Mutual Support

An exploration of peer support
for people with learning difficulties

Sarah Elizabeth Keyes

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Sarah Elizabeth Keyes

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Mutual Support is an in depth exploration of the role and impact of peer support by people with learning difficulties. Built on one of the seven aims of Centres for Independent Living, the project has constructed a model of peer support based on accounts of direct experiences from people with learning difficulties.

The overall aim of the research was to construct and critique the Mutual Support model of peer support and people with learning difficulties. This thesis reflects the process of that construction. The overall aim was met through a research situation in which knowledge was constructed in the interaction between the researcher and participants. This provided an opportunity for people with learning difficulties to reflect upon their relationships with one another, and the emancipatory potential of that support.

The focus of the research was two pre-existing settings involving people with learning difficulties supporting one another: a Theatre Company using Forum Drama to facilitate changes in attitudes and policy, and a course facilitated by people with learning difficulties who mentored small groups. Methods used within the research were based on an Inclusive Research process which prioritises meaningful research interaction that is accessible and guided by participants. The research process intertwined meetings with advisory groups, and contact with other local groups of people with learning difficulties, with formal data collection within the two main settings.

One to one experienced-based narrative interviews with people from the two main settings provided multiple opportunities for participants to speak about their experiences of peer support. These interviews formed the data used in formal analysis, which was a continual process, with subsequent interviews being based on views previously expressed. A further comprehensive descriptive content analysis of data, using the tools of Nvivo8 and mind-mapping, took place prior to the outputs of the whole project being evaluated during group sessions with those who had taken part.

The emerging model is one of collective support which challenges assumptions about the role and impact of people with learning difficulties supporting one another and their capacity to engage in insightful interpersonal interaction. Mutual Support has the potential to break down barriers to inclusion. Mutual Support also demonstrates the value that people with learning difficulties place on giving and receiving support from one another. The outputs of Mutual Support include contribution to current debate in the areas of service user involvement, inclusive research, and the academic field of Disability Studies.

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More specifically, thanks to those whose creative work resulted in the two settings which are central to Mutual Support. The dynamics and enