on Friday. …I feel this research group could just fall apart and there is nothing I can do about it. I also know that in some ways it is inevitable that this sort of thing can happen when other people are in control of a project. The problem is it seems so important to me that Chantelle stays. I am going out of my way to support her to attend, maybe even covertly encouraging her to attend and likewise with [finding] the new Research Group member. [My PhD supervisor] told me I had better try and build the group up. Well she [Chantelle] just doesn't want that… I am going to get the answering machine put back on rather than BT's answering service so that I can screen calls here at home because I need to be composed when I speak to Chantelle. (Research Diary 9.2.02)

My anger was triggered by feeling powerless to do anything about a situation that I was feeling stressed about and wanting to see changed. By working reflectively with and owning my feelings, rather than responding in an unaware fashion to them, I was better equipped to maintain the standard of my support and consistently respond to the Research Group member with

uncompromised positive regard. In short I was less likely to inadvertently

damage the support relationship in some way by acting upon or out of anger.

Reflectivity and conflicts of interest

There was a need to be reflective when the interests and needs of service

users and those of myself, as a user controlled research supporter, conflicted.

A range of such conflicts of interest arose during the course of this project.

They are explained along with the responses to them at various points

throughout this dissertation. However, although it didn't happen often, there

were also times when I found myself *balancing* my own needs and interests

against those of individual Research Group members and the group as a

whole. Reflection was also used in these situations to diminish the risk of

prioritising my own needs over those of Research Group members. Here is

one example from my research diaries. To put this quote in context; at the

point it was written, Pearl and Chantelle were the only members of the

Research Group and were saying at that time that they didn't want any other

people to join:

> The second situation adding to my anxiety levels is first Chantelle, then
> both Pearl and Chantelle, being absent from the Research Group [if the
> group had folded it would have been difficult for me and my research as
> well as being the end of their research, that both I and them had invested
> a lot in].
>
> I spoke to [a friend (Norma) whom I felt would understand the issues]
> about the situation with Chantelle [and Pearl]. Norma was visiting. I came
> to the following conclusion. I will tell Chantelle and Pearl together how
> valuable their work is and how important it is to the project that they are
> able to continue being involved. However I will recognise [verbally
> acknowledge and value] that Chantelle and perhaps Pearl for one reason
> or another may decide to take time out from the Research Group. I will
> emphasise how I respect people's choice around whether they feel able
> to attend or not. However I will express my concern about the group

> having no or just one member at meetings when people decide not to be there. I have a responsibility to try and alert the group to danger and the danger is the group will not complete the work or fold. It would take time for any new group member to get into the swing of the group and feel confident to join in and add their bit and therefore I think it is really important that we get some/a new member, to build up the numbers. It will make it easier for Pearl or Chantelle to not come for a week or so if there is someone else there. (Research Diary 19.2.02)

The above diary extract shows me reflecting upon a situation where, it seemed to me that, my research and that of the Research Group was in danger of folding. In the above extract I am attempting to find ways to communicate my concerns clearly and responsibly, in a way that does not take control away from the Research Group members, and is supportive of the researchers' needs. In this process I am focussing on what I need to do as a supporter.

There was another way that I as a research supporter had to balance my own needs against those of Research Group members. At times I felt I had to actively support Research Group members outside of the group to resolve crucial issues in their own lives, for example their housing and domiciliary support, This was sometimes at the risk of overstretching and stressing/distressing myself in the process, or putting what I wanted or needed to do in my own life or career on hold. I never really got a fully healthy balance established between what I felt I needed to do in my own life and the support I felt I needed to provide. However I wrote about these tensions in my diaries in attempts to get a clearer perspective. Here is an example. I wrote the following at a time when I was doing a lot of additional support in People First West:

> …on Wednesday I was completely worn out by Monday and Tuesday, completely drained… because of the strain of these two days. I decided that Wednesday should be my official day off to try and get some distance between People First and writing for my PhD. I can't wait to leave People First [I didn't leave] so that I can just… write the PhD and have my days spent on writing calmly (hopefully) and nothing else. This jumping in between roles is difficult. (Research Diary 12.6.02)

I am aware that it would have been a lot less stressful for me if I had been able to have tighter boundaries around my research support role. It could be argued that I allowed my role to be ambiguous on this project and that I could have adhered more firmly to the role of just supporting people to do research. However I could not justify refusing support to Research Group members who were going through difficult, painful and at times dangerous situations when no one else was in place to support them. Here are two examples of support I offered outside of the group; there were considerably more.

I supported a Research Group member who lived with his parents to open his first bank account and get direct payments and a support worker of his own. Then at a later date I supported him to meet with this support worker to air complaints he had about how she interpreted her role and then to develop an explanation of what he wanted from his support worker. Eventually I supported the same man to approach and work with social services to get his own flat with 24 hour support and to put across his views in review meetings about his housing and residential support.

I undertook this support work because the Research Group member was initially unable to get out in the evenings because he didn't have support and

then because he had become clinically and dangerously depressed living in his parent's home and wanted to get out of there. I am not claiming I was the only supportive person involved in these processes but the co-ordinator of People First West, the person with learning difficulties I supported, his family and I all felt the role I took on at the time was essential.

When a different Research Group member was about to be made homeless, I supported her to meet with social services to get a home that she felt suited her needs and to hold out for a place that she was going to feel comfortable in. At first she was offered unsuitable places. For example, one residential home she was shown only had minimum visiting staff support and no staff support at night. There were no locks on bedroom doors and all the residents were male mental health service users (only one of whom was identified as a person with learning difficulties). As a person with high support needs who felt she needed 24 hour support (which she eventually got) she was understandably very distressed about how insensitive social services were to her needs. I carried on giving my support until the housing problem was resolved.

I also used reflection in an attempt to locate conflicts of interest and work out how to best respond to them. For example, a member of the Research Group applied for a full-time post in another People First organisation. He knew that if he was successful in securing this post he would have to leave the Research Group. At this time I was also working on a part-time temporary basis as his supporter as well as being the supporter of the Research Group.

He asked me to support him to decide whether he should accept the post, should he be successful, and to help him prepare for his interview. I did both and he got the job and left the Research group. By the time I came to understand that perhaps I was not the best person to support him around this new post because of conflict of interest he had got the new job. I wrote the following in my diary about how I may not have been successful in separating out my interests when supporting him around his application for this post:

> I have questioned him...is he sure that this is what he wants? On the one hand this is appropriate as his supporter. I have genuinely not tried to influence his decision but it is true that I have pointed out potential pitfalls…I have told him if he works full-time it would not be so easy or may not be possible to develop the consultancy that he wants to do…I want him to stay and I think I would feel more secure if he stays and it is nigh on impossible for me to stay impartial about this…If this job is what he wants… I will feel pleased for him but very worried about the future of the research project… From now on I'm going to declare my vested interest to [the Research Group member] and say that I don't think I'm the best one to advise him and not bring up the subject again unless he directly asks my opinion or wants me to support him on something…the process of writing the diary has enabled me to recognise that I am uncomfortable about the ethics of what I am doing and [has] enabled me to see why, and now I've rounded it off with a decision; end of conflict, but still [I am] obviously left with the same sense of vulnerability. (Research Diary 9.11.01)

However, the above diary entry demonstrates that reflection can be used by the research supporter to both identify conflicts of interest and make decisions about how to manage them constructively.

Lack of status in the research support role

Throughout the course of this project I struggled psychologically to deal with the lack of professional status and financial reward that came with choosing to undertake face-to-face support work with people with learning difficulties. I

had recently left a much better paid post in education that was no more difficult, but afforded more status. The following diary entry demonstrates how I felt at the time about this subject:

> …taking lower wages, having officially less control and status awarded to me in the form of money… my job [supporting people with learning difficulties] is complex and subtle and my work with [a person with learning difficulties I was supporting] requires most of my skills, but in terms of how much it is seen as being hard ([a senior manager in social services] said go for the consultancy with her because anyone could support [the person with learning difficulties I was supporting]) and worthy of financial recognition; I've lost recognition officially... I myself enjoyed being the boss with money, feeling recognised and rewarded… I comforted myself with thoughts of my comparative financial and positional success. (Research Diary 20.11.01)

Also I felt that I would gain little or no recognition or professional status from the book I was supporting people with learning difficulties to develop. In essence, there were times I felt that the more involved I got in supporting people with learning difficulties to be in control of their own projects the further away I got from being rewarded either financially or by being afforded professional status. I wrote about the theme of status and money in my diaries in an attempt to deal with it constructively.

> What being [my living] in a co-op has allowed me to do is stand to one side of the services for people with learning difficulties (because I don't have a mortgage to keep me in fear, because my rent is so low) and side as fully as possible with people with learning difficulties. Doing this work…, [I am] taking lower wages, [and] having officially less status awarded to me. [But I am now in a role] that is better suited [to providing non-directive support] and [in a] less complex position to support people with learning difficulties from. I am in a better position to support people to challenge the services.

> Last night I went out with Bill [Research Group member] for a Chinese meal…Going out with Bill may have sparked all these thoughts [about status and supporting the researchers]. There was a man holding a guitar on the stairs out of [the name of a station]. I don't know what had happened previously but he was saying quite loudly (not aggressively)

"I'm my own man which is more than you are", and saying it about one of the hordes of besuited upholders of jobs in the town. No one (of course) was answering back. I didn't notice anyone looking at him in any way other than sideways. The flow carried on at the same pace down the… steps. Bill looked at him and answered him…Bill said "Go for it!". I am wondering what Bill made of the situation. Bill is keenly aware of power imbalances and lack of status…

At the time I thought how much of a lonely and pathetic claim the man was making…now I think [wonder if] he was informing ignorant people of a particular insight he had that he thought they didn't and he was probably right [that in his work he was less controlled and manipulated than they were]. However this man was not in the best place to put his views across. His thoughts were probably not being well received by the town crowd. People can [mistakenly] believe that the amount of money and to a lesser extent status that is bestowed upon them indicates their worth, places them higher or lower up the ladder of success and the pecking order. (Research Diary 20.11.01)

Sometimes Research Group members I supported were invited to high-profile national research and consultancy events. I found it difficult when their presence was ostensibly valued and mine was not. For example, in some contexts I was completely ignored by the organisers and participants, not even given eye contact or a verbal acknowledgement of my presence, yet the support work was complex and levels of responsibility were high. The following diary entry demonstrates what I felt at the time:

[The person with learning difficulties I was supporting] is getting lots of offers for consultancy work. Perhaps times are better for self-advocacy workers with learning difficulties. I feel a bit jealous (though rather shamefully). I've put in so much work and I'm getting so little money or status recently. (Research diary 2.10.01)

The issue of suitable professional recognition for research supporters is discussed in the next chapter of this dissertation. For now, it is enough to state that it was only by dealing with this lack of status reflectively that I was able to accept it and not become demoralised. It is important to mention here

that there were times when I did have the opportunity to push my own profile forward in front of the people with learning difficulties I supported. However being reflective about the politics of status and professional recognition helped me not to 'act out,' in a way that would be less than fully supportive of the self-empowerment of the people with learning difficulties I was supporting.

Conclusion

This research highlighted that reflection was an integral part of my role as a user controlled research supporter. It was used as a tool to develop and maintain my role throughout the entire course of this project. However I found that reflection was perhaps most urgently needed when interactions with researchers elicited psychologically uncomfortable feelings in me. At these times reflection was used to maintain the boundaries around my behaviour and interventions that I had needed to set to provide effective user controlled research support. Key areas where I found it difficult to stay within the boundaries I set myself on this project have been presented in this chapter, along with how reflection was used to deal with these situations.

In relation to living their lives as disempowered and vulnerable people, there were times when the researchers with learning difficulties on this project were distressed and expressed considerable emotional pain. It became clear that there was a need to respond reflectively around the issue of supporting such distressed service users. The purpose of being reflective in this area was to try to ensure that, as a research supporter, I did not shy away from being

supportively empathic towards the researchers at the times when they were most distressed.

I also found there was a need for reflection when I felt anger in response to the behaviour of researchers. It became clear during this research that reflection could be used to understand my reasons for feeling angry and to find ways of maintaining effective user-controlled support during these times. It also became clear that reflection was needed to maintain the standard of my support when conflicts of interest (between my ambitions as a researcher and the interests and needs of the researchers with learning difficulties) arose on this project.

As a research supporter I also found that reflection was needed to try to balance my personal needs against those of researchers when choosing how much time and effort to put into providing support outside of Research Group meetings. I found it difficult to refuse my services when researchers needed support to deal with crucial issues in their lives, and it seemed that they would not get support from anyone else. This dilemma was not entirely successfully resolved on this project. I found that at times, providing this additional support led to my becoming over-stretched. These pressures are not addressed in any of the literature on research or self-advocacy support for people with learning difficulties. I will be returning to this subject, in relation to mapping out the components of the research supporter's role, in the discussion chapter of this dissertation.

During the course of this research I found that little professional recognition or status was attached to supporting people with learning difficulties to be in control of their own projects. At times I found this difficult to deal with psychologically. I addressed this dilemma and maintained the quality of my support practice by reflectively analysing the politics of financial reward and status in relation to my user controlled research supporter role.

Chapter 8: Discussion

Introduction

When developing the questions and methods for this research I was aware that this project as a whole had the potential to contribute towards the further involvement of people with learning difficulties in several ways. It could enable a specific group of researchers with learning difficulties to participate in a full range of self-directed research processes, which still, at any level, is a relatively rare occurrence. Also as the above service users were to be supported to develop *their own* research questions, methods, findings and analysis, I was aware they could, potentially, provide valuable information about the lives and views of people with learning difficulties.

While undertaking my own research I aimed to find out about dilemmas and challenges inherent in the process of supporting self-directed researchers with learning difficulties within a self-advocacy group. I also aimed to reveal and discuss interpersonal skills that are required for supporting people with learning difficulties to be in control of their own research, self-advocacy agenda and self-advocacy group. Within this chapter I discuss, in relation to the support provided for the Research Group, and my own research into this process, how successful this project was as a whole.

The findings of my own research are critically discussed here. Also the Research Group's research is reviewed, specifically in relation to what it appears to show about how the support they received impacted upon them, or

allowed certain self-directed processes to happen. Then, drawing upon my research findings, skills and abilities that might be required for the role of user controlled research supporter with people with learning difficulties are presented here. The limitations and strengths of my own research methods and methodology are critically reviewed, along with my data collection and analysis processes. The chapter concludes with how this research might be evaluated and recommendations for future research topics.

An early finding of my research was that the service user researchers appeared to believe that the balance of power was weighted on the side of the people they called 'staff'. Although they said they felt supported at times by some 'staff', they unanimously claimed that all 'staff' assumed authority over them at the point of conflict of opinion or interest. This finding contributed towards my reflexively developing, and adopting (while actively supporting Research Group members to achieve their aims), strategies to counteract being viewed as a person who had any authority over Research Group members. I also researched into what I needed to do to ensure that I had strategies in place to avoid risking assuming any authority over them in response to their decisions and behaviour. In addition, I set about identifying ways to support the service user researchers to gain and maintain control of the agenda and management of their self-advocacy group. I also explored the impact that their being in control had on my role as a supporter, and the influence I had as a research supporter over the researchers' agenda despite wholeheartedly aiming to be non-directive.

I found there were a significant amount of organisational issues that needed to be addressed in relation to supporting people with learning difficulties to be in control of their own research on this project. We (the researchers and I) had to deal with the responses of various others who either were, or perceived themselves to be, stakeholders within it. I also had to support researchers through dilemmas we encountered around funding their research and their being employed as researchers. In addition there was a need to support Research Group members to address issues relating to their disempowerment outside of the group.

There were times, during this project, when maintaining a non-directive approach felt stressful or uncomfortable. I documented these occasions in my diaries, reflecting upon how I could work to uphold the boundaries of my support role. Drawing upon evidence from my research diaries I have illustrated how I used this process to avoid controlling the group. I have also drawn attention to aspects of research support I found psychologically difficult. I, like other individuals, have my own particular areas of psychological vulnerability, and I have aimed to take these into account. The focus of my research has been on the psychological pressures that I understood to be of particular relevance to a wide audience of those interested in further understanding the role of user controlled research supporter working with people with learning difficulties.

What the project achieved

The main focus of this section is on the reflexive narrative I am calling 'my own research' in this context, and what is different and new about it in comparison to related research and discussion. However, the Research Group's work is also discussed here in relation to what it appears to show about the user controlled research support role that has been developed during this project and discussed within this dissertation.

What 'my own research' has contributed towards the literature

My research has focused upon identifying both how people with learning difficulties can be effectively supported interpersonally *to be in control* of their own research, self-advocacy agenda and self-empowerment and what might prevent this happening. There is so little literature that directly addresses this subject that almost every finding in this dissertation has never been discussed before (let alone in any depth) in relation to supporting self-advocacy, or inclusive or user controlled research, with people with learning difficulties.

This research has opened up discussion around how personal attitudes, political values and intellectual understanding (in relation to disability and interacting with people with learning difficulties) can potentially impact upon the amount of control people with learning difficulties can have within the context of a user controlled research or self-advocacy group. Drawing on the principles of the social model of disability, Goodley (2000) has argued that the most positive type of self-advocacy support involves supporters challenging the discourses that disable and silence people with learning difficulties.

Dowson and Whittaker (1993) have posited that self-advocacy groups should be in the control of members with learning difficulties. However, as I mentioned in Chapter 2, the issue of how supporters might provide non-directive support has not been discussed in detail in previous research. Neither has the issue of how non-directive support might be developed in line with the social model of disability. My research has also developed understanding in the under-researched area of how supporters can act in research projects that are inclusive of people with learning difficulties (Walmsley and Johnson, 2003). It has gone into more detail about not only non-directive support, but the issue of research *support* in general, than previous literature on this subject, for example Williams (2002) and Buchanan's appendix in Hart et al. (2007).

This research has shown some of the complexities that exist around reconciling a non-directive support role with the political focus of the social model of disability. I have shown that even supporters who are aiming wholeheartedly to be non-directive can have a significant degree of influence over the service users' agenda. For example, unintended influence can occur when explaining information, or constructively responding to service users who are dealing with or recounting oppressive or unjust situations.

Attention has been drawn to the importance of supporters having a clear understanding of the nature of the oppression that people with learning difficulties face, and a commitment to working alongside them to support them to counteract such situations. I found that as a research supporter I had to

support much more than the research process itself. There was a need to be mindful of the whole context of the lives of people with learning difficulties and provide support for them to deal with their day-to-day disempowerment, exclusion and lack of choice and control (Shakespeare et al., 1996; Booth, 2003; McCarthy, 1999; Tregaskis, 2004; Lambeth Accord, in partnership with Change, 1995; Department of Health, 2001).

I found that the research supporter may need to address the interpersonal power imbalance between service users and those who are paid to support them. Otherwise, people with learning difficulties may not be able to exercise control over their own agendas. The importance of developing suitable rapport with research participants with learning difficulties has been discussed before (McCarthy, 1999). In addition the subject of how people with learning difficulties can say what they think people without learning difficulties want to hear, has also been discussed (Atkinson, 1989). However, practical ways of working and being that specifically aim to diminish the power gap that can exist between supporters and people with learning difficulties have not previously been discussed in the literature. This subject has been investigated within this research along with ways of supporting people with learning difficulties to feel confident and comfortable about doing what they choose, rather than aiming not to displease the supporter to avoid conflict. All of the above have been discussed and developed through a politicised lens of emancipatory research principles, the social model of disability and a model of self-advocacy support that focuses on people with learning difficulties being in control of their own agendas and self-empowerment.

Other writers have suggested in passing that there is a need for people who support the self-advocacy of people with learning difficulties to reflect upon or monitor their behaviour (Moseley1994; Williams and Shoultz, 1982). However, this research has gone much further into why this is necessary. It has also brought to light a range of specific areas where this process could be of particular importance in relation to people with learning difficulties exercising maximum control over a project. For example, I found on this project that there were times when conflicts of interest or feelings of psychological or professional vulnerability led to me, in my support role, feeling pressure to assume control over the group. Various reasons for such feelings arising were identified in this research, for example, service users expressing emotions that supporters may find painful to empathise with. Also pressure may be placed on the supporter, by managers or other workers they come into contact with, to implement rules within the group or boundaries on service users' behaviour.

The findings in this research have also opened up discussion about how the supporter's experience of psychological vulnerability, or discomfort in relation to their role, can potentially impact upon the level of control service users with learning difficulties could have over a user-controlled project. This research revealed that critical reflection can be a powerful tool that can be used to prevent the supporter responding impulsively, for example, out of anger or anxiety. The process of critical reflection can create a space for supporters to consider their responses in relation to their support aims. It can thereby

decrease the likelihood of impulsively assuming authority over service users at times when for one reason or another they may experience uncomfortable feelings or competing role obligations. The subject of using reflection to develop or monitor a supportive role is not new as such. It has been discussed before, for example, in relation to education, (Loughran, 2002; Joelle and Johnson, 2000) and nursing (Johns and Freshwater, 2005). What is new here is that this process has been linked specifically to self-advocacy support and discussed, in detail, in relation to avoiding exercising authoritative control over people with learning difficulties.

My research has drawn attention to practicalities that have been overlooked in the national agenda for the empowerment of people with learning difficulties currently put forward by the Department of Health (2001; 2005). This dissertation is a rare example of research that explores, in significant detail, non-directive interpersonal support in relation to the self-empowerment of people with learning difficulties.

This may be the only example of research that has focused so specifically upon this subject, and in such depth. However, while it still remains a much overlooked subject, the dilemma of disempowerment in relation to 'professional' and societal interpersonal interventions towards people with learning difficulties has been powerfully discussed at intervals since at least the 1970s. For example, the research of Oswin (1971; 1978) drew attention to ways of interacting towards children within institutions that were profoundly disempowering and dehumanising. She wrote about the appalling conditions

within long-stay hospitals where children with learning difficulties were deprived of individual attention and affection and controlled en masse to fit in with institutional routines. Sinason (1992) has argued that often unacknowledged, feelings of hostility and fear are projected onto people with learning difficulties, lowering their self-esteem, and having the effect of increasing any original intellectual impairment they might have. Shakespeare et al. (1996) have discussed how people with learning difficulties can be denied both a sexual identity and the opportunity to engage in sexual relationships by others who frame them in ways that deny their adult status.

Bearing the focus of these various studies in mind, it seems surprising that there has not been more in-depth research into the effects of interpersonal interventions by 'professionals' towards people with learning difficulties. Recently there has been a rise in literature on rendering information accessible (Poncelas and Murphy, 2007; Ward and Townsley, 2005) and person centred planning (Millard, 2009; Wigham, et al. 2008; Cook and Abraham, 2007); both of these subjects are related to the 'empowerment' of people with learning difficulties. However, currently there is precious little written about how the day-to-day interpersonal interventions that 'professionals' make towards people with learning difficulties can disempower and control service users.

A few texts have been produced recently that address this issue. For example Finlay et al. (2008) have discussed how individuals working with people with learning difficulties and high support needs can control them (not necessarily

consciously) in order to meet organisational goals. These authors also made a connection between the educational agenda that many people with learning difficulties face throughout their adult lives and disempowerment, lack of acceptance of the individual's present state, and control. This point had been highlighted almost two decades previously by Brechin and Swain (1989) who also argued that the educational approach, often adopted in relation to people with learning difficulties, can be used in an attempt to make people 'as normal as possible' rather than enhancing who they really are.

In her autoethnographic research on the 'interface between disabled and non disabled people' Tregaskis (2004), a disabled woman herself, found that people with learning difficulties faced more attitudinal oppression than people with physical impairments. She argued that there is a need to make further links between the experiences of people with learning difficulties and those of other disabled people, and claimed that the effects of oppressive attitudes on disabled people are currently undertheorised. Tregaskis (2004) posited that the underlying reasons for this are firstly, the lack of discussion about disabling attitudinal barriers by authors working with the social model of disability and secondly, traditional quantitative research methodologies that tend to isolate individuals from the wider society. My research is an example of a situated study, rooted in the social model of disability that has taken into account the society that the research has taken place in, and focused upon the impact of supporter attitudes on people with learning difficulties. As such it can be viewed as a contribution to the literature on attitudinal aspects of the social model of disability in relation to people with learning difficulties.

However, I would like to add, that the relationship between face-to-face interventions towards people with learning difficulties and their disempowerment is also undertheorised, along with active interpersonal interventions to support the self-empowerment of this group of people.

This research has drawn attention to some positive steps that can be taken to move towards interpersonally supporting people with learning difficulties to have as much control as possible when undertaking user controlled research and other self-directed projects. In it I have focused in depth on the role that interpersonal support can play in facilitating people with learning difficulties to exercise *self-directed control* over any supported activity. The focus of my research has been the support of user controlled research with people with learning difficulties. However, this research may be relevant to any interested people who are concerned about the issues involved in supporting the further self-empowerment of people with learning difficulties.

Finally, what has been indicated in this research is that the role of user controlled research *supporter*, with people with learning difficulties, requires more than research skills and academic understanding. Although this research has indicated that these skills are necessary, it has also indicated that user controlled research supporters need highly developed *support skills* to provide adequate non-directive, non-authoritarian support. To my knowledge this is the first research that has clearly illustrated in significant depth what form some of these support skills might take, and why highly

developed support skills may be an important aspect of supporting user controlled research with people with learning difficulties.

The Research Group's research in context

Although the findings of this research have been developed using a reflexive critical ethnographic approach, on a broader level, this project (as a whole) is an attempt at practising emancipatory research with a group of people with learning difficulties. Therefore, I have not only been concerned with the production of knowledge; I have also taken the act of supporting the further empowerment of people with learning difficulties just as seriously. I developed my support practice throughout this project, while exploring the political and philosophical aspects of the role in relation to the social model of disability and theory on emancipatory disabilty research.

The Research Group's book *What We Know* was published in 2007 (Robinson, P. et al). At the point of writing this, Research Group members continue to sit on two national high-profile research boards and committees. In addition, individual Research Group members have recently advised on a number of published research projects. They are also acknowledged as co-authors of several different research texts and have given talks at a number of research, and service development, related conferences.

Clearly, choosing to initiate and support this project as the 'fieldwork' for my own research was beneficial to Research Group members; who have gone on through their own merit, to be recognised researchers, development workers

and speakers on issues related to the inclusion and further empowerment of people with learning difficulties. I could never have imagined the level of recognition they would gain, or the number of opportunities that would be afforded them, to put across their views in national forums that have contributed to policy and service development, as well as knowledge about involvement and inclusion.

I am not suggesting here that the Research Group members' success happened just because of my input. *They* were invited to work with a range of organisations. They also made good and positive relationships with people who valued and appreciated their input, and asked them if they wanted to be involved in further projects. I am merely pointing out that choosing to initiate this project and offer support to a group of people with learning difficulties, to both undertake research they were in control of, and participate in work that grew out of this, was a strategy that led to wide-ranging opportunities for Research Group members. This outcome *implies* that the non-directive support that was offered on this project made a difference to their skills and confidence, but as the critical evaluation of my data collection and analysis processes shows this cannot be assumed until further research is conducted.

When comparing the Research Group's book to other research that has been carried out by people with learning difficulties, several differences are apparent. The Research Group's book is written almost entirely in direct quotes from statements that have been made by individual researchers

themselves and their research participants. All the other words were chosen by members of the group. Every word in their book was selected by them.

When an academic and disabled activist with learning difficulties, Susan Green [pseudonym] reviewed the book in 2008, within a journal for issues related to working with people with learning difficulties, she claimed this aspect of the book made it different to others by people with learning difficulties. What is important to mention here, is that the Research Group's book has not been written by a researcher without learning difficulties and then approved by service users as in Hart et al. (2007) for example. The Research Group members have constructed what is written in it themselves (with support). This process was very time-consuming but it ensured that what is written is more wholeheartedly or thoroughly the work of people with learning difficulties than may be the case with other related texts. As such it could be argued that it reveals more about their lives from an 'insider' perspective.

There are other reasons why the work of the Research Group is so markedly different from other research that has been carried out by people with learning difficulties that further suggest the value of the non-directive support process. When comparing the focus of the Research Group's work to other related texts such as those mentioned in the literature review (Hart et. al., 2007; Gramlich et, al. 2002; The Learning Difficulties Research Team with assistance from Catherine Bewley and Linsay McCulloch, 2006) the text is far more critical of current social care practices, in a direct and immediate way. In

no uncertain manner *What We Know* presents a clear picture of negative or disempowering circumstances that the researchers and their participants have experienced. I have not found any other in-depth research by people with learning difficulties that does this to the same extent.

In another review of the book in a well known academic journal for issues connected to learning difficulties the same critic, Susan Green, claimed that it was 'not for the faint-hearted' because of the painful subjects that are addressed within it. In the same review she mentioned the 'boldness of the voices' of the researchers. Negative experiences of social care are often described in detail in the book with an intensity that comes from the researchers having lived through them. The suggestion here, about the nature of the support they were offered, is that they felt able to disclose these experiences and include them in their research without being judged or constrained by the research supporter.

In her blog about her experiences at an ESRC research methods festival in 2008, Mary Edwards [pseudonym] a senior university lecturer and co-director of a well known centre for research methods had the following to say about how the Research Group's book was a good example of user led, emancipatory, research (two of the Research Group members had spoken at the festival about how they did their research and I had also spoken about how I had supported them):

> The best gem was the "[*What We Know*]" book that I bought from [Pearl] and [Maria] at the end of the session. It's a great example of an

accessible book, but the contents also give testament to a great example of user-led (emancipatory) research.
They write:

"We wanted to look into the things we cared about the most and write about them in our book. What we cared about was what was happening in the lives of people with learning difficulties".

The activist with learning difficulties, Susan Green, wrote the following about

What We Know in her review of it in the well-known academic journal about

issues relating to people with learning difficulties:

This is truly the only genuine emancipatory research I have seen where people with learning difficulties have really been in control over the whole research process.

I think I can conclude this section by stating that the Research Group's book

does appear to reflect the amount of control they were supported to have over

their own research. As such, the above comments might be viewed as

evidence towards the value of supporting people with learning difficulties to be

in control of their own research group in the way that was developed on this

project.

The role of user controlled research supporter working with people with learning difficulties

This section of the chapter is in two main parts. Drawing upon the findings of

my own research, the first part summarises what was indicated about the

skills and abilities that would be needed for the role of 'user controlled

research supporter' working with people with learning difficulties. The second

part of this section also draws upon my own research to form the basis of a discussion on the professional status of the role of user controlled research supporter.

The skills and abilities needed for supporting user controlled research with people with learning difficulties

My research has indicated that a range of skills, abilities and personal qualities would be needed when supporting people with learning difficulties to be in control of their own research group. The following description of what these skills and abilities might be draws upon the findings of this research. However it is important to mention here that the findings of a single setting ethnographic study of this nature can not be generalised with any degree of certainty. Further research would have to take place before any solid claims could be made about the transferability of these findings.

This research has indicated that a comprehensive understanding of research processes (in order to support people with learning difficulties to (a) make research related choices and (b) successfully undertake their own research) would be helpful. It would also be useful if supporters had the skills to give informed support around publishing issues and other forms of research dissemination, including providing necessary support for service users to give presentations about their work.

In addition, an ability to support service user researchers to fundraise and address issues connected their employment and benefits would be a useful

skill. A thorough and comprehensive understanding of the principles of user controlled and emancipatory research processes would also be of benefit, as would a commitment to the political beliefs that underpin them. In addition, research supporters would need to be able to apply their understanding of this field of research to working interpersonally with people with learning difficulties.

Skills to support service user researchers without exercising authority over them would be of use. Also the supporter would need to be committed to supporting service users to be in control of their research group, and be able to put strategies into place that would be facilitative of researchers having power over what happens in their group. For example, as has been explained in chapters 5 and 4 of this dissertation, the research supporter may need to make it clear to the researchers that the research really was theirs and then set about placing boundaries upon their own behaviour to ensure that they (the supporter) did not take over.

It would be beneficial if the supporter had the ability and skills to reflect actively and constructively upon their own behaviour and attitudes, to ensure that they did not assume authority over the group at times when they felt pressured or stressed by the researchers' reactions or decisions. It would also be helpful if the supporter knew how to facilitate working relationships that made it safer for researchers to behave as they chose within the group. They might do this, for example, by taking responsibility for miscommunication (as explained in chapter 5) and by not expressing annoyance or irritation with any

decisions the researchers may take and by making it easier for the researchers to confront disagreement openly. That is not to say that the supporter should not respond as they would in any social situation, as an equal citizen, if there was an immediate risk of harm.

Skills in making complex research related information accessible to people with learning difficulties would be essential. Supporters would not only have to be able to understand all necessary research related information. They would also need well- developed skills in putting such information into language that is accessible to a group of researchers with a range of differing abilities. In addition they may need to be able to check out if the language was being understood, by noticing if researchers appeared to be confused and by asking researchers if they (supporters) are making themselves clear, while taking any responsibility for being misunderstood by any researchers.

Supporting user controlled research with people with learning difficulties is tantamount to supporting a self-advocacy group that is undertaking their own research. Therefore, the user controlled research supporter would need self-advocacy group support skills. In order to be clearer about how best to work in a non-directive way it could also be helpful if the supporter had trained in person-centred or Rogerian group facilitiation (Rogers, 1967). A further requirement of the role would be experience in supporting people with learning difficulties to make informed decisions, in relation to research and other subjects that are a priority for them. This would involve having the capacity to explain options to the researchers (and if necessary possible

outcomes and/or consequences) in language that was accessible to them. It would also involve the supporter convincing researchers, through their behaviour and attitude, that whatever decision the researchers took it was theirs to take and would not be met by anything other than support and demonstrated goodwill by the supporter.

In order to support the self-empowerment of people with learning difficulties, the user controlled research supporter would need a thorough understanding of the processes that disempower them, including those that are embedded into certain current social care practices, as well as the wider society. Some examples of these are, that people with learning difficulties can be infantalised and patronised by people without learning difficulties (Shakeseare et al., 1996), and that people who work in services may seek to mould or educate people with learning difficulties into what they see as more 'normal' people (Perrin and Nirje, 1989). An understanding of the meaning of the social model of disability in relation to both the support and lived experience of people with learning difficulties would be beneficial. It would be helpful if the supporter had a commitment to supporting service users, from a social model perspective, to empower themselves. This would include finding ways to support that are controlled or sanctioned by people with learning difficulties themselves, and not based on oppressive or normative values that place the responsibility for the disabling processes that can be experienced by people with learning difficulties on individual service users.

An ability to keep a positive outlook, and continue to provide effective support, through periods of uncertainty about the progress of the service users' research and the stability or cohesiveness of the service user research group would be part of the role. This effectively means supporters being required to practise 'emotional labour' (Mazhindu, 2003; Naring, et al., 2006), by both controlling and managing difficult emotions and perhaps (at times) masking their own feelings to be supportive to others. Supporters would need the skills to reflect constructively upon their own practice at such times of uncertainty, particularly if they found these times personally stressful or psychologically uncomfortable. They would also need to be flexible enough to provide the support service users want, and be prepared to learn a subject if researchers find they require support around it.

The skills to liaise with other people in a supportive role in the lives of the service user researchers would also be useful. Supporters may be required to work with other professionals to co-ordinate the support that is needed for researchers to safely and comfortably attend research meetings and related events such as research conferences. They may also need advocacy skills (Henderson and Pochin, 2001), as at times service user researchers may request that the supporter speaks on their behalf to service staff they are nervous or afraid of and who may override their choices.

Developed assertiveness skills would be required, to (a) clearly communicate personal boundaries to service user researchers in a non-controlling, non-authoritarian way and (b) constructively confront, if necessary, other

professionals who are involved in the support of the researcher. There may be a need for this when/if other professionals behave in ways that may compromise the amount of control service users have over their own research or what they choose to do in their own lives outside of the research group. This is especially important when advocating for researchers who are being actively disempowered or placed in a position of danger in their lives. In addition, it would be useful if the supporter had the necessary skills and strategies to be able to identify how and when their own personal ambitions, values or psychological makeup may render them vulnerable to exercising control over service users. The supporter would not only need to be capable of the levels of self-reflection necessary for this task but also able to put practical strategies into place to ensure that they reflectively monitored their own support practice.

The status of the role of user controlled research supporter

This research has indicated that if user controlled research supporters are working effectively, they are perceived as being, and are, very much in the background. In academic positions publications are vital, yet research supporters cannot be accredited as being authors of the work. It is fitting that service user researchers should receive the attention and credit for their work and not the supporter. However, my research has indicated that there is a lack of appropriate recognition and status for people who support people with learning difficulties to produce their own research by putting user controlled emancipatory research principles into practice. This could be seen as a barrier to increasing the amount of research that is controlled by people with

learning difficulties. Conversely, appropriate professional status and recognition could be a positive factor in enabling more people with learning difficulties to undertake their own research.

While Lawton (2006) has written about the importance of appropriate training for self-advocacy group supporters, and that people with learning difficulties themselves should be involved in this, the professionalisation of self-advocacy support has received little attention. However, support work is seen as a low-status occupation (Smith, 2008). Recently there has been a growth of discussion on the subject of professionalising social care and support, in relation to increasing quality of delivery and the status of the role (Saks and Allsop, 2007; Smith, 2008). Earlier on in this dissertation I wrote about the conflict of power I felt when working for social services and People First West at the same time. Being answerable to social services managers compromised my non-directive support role. It would be of paramount importance that any moves towards increasing the professional status of self-advocacy supporters did not compromise the degree of control that self-advocacy group members should ideally have over their own agendas, groups and the nature of the support they receive. Insensitively professionalising any support roles (including self-advocacy supporters) and subjecting them to regulation could lead to disabled people further losing control of their support to professional regulating bodies.

While there may be a need for better training and status, and perhaps qualifications, for user controlled research and self-advocacy supporters these

would need to be developed with the close involvement of existing supporters, and most importantly people with learning difficulties. To avoid conflicts of interest it would be best if people with learning difficulties were involved as members of user controlled organisations, as Beresford and Hasler (2009) have suggested, albeit in relation to disabled people in general.

As I mentioned in Chapter 1, towards the end of the time I spent writing up this dissertation I was invited (along with the service user researchers) to speak about my role on the *What We Know* project at an ESRC research conference. Hopefully this is an indication that in future this type of support role will be valued and recognised.

A critical evaluation of my data collection and data analysis processes

Introduction

The following section is a critical evaluation of my data collection methods and data analysis processes on this project. Here I explain both why I took the approach I took (rather than alternative approaches), and what I might do differently in relation to collecting and analysing data were I to do this, or similar, research again. In this section of the dissertation I also explain the difficulties I encountered in data collection and analysis. In addition, I identify what I have learned about data collection and analysis by carrying out this project. I also include here a critical discussion of the subjectivity of my writing

about my research into my own role as a research supporter and propose a hypothetical 'ideal world' independent evaluation of my role as a supporter on a user controlled research project. In doing this, I discuss the difficulties that might be encountered if this hypothetical evaluation were to be implemented.

This evaluation in context

My research, which is informed by critical ethnographic principles, is a reflexive narrative. Reflexive narratives require writers to draw (to some extent) upon personal experience as a data source and actively situate themselves within their texts (Etherington, 2004). Over the last few decades there has been a growth of interest in more intimate and embodied writing (Ellis and Bochner, 2000). This has led to a recent growth of reflexive narratives within disability studies (see for example, Tregaskis, 2004; Goodley et al. 2004; Neville-Jan 2004). In addition there is a growing body of reflexive narratives by therapists and practitioners (within social care and education) who have sought to explore the interface between themselves and the students or clients they work with (see for example, Etherington, 2004; Shuttleworth, 2004; Benjamin, 2002).

My research could also be categorised as autoethnographic. In relation to my research in particular, the terms 'reflexive narrative' and 'autoethnography' are interchangeable at times. There are a large amount of differing names for research that uses, to a significant extent, the self as a source of data. Ellis and Bochner (2000, 739) have argued that, like a lot of other social research terms, these have evolved in a way that makes it difficult to precisely define

and apply them. They claim that all ethnographic research that uses the 'self' as a significant data source (including the terms 'reflexive ethnography', 'personal narratives' and 'auto-observation') can be fitted under the broader 'rubric' of autoethnography. Autoethnographic approaches require that the researcher writes about themselves (as well as the interface between themselves and the studied culture). This process, as Etherington (2004) has argued, allows the researcher to legitimately explore how their culture, self, status and power interacts with research participants and the 'written word'. Doing this was a major aspect of my work on this project.

Autoethnography, as a research methodology, developed in relation to feminist and postmodern philosophical critiques of 'traditional' research that challenged both the use of the disembodied, 'unsituated', authoritative voice within research texts and the idea that the researcher could objectively work to reveal truths that exist independently of either their own or other people's interpretive processes (Denzin and Lincoln, 2000). Postmodernist and feminist critics argued that research need not be viewed as the clearest path towards achieving objectivity as such. They postulated that the focus of research could be on understanding the process of research whilst acknowledging both the relationship between research and power, and how knowledge itself is influenced by historical and cultural issues (Gerstl-Pepin et. al., 2002). The above arguments led to crises of representation, validity and praxis within qualitative social research that arguably remain with us to this day (Denzin and Lincoln, 2000). Autoethnographies have contributed further to arguments about representation and validity. Their authors have

written themselves into these texts as major characters, who reflexively work with emotions and feelings. Therefore, they have further challenged the notion of silent 'objective' authorship (Holt, 2003).

This evaluation has been constructed within the context of the above challenges to more traditional or positivist approaches to research. It is important to note that, in relation to autoethnographic methodologies, these remain challenged and continue to be controversial within the academy (Holt, 2003; Etherington, 2004; Ellis and Bochner, 2000). In addition it is important to note that the shape and components of valid and good quality autoethnography continue to be contested by a range of authors, who appear to approach the subject from a variety of differing perspectives and paradigms.

The issue of how best to evaluate the quality and validity of ethnography and autoethnography is complex. There are those who argue that autoethnographic approaches are radical and as such should not be evaluated by the traditional methods used to judge the quality of social research (Holt, 2003; Etherington, 2004; Ellis and Bochner, 2000). Others propose ways of bringing autoethnographies further into the mainstream by applying relatively traditional criteria for ensuring validity and objectivity to ethnographic and autoethnographic research processes (for example, Anderson, 2006).

While undertaking this evaluation I have endeavoured to keep an open mind and address both the limitations and benefits of adopting an autoethnographic approach while working within a critical/ideological paradigm. All methodologies have their limitations, and the skill is to define the most suitable research approach for a particular research project (Haverkamp and Young, 2007).

Autoethnographers have discussed how, in relation to the subjectivity of the methodology, some critics regard autoethnography as, at worst, *inherently* narcissistic as a methodology, and at best one that puts the researcher *in danger* of producing narcissistic or self-indulgent work (Ellis and Bochner, 2006; Holt, 2003; Etherington, 2004). Holt (2003) has argued (in relation to getting his own ethnographic work published) that he encountered two types of reviewers who found autoethnography problematic. He claimed there were those who apparently valued autoethnography but had concerns about its rigour, and those who seemed to believe that autoethnography was simply not scientific research. Other writers of autoethnographic research have pointed out how they or others have had a struggle to produce autoethnographic texts in the face of dominant positivist assumptions about the nature of academic research (Ellis and Bochner, 2000; Etherington, 2004).

Throughout this critical evaluation of my data collection methods and data analysis processes there has been a need to address a range of discussions within the literature, which are by no means underpinned by the same, or closely related, philosophical stances. Therefore, it is important to reiterate at

this stage that within qualitative research there is a need to use data collection methods and analysis processes that are compatible with each other (Crotty, 1998) and the paradigm that the researcher is working with on any specific project. This evaluation has been constructed in a way that takes this into account.

This project as a whole (including the support role I occupied while undertaking this research) has been informed by the concept of emancipatory disability research (Oliver, 1992; Barnes, 1992). However, I have drawn upon the principles of critical ethnography to construct my own research (which has culminated in this text). Before going any further, it would be useful to explain how my research is compatible with what Haverkamp and Young (2007) have called a critical/ideological paradigm, although not in a traditional way. Traditionally, the critical/ideological paradigm (which underpins critical ethnography) is informed by a critical realist ontology, which holds that there is a discernable objective reality or truth which reflects social, political, historical and oppressive elements (Haverkamp and Young 2007). However, as Manias and Street (2001) have argued, it is not necessary to uphold the idea that there is a discernable objective reality or truth to practise research that is informed by the principles of critical ethnography. It is possible, instead, to explore the interactions between power, subjectivity and discourse, as I have done. By doing this, the crisis of representation can be acknowledged. In addition, the original goal of critical ethnography can remain intact; that of facilitating change away from social oppression or restriction, whilst

discussing oppression and injustice (and ways that these might be

counteracted) within a social and political framework (Thomas, 1993).

Reasons for selecting this approach to data collection and analysis

My approach to data collection and analysis on this project was chosen for

three interconnected reasons. Firstly, in keeping with the principles of

emancipatory disability research (Barnes, 1992; Barnes, 2001; Oliver, 1992)

and user controlled research (Turner and Beresford, 2005), I wanted to

support the Research Group to do their own research, rather than take part in

a shared research project with me. By choosing to study my own practice, I

could work towards gaining further understanding of how I could best support

the Research Group while undertaking my own research. Secondly, having

identified a gap in the literature, I wanted to explore the interpersonal aspects

of how supporters of research and self-advocacy might behave to facilitate

people with learning difficulties to have control and authority over their own

projects. I ascertained that an autoethnographic approach would allow me to

include as data (and reflexively work with) not only the enacted responses of

my support role, but also significant felt pressures and inner reflections on

these. Thirdly, combining this approach with critical ethnographic principles

(Thomas, 1993; Manias and Street, 2001) further enabled me to take a

necessary politicised stance (informed by the social model of disability)

towards both supporting the self-empowerment of Research Group members

and the construction of this text.

Autoethnography and support

One significant reason why I was drawn to autoethnography and reflexive narrative on this project was because I thought it would afford me opportunities to reflexively develop as a supporter. Etherington (2004; 101) has argued that autoethnographic reflexive narrative approaches to research can be particularly relevant for people involved in 'helping' professions, where there is a need for practitioners to understand how their self impacts upon their work. As she puts it:

> These methodologies are of course particularly relevant in counselling, psychotherapy and other helping professions, where it is important for practitioners to understand their motivations, and the influences of their history on the work they do and the people with whom they work.

It was important that the approach I took allowed me to work with a significant amount of personal reflective data.

If I had chosen another, less contentious, approach that could be suitable for researching support practices such as, for example, discourse analysis, I would have limited the extent to which I could have studied my 'motivations' and 'influences'. However, by choosing such an approach I could have avoided the comparatively greater degree of subjectivity that is inherent in autoethnography. In discourse analysis informal conversations and formal interviews are most likely to be the main data used (Oberhuber and Krzyzanowski, 2008). Discourse analysis would have allowed me to work in greater linguistic detail with the tapes of transactions and minutes of meetings I had. In addition I could have used a more ostensibly objective process of

data analysis. By doing this the problems with generalising and quantifying results, that can exist with ethnographic research generally (Quimby, 2006), let alone autoethnography, would have been reduced. However, drawing mainly upon this approach would not have allowed me to focus on *felt* pressures to assume authority over group members, or the reflective processes that led to my not doing so. In short, discourse analysis as a process does not lend itself as readily to working with more personal reflective data as autoethnography does. I found no other approach outside of autoethnography that offered the opportunity to work overtly with this category of data.

The autoethnographic process seems to be particularly useful for not only developing understanding of supportive roles but also for developing reflexivity in relation to such roles. For example, Anderson (2006; 383) has argued that autoethnographic self-examination can lead to the researcher undergoing fundamental changes in themselves. This is how he puts it:

> Indeed, the autoethnographic interrogation of self and other may transform the researcher's own beliefs, actions, and sense of self.

I was seeking to develop my support role through increasing my understanding of it in relation to issues of power and control. Therefore, a focus on self-transformation was a significant aspect of this project as a whole.

In response to the criticism that autoethnography is narcissistic, Smith and Sparkes (2008; 25), have argued the following about how autoethnography can be used to develop useful self-awareness:

> …rather than always being self-indulgent, autoethnographies can encourage acts of witnessing, empathy and connection that extend beyond the self of the author and thereby contribute to our understandings in ways that, among others, are self-knowing, self-respectful, self-sacrificing and self-luminous.

My own focus throughout this project was on ways of thinking and being that were supportive of the people with learning difficulties I worked with. Therefore the reflective aspect of this research, and my self examination, went towards the aim of supporting others to undertake their own research, as well as my writing about this process and the dilemmas I encountered along the way.

However, while autoethnographic methods can be useful for people who are aiming to develop supportive roles, group support or group facilitation differs from research. Etherington (2004; 110) has succinctly described this difference in relation to psychotherapy (which renders it nonetheless relevant to my role on this project):

> ... as a therapist my purpose is to assist my clients re-search (into themselves and their lives), and in my role as a researcher the positions are reversed: they are there to assist *me* in discovering something about a topic or concept that I am curious about.

On this project, these roles were not so much interconnected as operating simultaneously. Therefore, the reflexive observation of my own support role fed into two practices, my support role itself and the development of this reflexive narrative. However both of these practices impacted upon one

another. The research informed my support responses and my support practice informed my research.

Reflexive narrative and necessary politics

As my research was informed by the principles of critical ethnography and emancipatory disability research, it had a political element to it. It was important that I chose a way of collecting and analysing data that allowed me to adopt openly a politicised emancipatory approach, and in turn write about it. Goodley et al. (2004) have argued that all narratives are politicised, and that they may be the best way of capturing oppressive structures within society. Certainly there is the potential within narrative to challenge oppression by providing what Smith and Sparkes (2008; 19) have called 'alternative maps' to taken-for-granted practices. Smith and Sparkes (2008; 19) have claimed that narrative enquiry allows researchers to be committed to producing texts that may lead to societal and individual transformation:

> …narrative enquiry bears within it the promise of fashioning a kind of scholarship that seeks to practice a deep fidelity to the possibilities of societal and individual transformation, resistance and living life differently.

Holt (2003) has claimed that autoethnography is good for confronting dominant forms of power through self-reflective responses. Manias and Street (2001) have furthermore argued that critical ethnographers recognise and value the political and historical aspects of the participant-researcher project. Therefore, I adopted appropriate data collection and analysis strategies for working with the politicised and emancipatory nature of this project. Certainly the approach I adopted allowed room for openly holding politicised views

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while writing about the oppression of people with learning difficulties and the support of their self-emancipation.

However, (in relation to validity criteria) holding emancipatory aims and being committed to political principles when researching, can be viewed as potentially negative by some critics. For example, in his book on interpreting qualitative data Silverman (2006; 275) states the following about emancipation as a goal of research:

> To assume that emancipation is the goal of research conflates yet again 'fact' and 'value'. How research is used is a value-laden, political question…To my mind, the first goal of scientific research is valid knowledge. To claim otherwise is, as Searle implies, to make an alliance with an awful dynasty that includes 'Aryan science' under the Nazis, and 'socialist science' under Stalin.

It is clear from the above statement that Silverman strongly believes that the first goal of scientific research is valid knowledge.

However, what he and other researchers mean by valid knowledge varies a great deal. For example, although he does not address autoethnography, Silverman's (2006) criteria for validity in ethnography differ a great deal to Ellis and Bochener's (2000; 2006) validity criteria for autoethnography. Silverman's focus is on objectivity and evidence whilst Ellis and Bochner's is on engaging the empathy of the reader by creating a rich convincing text that emotionally and intellectually involves them; they make no suggestion of aiming to produce 'objective' research. Ellis and Bochner (2000; 751) have written the following about what validity means to them in relation to autoethnography:

> I start from the position that language is not transparent and there's no single standard of truth. To me validity means that our work seeks

verisimilitude; it invokes in readers a feeling that the experience described is lifelike, believable and possible. You might even judge validity by whether it helps readers communicate with others different from themselves, or offers a way to improve the lives of participants and readers or even your own.

Etherington (2004; 85) has made the following statement in response to those who question the bringing of the personal self into research:

…that perhaps rests upon the false assumption that there can be any text that does not show the presence of the author – in *some* form.

However, leaving aside discussions of validity for the time being, I would argue that while I can see Silverman's (2006) point around wanting to avoid repeating the equivalent of Nazi or Stalinist research and political absolutism, I find it hard to believe it is possible for researchers to create qualitative research about 'professional' interventions with people with learning difficulties without holding a political stance in relation to them.

As I wrote in the methodology chapter of this dissertation, Denzin and Lincoln (2000) have claimed that within all qualitative research the practice of analysing data is political. Ostensibly 'objective' research about people with learning difficulties does not always (if ever) read as such. It can convey attitudes held by researchers towards their research subjects or participants, and the model of disability (or their interpretation of it) that they are using while undertaking their research.

For example, in their journal article on research about the implementation and evaluation of a specific type of support intervention called 'active support' for people with 'severe' learning difficulties, Bradshaw et al. (2004) make no

declaration of the stance they are taking towards people with learning difficulties. While they used more than one observer to increase inter-observer reliability when collecting their data, they made no mention of power imbalances between the professionals and the people with learning difficulties they were observing. They also did not mention which model of disability they were working with.

Their research was based on measuring the effects of 'active support', based on 'apolitical' categories of interaction. Within their text there is nothing written about the manner of the professionals or the values they held. The focus is instead on the responses of the people with learning difficulties in relation to the model of support that they were being subjected to. The subjectivities of the researchers and the workers they observed are not addressed.

They found that when 'active support' was practised there was not only an increase of participation by people with learning difficulties in activities (because they were being actively encouraged to do so) but also an increase of 'challenging' behaviour in them. The label 'challenging behaviour' was ascribed to the people with learning difficulties independently of what they may or may not have been (possibly justifiably) responding to within their social environment. The analysis did not include any consideration that the increase in challenging behaviour might have indicated something less than positive about the implementation of 'active support', or whether such a negative label might reflect the researchers' attitudes to more assertive or confrontational behaviour in people with learning difficulties. It appears that

the writers of the article were working under the assumption that active support, and its resultant increase in participation in activities, by people with learning difficulties was uncritically positive.

From reading the article I could not tell how the people with learning difficulties perceived these interventions. I read this research as being based on both positivist assumptions of objectivity in research and medical model approaches towards supporting people with learning difficulties. In short (leaving aside the possible benefits of 'active support), this apparently objective research can be read as another example of a traditional situation where dominant professionals impose their ideas of what is best upon people with learning difficulties and perpetuate the process of controlling them.

Silverman (2006) has argued that it is not researchers' political credentials that make research valid. I would not disagree with this, or with working to make research as credible and valid as possible. Traditional ethnography has been criticised for the apparently omniscient presence of the hidden author (Anderson, 2006). Ellis and Bochner (2000) have argued that the passive third person voice erases personal accountability and subjectivity. I would argue that researchers who avoid discussing their subjectivity (and political positioning in relation to people with learning difficulties) not only place themselves in a potentially ethically problematic position but also may compromise the validity of their research, as an important part of it could be missing. However, as Etherington (2004) has pointed out, necessary reflexivity that allows the reader to contextualise research is not always seen

as important within the academy, where positivist assumptions can still prevail. The issue of reflexivity is barely mentioned in Silverman (2006). It seems that while he puts forward criteria for ensuring validity when interpreting qualitative data, he and other critics, for example (Bryman, 2008; Sarantakos, 2005) who appear to place a premium on 'objectivity' choose to pay relatively scant attention to the arguments that have led to, or underpinned, the crises of representation, praxis and validity within contemporary qualitative research.

Reflexive narratives allow the researcher to expose their own uncertainty and vulnerability (Etherington, 2004). This in turn can be viewed as a political act as it works against being seen as a powerful pedant dispensing empirical 'facts' for the good of people with learning difficulties. In addition, as Ellis and Bochner (2000) have argued, it helps towards the broader goal of autoethnography of encouraging empathy and compassion in the reader. I wanted to learn how to produce text that stood a chance of facilitating change for the better for people with learning difficulties, even in a small way. In addition, I wanted to write not only for academics but ultimately for a broader audience that included interested practitioners. Therefore, I sought to learn how to write in a way that would engage the empathy of a range of differing categories of reader. Choosing the approach I did towards my data collection and analysis also allowed me to write in a more vulnerable and open way that I hoped readers would be able to empathise with. Instead of assuming an air of distanced authority I aimed to engage the reader by creating a text they could relate to and, to some extent, analyse for themselves. This approach is

very much at the core of Ellis and Bochner's (2006; 2001) and Etherington's (2004) interpretation of the function of autoethnography and reflexive personal narratives.

However, I do not want to imply that reflexive narratives are the only way to undertake research that is supportive of the further self-emancipation of disabled people. Barnes (2001) has stated that different methodologies can be used within an emancipatory disability research paradigm. There are examples of research written from the perspective of service users, that are not reflexive narratives as such, for example Beresford and Turner (1997) and Branfield and Beresford (2006). However, while the approach to data collection and analysis is not ethnographic in the above examples of user controlled research, and the texts are not reflexive narratives, the political position of the researchers in relation to other disabled people and services, for example, is clearly informed by social model thinking and the principles of user controlled research.

Single case ethnographies like my research are far from being the most effective approach to use for testing out hypothesis. Tregaskis (2004; 140) has stated that it would be wrong to claim that the findings of her small-scale single-site, reflexive narrative research could be 'universally applied elsewhere'. Comparative studies, carried out with a multitude of participants across a broad demographic are likely to be better suited to this task.

Ethnographies and autoethnographies, more specifically, can be used to open up questions that confront dominant forms of power (Holt, 2003). However,

they are not particularly appropriate for generating the sort of analyses that

can lead to tight comparatively scientific conclusions, or what can appear to

be relatively hard evidence. As the following quotation shows, Ellis and

Bochner (2000; 744) have postulated that evocative narratives and

autoethnography (as they define it) have different strengths that, in essence,

are in contrast to the above aims:

> Evocative stories activate subjectivity and compel emotional response.
> They long to be used rather than analyzed; to be told and retold rather
> than theorized and settled; to offer lessons for further conversation rather
> than undebatable conclusions; and to substitute the companionship of
> intimate detail for the loneliness of abstracted facts.

Anderson (2006) has claimed that discussion on autoethnography has

focused round an evocative model and post-modern sensibility, and that

within these texts autoethnographers have distanced themselves from

analytical and realist traditions. He has argued for the development of

'analytic autoethnography' that is more compatible with the above analytical

and realist traditions. However, As Ellis and Bochner (2006) point out there is

disagreement between people who identify as interpretive ethnographers and

those who identify as realists.

Traditional criteria for validity and reliability are not addressed in discourses

on autoethnography that are largely informed by postmodernist feminist

thinking. Within these texts alternative criteria for addressing validity issues

are put forward. For example, in relation to the construction of reflexive

narratives Etherington (2004) has written that questions of validity rest upon

several issues. These include whether researcher reflexivity has provided the

reader with enough information on the cultural and historical context of the story, whether the text is sufficiently creative and layered, and whether the work leads to new understandings about the subject of enquiry.

At the other end of the scale, more positivist researchers can appear not to recognise any form of ethnography as being valid research in itself. For example, in a journal article titled 'Ethnography's Role in Assisting Mental Health Research and Clinical Practice', Quimby, (2006) has argued that ethnography has some value as it allows the culture of service users to be further understood. He claims that ethnographic data can be used as a supplement within statistical research. He postulates that ethnography is useful for generating data that could be used towards informing or developing hypothesis, intervention models and theories. Quimby (2006) suggests that by integrating both qualitative and quantitative methods more verifiable data can be produced.

The approach I have taken throughout this research owes much to postmodernist, feminist ideas of what makes for good quality autoethnography. From this perspective all ethnographies can be viewed to some extent as partial truths or forms of fiction (Gerstl-Pepin and Gunzenhauser, 2002). However that does not mean that the issue of validity can be ignored. The credibility of my research has been actively enhanced by integrating evidence from a variety of different sources within my text, for example, transcripts of meetings and interviews and minutes of meetings. I have also been reflexively open about my motives, politicised stance and

focus. That is not to state that the approach I took to data collection and analysis has been unproblematic and completely successful in every aspect. The complexities and dilemmas inherent in the approach I took in relation to this project are discussed throughout the rest of this section.

In conclusion, the approach I took to data collection and analysis on this project fitted well with the aim of supporting user controlled research and creating my own research that was informed by the principles of critical ethnography. To begin with, the approach allowed me to separate my research from that of the people with learning difficulties I supported and to concentrate on how I could support them to represent themselves. It seems that ethnographic reflexive narrative approaches are particularly well suited for the study of roles within the 'helping professions'. They can facilitate practitioners to understand how their self impacts upon their relationships with the people they support. This can lead to ongoing constructive changes in practice.

In addition reflexive narratives are particularly well suited for the production of research that has a politicised focus. They allow the researcher room to explore openly, motivational attitudes and values within the text. They also demand that the research text addresses cultural and relevant political issues, whilst being situated and contextualised throughout as being the product of specific individuals with particular histories and subjectivities. In the process they can challenge dominant and oppressive assumptions about practice and provoke discussion towards change. Reflexive narrative approaches also

allow room for researcher vulnerability and support the use of emotional data in the text that can engage with the reader's sense of empathy.

However, they are contentious because of how much they use the self as a source of data. Although researchers who have utilised these approaches have presented alternative theories about how such research should be evaluated, it seems that reflexive ethnographic narratives and autoethnographic approaches are currently at the fulcrum of often diametrically opposed and apparently incompatible arguments about validity. Working in this way presents challenges to traditional criteria for the evaluation of qualitative research. The approach I took leaves this research vulnerable to accusations of being overly subjective. Holt (2003) has discussed how postmodernist criteria for valid autoethnographic research did not help him when faced with reviewers who demanded traditional criteria for verification be applied to his research. Ellis and Bochner (2000) have discussed the empathy they feel for young students who have to struggle with the positivist assumptions of others in order to carry out their work.

However, it is clear that what reflexive ethnographic approaches are good for is opening up discussion around taken for granted cultural interactions and practices that have the potential to be oppressive. It is not easy to frame them as 'scientific' research approaches as they make a virtue of working with subjective data and the subjectivities of the researcher/s. However, they hold within them the potential for constructing research that leads to new ways of thinking about and relating to cultural practices that have not previously been

explored or questioned. As such they can lead to the construction of discussions that can change the way we view current normalised ways of behaving within our culture.

From the start of this project I have sought to produce research that could be a part of a broader discussion around ways of viewing and responding to people with learning difficulties, which are supportive of their self-empowerment. If I had chosen to focus my research on the mechanics of supporting people to do their own research I could have used an approach which was ostensibly more objective, such as discourse analysis. However, I was studying how to be in relation to people with learning difficulties in ways that were facilitative of them feeling confident enough to be in authority in the group. Also, I was studying what I could do to avoid assuming authoritative control over them. This subject intrinsically involved my personal self and inner thoughts as well as outward responses. As such, I wanted an approach to data collection and analysis that allowed these processes to be utilised as data, analysed and discussed.

The difficulties I encountered in data collection and analysis

Narrative approaches and ethnographic research can generate inordinate amounts of data that can be difficult to manage (Etherington, 2004; Gomm, 2008). With the exception of the interviews undertaken towards the end of this project, to provide reliability checks (Ellis and Bochner, 2000) and respondent validation' Silverman (2006), and the Research Group's notes towards the construction of their book, I stopped collecting data twenty nine months after

beginning to work with Research Group members. This was because I had an inordinate amount of data from a variety of sources, and I feared I would have too much to manage. In addition as my focus was not so much on the mechanics of supporting the researchers to access specific research processes and more on the interpersonal aspects of supporting them to be in control of their own group and agenda I thought I had enough to work with. I had noticed that the content of the data was becoming repetitious. However stopping collecting data when I did led to limitations on what is written about in this dissertation. For example, I could not write about issues connected to supporting researchers with learning difficulties through the publishing process because I had stopped collecting data by the time that happened.

Silverman (2006) has argued that including sufficient raw data and long transcripts aids validity in ethnographic reports. The purpose of including the amount of evidence I did into this dissertation was to avoid the situation of the reader having to accept unsubstantiated analysis. However, working with so much evidence was time consuming and complex to access, manage and write into the text.

Ellis and Bochner (2000) have discussed how difficult it is for autoethnographers to get a balance between not betraying the trust of research participants and giving readers the information they might expect. Etherington (2004) has commented on how complex the representation of others can be within reflexive narratives. Although I did rely on my diaries/field notes for some of the representations I gave of researchers, I also (as far as

was possible) used extracts of both research group minutes and transcripts of tape recordings of meetings to demonstrate concretely to the reader what was actually said by members of the Research Group. Largely I aimed as far as possible to keep my focus on Research Group members only so far as their interventions impacted upon my own role in a way that was of interest in relation to my research questions.

I have discussed some incidences where Research Group members were distressed after being involved in abusive or oppressive situations. In these cases I chose to keep even the pseudonym of particular Research Group members out of the text. In addition, (as I made clear earlier on in this dissertation) I read everything that was written about particular Research Group members to them, and made it very clear that they could (without it bothering me in any way) have anything they wanted taken out of the text. Even after explaining that people who already knew them might be able to identify them from what was written in my dissertation, none of them asked for anything to be removed. In effect, as with their own research, they were keen for people to know about the difficult and oppressive situations that had happened to them.

In addition I had decided from the beginning of this project that I did not want to include anything in the text that would be harmful to People First West. As I also reported earlier, this dissertation was read by the co-ordinator of People First West and one of the members of the management committee (who discussed what he had read with the management committee). The

management committee agreed that this text as it stands was not harmful in any way to People First West or any of its members or workers.

Knowing all along that I would have to read the text to the people I supported and that I was going to submit it for approval by members of People First West encouraged a particular ethical and respectful way of writing about the researchers and People First West workers. I would not like to claim that this was a negative aspect of this research in relation to data collection and analysis. I think it could be argued that, in relation to this project, it was a positive element. However, it did mean that I had to pay particular, time-consuming, attention and thought to what data I collected and included in my final analysis and the way in which I wrote about the researchers and People First West workers.

The heuristic process that writers of reflexive narratives become involved in requires a lot of attention to detail and time (Etherington, 2004; Janesick, 2000). In addition, reflexive researchers need space to step back from their experience in the field to turn to the literature, analyse their data and write their texts (Etherington, 2004). However, because I was active as a supporter, and at times deeply concerned about the situations that Research Group members were in, it was not always easy to step back from my position or find time to be focused on the literature. At times I felt I needed space to be a researcher, but my mind was occupied by the challenge of working out how best to respond as a supporter. This dilemma led to my feeling stressed at

times and I would posit that it slowed down the process of completing this research.

In reflexive research, the author's personal experience is written into the text. Disclosing inner feelings and emotions in this way is risky (Smith and Sparkes, 2008) and can feel frightening (Ellis and Bochner, 2000). Etherington (2004) has argued that disclosing personal information could damage researcher's careers, and that readers may pathologise researchers who expose their vulnerabilities. My research began with the development of an ethical stance in relation to people with learning difficulties, which I sought to maintain throughout this project. Personally I have worried that because to some extent my research was based around aiming to maintain an ethical stance some readers might view me as 'pious'. However, I cannot know how I will be judged, but 'I' (with my emotions and feelings) am in the text, vulnerable to being judged not only as a researcher but as a person. This vulnerability to being judged in this way is one of the difficulties of the data collection and analysis processes of autoethnography and reflexive narratives.

What I learned about data collection and analysis by carrying out this project

I learned a lot about data collection and analysis by carrying out this research, far too much to describe in a dissertation of this size. However, here is a short description of what I consider to be my main areas of learning in this context. I learned that, as Ellis and Bochner (2000; 751) have put it:

> …there's no such thing as orthodox reliability in autoethnographic research.

I also learned that in autoethnography generalisability is not the same as in other types of research. I agree with Ellis and Bochner (2000) who claim that as we all participate in a limited number of institutions and cultures our lives are not only particular, they are also generalisable. They posit that a good autoethnographic text should stand up to the testing that readers do as they determine if the text speaks to them about either their own experience or that of others, or brings believable news from outside of their circle of experience .

I learned that while both ethnographers and autoethnographers can rely heavily (if not exclusively) on their own ultimately subjective, interpretive, field notes of one form or another (Silverman, 2006), other forms of data can also be used within ethnographic research. On this project I used different types of data for different aspects of this research. For example, I used interviews as reliability checks to find out Research Group members' views about possible positive interventions I had identified in analysis that may have been supportive of them feeling comfortable in the group, and exercising control within it. I also used tapes of meetings in the analysis process (particularly in relation to researching into and providing evidence about specific potentially supportive interventions), situating verbatim transcripts within the text. I also included long extracts of transcripts wherever possible to give the reader as full a picture as possible of the situation. In addition, I used minutes of Research Group meetings to discuss the focus of their agendas.

It is important to mention here that my diaries did not just contain reflective data. Silverman (2006; 284) has discussed the benefits of collecting a range of observational data, referring to Spradley's (1979) recommendations to keep four different categories of notes. This is how he explains them:

1. short notes made at the time
2. expanded notes made as soon as possible after each field session
3. a field work journal to record problems and ideas that arise during each stage of field work
4. a provisional running record of analysis and interpretation

I collected all of the above categories of data, to some extent, under one heading, 'diaries' (my running record of analysis and interpretation was also present in the clusters of themes and many drafts of chapters of this dissertation that I stored for reference throughout this project). This goes some way to explaining why I had so much data under 'diaries'. I also used the 'dairies' for a further purpose, recommended by Chang (2008; 36): for self-description and self-reflection, as well as to describe 'daily happenings'. In addition I used my diaries as Etherington (2004) (b) has recommended, to record the heuristic processes of the research, or the effects of the research process on myself, and to reflexively develop my support role.

I used thematic analysis to analyse my data on this project. Braun and Clarke (2006) have discussed how although this method of data analysis is widely used it is rarely acknowledged and poorly demarcated. However, I learned how to use this flexible approach in a manner that was compatible with the postmodern constructivist epistemology that has informed this research.

The procedures I used for coding data were as follows: keeping in mind my research questions, (which, although I refined them during the research process, essentially stayed the same throughout the course of the whole project) I sought to find any themes that fitted with what Braun and Clarke (2006; 82) have pointed out as being criteria of the 'keyness' of a theme in thematic analysis:

> …the 'keyness' of a theme is not necessarily dependent on quantifiable measures – but rather on whether it captures something important in relation to the overall research question.

The theorising of self-advocacy support and disability, in relation to people with learning difficulties, at the beginning of and periodically throughout the course of this project, enabled me to identify themes more effectively, in particular latent themes, that were concerned with developing theoretical meanings from the data.

In the main, themes were identified because the issues in the data appeared to have captured something important in relation to the issues of power and control that I had identified in my research questions. Although my analysis was iterative or recursive and not strictly a linear process as such, after identifying themes I progressed my analysis by looking for patterns of meaning in the data. During the time I worked on the analysis I moved back and forth, as and when necessary, immersing myself in, and familiarising myself with, the data. I generated initial codes and over time matched them to themes of analysis, then grouped these themes into broader themes (the

broader themes of analysis eventually became single findings chapters within this dissertation).

Throughout the process I reread the data set and checked that my themes worked in relation to it and sought to find any further themes I had missed earlier. I wrote detailed analysis of each theme and in this process demarcated sub-themes, and worked out how each theme fitted into the overall story. For me, the writing of the story was also an important part of clarifying the analysis. This very much concurs with Ellis and Botchner's (2000) views on the successful construction of authoethnographies and Etherington's (2004) views on making tacit knowledge clearer. Therefore, the process of constructing the many successive drafts of this dissertation served to clarify the themes within this research.

I learned during the construction of this research that the process of triangulation for validity can be viewed in different ways that may be more helpful for reflexive narratives and autoethnographies. For example, Ellis and Bochner (2000) have argued that researchers who have representation as their goal should have as many levels and sources of the story as possible. Richardson (2000) has discussed how the image of a crystal rather than a triangle could be more effective for ensuring validity in reflexive narratives. This echoes Ellis and Bochner's (2000) suggestion for best representation, as the principle idea of the 'crystal model of validity' is to reflect different angles of the story without presupposing that there is any single truth. Etherington (2004) proposes that the crystal model of validity is best suited for reflexive

narratives. The aim of Richardson's crystallisation is to present a complex, deepened understanding of the story, to enable the reader to understand more, while appreciating the partiality of the text (Richardson, 2000).

I believe that I learned more on this project about how to present a rich text, from a variety of angles, that could enable the reader to engage with it both emotionally and empathically. In addition I believe I also learned more about how to effectively produce a story that could enable the reader to find a fleshed-out expression of reality within it and validate it from their own perspective. All of the above qualities are recognised as being indicators of good-quality reflexive ethnography and autoethnography (Etherington, 2004; Ellis and Bochner, 2000; Richardson, 2000).

Critical discussion of the subjectivity of my writing about my research into my own support role

I have already explained how subjectivity is an integral part of reflexive narratives and autobiographical approaches, and how it was a crucial element in the construction of my research and this text. The next part of this critical evaluation continues this discussion, but also points out some of the drawbacks of my subjectivity in relation to researching into my own support role. However, I would like to make clear that it does not negate what I have already written about the inevitable subjectivity (to one extent or another) within all social research. Nor does it negate the benefits of undertaking research where an attempt is made to self-consciously, transparently and reflexively put that subjectivity to good use within the research process.

Anderson (2006; 379) has posited that an element of all autoethnographies is that the researcher is a 'complete member' of the social environment that is being studied. Yet while this allows the author to write from experience of 'being there' it is not an unproblematic position to be in. Within both ethnography and autoethnography there will inevitably be interpretive variation between what one individual experiences or chooses to record and another's experience and choices (Gerstl-Pepin and Gunzenhauser, 2002; Anderson, 2006). It seems clear that an unchallenged aim of all autoethnographies is that the valuable insider issues that autoethnography reveals need to be contextualised into a broader cultural story or discussion (Anderson, 2006; Etherington, 2004; Ellis and Bochner, 2000). I have been careful to do this from the start of this project. Indeed, I began the construction of this research by theoretically mapping out how people with learning difficulties are framed within our culture and what might be the most helpful starting point to begin supporting their self-empowerment. Throughout the course of this research I have continued to address cultural and historical issues in relation to how people with learning difficulties have been, and continue to be, responded to within society.

However, having done this, there are still dilemmas connected to the process of researching autoethnographically into one's own support role. There are others who have used reflexive narratives and autoethnography to research into their own supportive or educational practices, for example Schelly (2008) and Alexander (1999). This discussion is as much about the limitations of

adopting autoethnographic approaches to research into one's own practice as a limitation within this specific research project. Before going any further I would like to state the following. People who undertake autoethnographic research into their own supportive or educational practice are members of whatever group they are affiliated to, for example 'teachers', 'supporters' or 'therapists'. However, while occupying these roles they are not a member of the group that their research participants are in, for example 'students', 'clients' and 'members of self-advocacy groups'. Therefore, while I was a supporter discussing support, and a member of that group as such, I was not a person with learning difficulties receiving support. At this point my subjectivity, and that of other people in supportive roles who use autoethnographic approaches to research into their own practice, becomes somewhat of a dilemma.

In addition, taking into account the value of first-hand knowledge (Beresford, 2003), is anyone, in any 'helping role' best equipped to evaluate or even accurately witness their own role, in isolation? For example, supporters of people with learning difficulties (even those who are consciously trying to support the empowerment of service users) may not realise subtle controlling elements of offering choice, (Finlay, et al., 2008).

I was particularly focused on the subject of avoiding exercising authority over, or directing the group, and had worked to separate my needs from those of the Research Group members. Also as someone who had trained as a person-centred psychotherapist and had facilitated groups for a long time I

had considerable experience of working with reflective awareness. However it would be foolhardy to suggest that I could possibly be aware of every aspect of my own behaviour.

Another layer of credibility could be added to my research if an appropriate independent assessment of my role had been undertaken; one that suitably involved the people with learning difficulties I supported. This could have helped me and people reading this research to understand aspects of my own practice that went unnoticed by me. It could also have added further credibility to the themes I identified and brought in other perspectives on what was happening in the group, adding further richness to the analysis, and more facets to the crystallisation model of validity mentioned earlier. In the next part of this evaluation I discuss what I would have done differently if I could do this or similar research again. Then I move on to discuss what form a hypothetical, ideal-world, evaluation of my role on this project might take.

What I would do differently were I to do this, or similar, research again

In relation to collecting and analysing data, I would consider the following if I were to do this or similar research again. I would make more use of interviewing the researchers I was supporting about their experience of being supported and their views about what they did and did not experience as useful or supportive. With hindsight I think it would have been useful to have interviewed them at repeated intervals at the start, middle and end of the project, for example, to try and ascertain how they were experiencing the

project and the support process. I would also aim to find ways for them to be supported to formally evaluate my input. This issue is discussed later in more detail in this evaluation.

Although I have come across no examples of autoethnographic researchers using second coders it may have been useful to have had second coders on this project or any similar one I embarked upon. Ryan and Bernard (2000; 785) have argued that high levels of inter coder agreement provide evidence that research has some 'external validity'. This view implies that if I'd had a second coder on this research, or even several coders, for a proportion of the field notes called 'diaries' there is a possibility that a proportion of the themes within the research could have been given a further degree of validity, through consensus. This might have entailed perhaps 10-20% being second-coded, at three-monthly intervals from the onset of this project until several months after I had stopped collecting data. In addition, this may have added a further degree of rigour to the process of establishing themes. Establishing a 'log trail' of the coding and subsequent analysis along the way could be helpful, to ensure that each stage of the coding and analysis can easily and accurately be accessed and transparently conveyed to the reader if necessary (Richards, 2005).

However, using a second coder in this way would not address the issue of how in reflexive research the structuring of the 'story' contributes towards the development of the analysis, or how being immersed in the field allows understanding of research issues to grow, and tacit knowledge to become

clearer during the process of analysis (Etherington, 2004). In addition, with ethnographic methodologies, analysis generally starts while the researcher is in the field (Hammersley and Atkinson, 2007; Soyini Madison, 2005).

Also without the second coder being involved in the field for hundreds of hours (which would, encourage greater degrees of subjectivity) they could not be expected to have a deep appreciation of the situation. However, qualitative researchers working with a clear understanding of the research questions should have been able to corroborate some of the themes that I found in the data and perhaps even identify others. At the early coding stage this could have been useful for adding further validity to themes at this first level of abstraction.

In addition, second coders could have analysed tapes of the interviews undertaken towards the end of the project. Again this could help to validate themes and if they saw some different themes this could help to enrich the findings. Gerstl-Pepin and Gunzenhauser (2002; 137) have discussed how their collaborative team ethnography led to the following occurring:

> …greater understanding through multiple meanings but, paradoxically, greater fragmentation and uncertainty.

However uncertainty can be a sound stage in research, enabling researchers to avoid making premature claims on the basis of too little data.

In addition I would seek to work more in collaboration with people with learning difficulties if I did this or similar research again. On this project I did not feel I could share the analysis with other people as this research was work towards a PhD examination. However, not including people with learning difficulties in the data collection and analysis, of this research about their support, was nonetheless not completely congruent with the politics and emancipatory aims of this project.

Thoughts on a hypothetical independent evaluation of my support role

The following suggestions for a hypothetical ideal world independent evaluation of my support role on this project would, in theory, be carried out by people other than me. In order to carry out any evaluation of my role, the aims I held on this project would have to be taken seriously and my research questions addressed. However, the researchers involved in this evaluation would not be using the same data collection and analysis processes as I did on this project, and in all probability relying on different epistemological perspectives. Therefore the epistemology of this hypothetical evaluation and the methodology used would not have to be compatible with the research described in this reflexive narrative. However, while constructing these thoughts on a hypothetical evaluation of my support role I have borne in mind how Research Group members, and other people with learning difficulties, could actively and powerfully be involved in the processes that are discussed in this section.

Members of the Research Group could be supported to evaluate my role. Another supporter could interview them and possibly support them to analyse the results. It is interesting to speculate on who would devise the interview schedule. As it would be an evaluation of the role I developed through undertaking this research, in one way it could be positive if I devised it. After undertaking this research I have considerable experience of considering the issues related to supporting people with learning difficulties to be in control of their own group and agendas. However, it could be argued that this would compromise the independent nature of this hypothetical evaluation.

The interview schedule could be constructed by another supporter who had a keen awareness of the issues that were being explored. It could possibly be developed with Research Group members themselves, or other self-advocacy group members who had experienced being in control of their own agenda. Possibly, someone like Simone Aspis, who has learning difficulties and a lot of experience as both a researcher and political campaigner for the self-empowerment of people with learning difficulties (Aspis, 1997; 2002), could construct the interview schedule and conduct the interviews. This might be achieved with, or possibly even without, Research Group members, as she has learning difficulties herself. However, there are very few people with learning difficulties who have Simone Aspis's level of academic and theoretical understanding about issues relating to the oppression and control of people with learning difficulties.

In addition as this research is about *support* of self-advocacy, from a *supporter's* view it would seem useful if this person had considerable experience of supporting people with learning difficulties themselves. Perhaps, the most effective approach could be to have a supporter involved, alongside an experienced person with learning difficulties (unless of course the supporter was a person with learning difficulties themselves, as some are). However, any supporter involved in undertaking an independent evaluation of my role on this project would also need academic skills, and as Schelly (2008) has pointed out, very few supporters are also academics with the necessary skills to construct an evaluation of this nature.

Assuming that a suitable supporter could be found, they could support Research Group members (if they were interested in doing so) to analyse their experience of the support they received while undertaking their research. Issues that could possibly be explored in the interviews are, for example, how they saw their role on the project, the development of their self-confidence and what they found least and most helpful about my support. Imagining that this hypothetical evaluation could have been implemented throughout this project, it could have been useful if researchers were interviewed at different stages of it, for example, near the start, in the middle and at the end. Other issues that might be looked at in the interviews are if/how the project affected both their self-esteem and the quality of their everyday lives. If Research Group members were involved in the construction of the questions they may come up with different criteria.

As I mentioned previously, Atkinson (1989) has posited that people with learning difficulties may say what they think the interviewer wants to hear. They may do this in an attempt to avoid conflict with a powerful person (Sinason, 1992). Research Group members would need to feel comfortable with an interviewer to say whatever they wanted, and not be in a disempowered position in relation to them. Oakley has made the following comments on this subject:

> ..it becomes clear that, in most cases, the goal of finding out about people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship. (1981; 41)

A suitable rapport would need to be developed (McCarthy, 1999; Booth and Booth, 1998). This implies that it could work well if the interviewer was already known to some extent and trusted by the group members.

However, as I am friendly with all the supporters at People First West, possible feelings of loyalty towards me may compromise any capacity they could have to provide an evaluation that is sufficiently independent. On this note, the same could happen with Research Group members who may choose not to express any views they may hold that are less than positive about my role in relation to them. They may also feel loyalties towards me that could lead to them not wanting to say anything negative. Gestl- Pepin and Gunzenhauser (2002) have discussed how they, and other researchers involved in collaborative team ethnography, felt reluctant to say anything negative about the schools they conducted their ethnographic research in.

This leads on to another issue. The person who interviewed Research Group members would also need skills in facilitating people with learning difficulties to say what they thought. It is likely, that this would involve them being perceived as being unthreatening in any way by Research Group members. They would also need to be able to make any questions accessible to people with learning difficulties, and ensure that they were being understood in the field (Moffatt, 1996). However, these issues might be overcome if the interviewers were suitably experienced or trained and a period of time was given prior to the interviews to develop rapport and trust with Research Group members. Sarantakos (2005) has discussed how interviewees can feel more comfortable with people similar to themselves. This suggests that the most positive approach could be to have a person or persons with learning difficulties conduct the interviews.

Finlay, et al., (2008) have used videotape as data to analyse how supporters presented choices to people with learning difficulties with 'high support needs'. Another way of evaluating at least part of my role on this project could have been to have videoed or filmed me supporting Research Group members. This may have been particularly useful for critiquing the subtleties of how I presented choices. In addition on this project, it could have been useful if findings had been fed back to me periodically. Such feedback could have contributed towards the reflexive development of my support role during the time I met with Research Group members.

Filming my role may have enabled independent researchers to see subtle or unconscious aspects of my interventions, that I did not notice myself, that led to me influencing the decisions of Research Group members. In addition, independent analysis of such data may have led to the identification of positive responses, which were supportive of the self-empowerment of Research Group members, and not picked up by me in my data collection and analysis process. Again, any analysis made should ideally, appropriately, involve service users with learning difficulties.

It is possible that any directive interventions I may have made would be considerably more subtle than those presented in Finlay et al.'s (2008) research about staff in day centres for people with high support needs. It is likely that the staff in this environment had less experience of academically analysing the subject of control and support, and possibly a great deal more pressure on them to fit in with institutional practices than I did. The researchers who analysed my interventions would need to be particularly informed about issues relating to subtle elements of control or direction within supportive relationships.

Before any filming by independent researchers could take place several issues would need to be addressed and overcome. Both the presence of the camera and the person filming could lead to both service users and myself being self-conscious or uncomfortable, and therefore responding differently because of this. Although film is considered a relatively low inference descriptor (Silverman, 2006) (as filmed data has not been constructed, in

relation to the subjectivity of researchers, and as such is more objective evidence) it cannot be assumed that issues of reliability can be totally overcome by using film. Where the camera is pointed and decisions about when to stop and start filming are fallible (Silverman, 2006).

When it comes to analysing video film, the same dilemmas about subjectivity and representation that have been discussed throughout this section come back into play. Nevertheless, having at least two independent coders analysing the behavioural sequences (which relate to power, control, support and direction) systematically, and reaching consensus, would potentially reveal subtleties of social interactions which may have been missed in both my fieldwork notes and interviews. In addition this form of analysis could add another layer of credibility to some of the findings that are in this dissertation.

Another potential way towards an independent evaluation of the role I developed on this project could be to train a group of supporters in the non-directive processes of support I have identified through my data collection and analysis. Then comparisons could be made between their behaviour, concerns and effectiveness and those of a control group of supporters who have not been educated in this process of support. This research could be constructed as a field experiment, comparing processes and outcomes in, for example, six separate groups. Theoretically, I could be involved with Research Group members in developing and carrying out the training, while not being one of the researchers on this project.

The study could focus upon both how group dynamics were influenced as well as the project outcome. The research texts produced by the people with learning difficulties could also be analysed in this evaluation. The aim here would be to see how these texts varied in both content and tone, according to whether their supporters had been trained in the principles and approaches identified in my research, or not.

It would also help towards claims of objectivity if second observers periodically worked with the main observers to check that there was agreement over the quality and focus of the observations and the methods of recording data. All of the observers could work with the same criteria of what they were looking to comment on, thereby lessening any claims against the research findings being 'contaminated' by subjectivity.

The analysis could be undertaken by a team of researchers, who were perhaps overseen or advised by a steering group. This would work against the research being criticised as the views of one or two individuals. The data could be analysed using a computer programme such as NUDIST qualitative data analysis system, to add a further degree of distance to the analysis process, and more 'objective' rigour.

In addition, the interventions of the research supporters could be filmed at intervals, to provide data that could be analysed independently at the behavioural level by more than one analyst. This approach however, would not be unproblematic. Experienced supporters would need to be trained and

paid to support people to carry out user-controlled research, a process where both the outcome and the length of time required can be difficult to predict. Also the people with learning difficulties in the Research Group wanted to be, and were, paid for their work and there is no reason to argue that the situation should be any different for the researchers with learning difficulties involved in this hypothetical evaluation of my role. This project could be expensive.

Consent issues would be complex as people with learning difficulties would need to understand and agree not only to taking part in their own research project but to being observed periodically by people they are unlikely to know very well. In addition there would be a whole new layer of consent issues in relation to their images being used in research. In order to feel comfortable with observers, the people with learning difficulties would perhaps have to spend time getting to know them and feeling comfortable. Trust and confidentiality would be issues that need careful nurturing and monitoring throughout.

Recommendations for future research topics

The previous section of this chapter ended with a discussion on how my research could be evaluated and the findings tested using alternative research designs. In this section I make some recommendations for future research *topics*. These recommendations have grown out of my experiences of both researching relevant literature for my research and conducting research in the field.

The issue of supporting people with learning difficulties to be in control is very much an under-researched area. While this research, and that of the Research Group, has implied that people with learning difficulties are commonly disempowered, there is little research that specifically addresses how the balance of power, within supportive environments, can be shifted in favour of people with learning difficulties. Therefore taking this research into account I would like to make the following recommendations for future research.

This research has indicated that there is a need for more research around the subject of defining both what self-advocacy is and what the responsibilities of self-advocacy supporters are. However I would stress that the focus of such research would need to be based around defining the above processes in relation to *people with learning difficulties being in control of their own self-empowerment*.

Taking into account the contextual challenges to supporting researchers to be in control of their own agendas that have been presented in Chapter 6, this research has indicated that *ultimately* the environment that the Research Group worked within had a positive effect in enabling them to define their own agenda and produce research that reflected their views in an undiluted and direct way. Therefore, I would suggest that perhaps there is room for research into how academic institutions (and even service providers such as social services departments) can interact with user controlled organisations for

people with learning difficulties in ways that shift the balance of power further towards service users.

This research has indicated that the role of user controlled research supporter seems to be undervalued and as yet is unrecognised. I would suggest that there is room for research on how this type of support can be utilised by academic and user controlled organisations. In addition there is a need for research on how user controlled research supporters can be effectively assimilated into the workforce of these organisations as recognised professionals.

This research has demonstrated that there are many opportunities for imbalances of power to exist between people with learning difficulties and the professionals who support them face to face. Therefore I would argue that there is a need for research into the structures that could be put into place to teach people who work face to face with people with learning difficulties about how they could consciously support the self-empowerment of service users. I would suggest that a key focus of this teaching could be on supporting without controlling and/or supporting without holding power over service users.

After undertaking this research (and finding that Research Group members needed so much support at times to deal with problems relating to their social care), I would also suggest that there is a need for research, from a social model perspective, into a range of different support roles with people with learning difficulties to ascertain if the official role encompasses the support

that is actually needed or requested by service users. Conversely I would suggest that there is room for research into the stresses faced by people who support from a social model perspective if they aim to offer the support that people with learning difficulties are requesting.

Conclusion

In the introductory chapter I explained that this dissertation would be a story about finding ways to support people with learning difficulties to be in control of their own research group and the dilemmas I encountered along the way. This dissertation explains how I came to support a group of people with learning difficulties to establish their own research group, and worked to assist them to both gain and maintain control of it. However, it also tells a story of how the people I worked with needed support to deal with the control they experienced outside of the research group, much of which came from the services and organisations that were there to support them. This research has been about finding ways to support without exercising authoritative control over people with learning difficulties. It has also been about trying to discover ways of supporting people with learning difficulties both to exercise control over their own lives and counteract the oppression they face.

Little is known about the process of interpersonally supporting people with learning difficulties to be in control of their own agendas at this level and little status and recognition is currently attached to this pursuit. This seems

particularly ironic in an age when the subject of the 'empowerment' of people

with learning difficulties is part of Department of Health (2001) policy and

therefore ostensibly a significant aim of the services and organisations that

are in place to support them. A finding of this research was that, in a society

that places little emphasis on the importance of this practice, supporting

people with learning difficulties to be in control is complex, time- consuming

and emotionally, psychologically and intellectually demanding.

There is scant discussion on the subject of providing interpersonal support for

people with learning difficulties to be in control of their self-empowerment. My

research has indicated that a starting point in this process is for supporters to

actively work against being (and being perceived as being) in an authoritative

position of any sort in relation to service users. An implication of this research

is that non-directive support can be used when assisting people to make

informed choices and access research and other activities. This research has

also indicated that specific constructive responses can be made in an attempt

to counteract being in a position of authority.

I discovered during the course of this research, both in relation to the literature

on the subject and by listening to the researchers with learning difficulties, that

it may be unusual for people with learning difficulties to be supported without

being controlled or directed by the day-to-day interventions of supporters or

support workers. A crucial part of the development of the role I put into

practice on this project was to actively enquire into how I could best perceive

who people with learning difficulties were and how I could interact with them, in relation to interpersonally supporting their self-empowerment.

This research has been about uncovering both oppressive attitudes towards people with learning difficulties and those that are compatible with supporting their self-empowerment. Supporters work face to face with people with learning difficulties, and the attitudes they hold in relation to them are of great significance. This research indicates that critical reflection on attitudes and values, based around the principles of the social model of disability can be a crucial element in ensuring that support roles remain focused on the self-empowerment of people with learning difficulties.

The issue of how to support people with learning difficulties, actively and interpersonally, to be *in control* of their own agendas has been missed out of Department of Health policy and not seen as a subject worthy of serious research before. This research has problematised a largely taken-for-granted aspect of supporting people with learning difficulties. However, it is only one research project. There is a need for more work to be done in this area and not only in relation to user controlled research with people with learning difficulties. There is a need for further research into how services and organisations for people with learning difficulties can actively interpersonally support them to be in control of their own lives. Wider recognition of the importance of this subject and suitable structures to implement this type of support are vital to further development in this area.

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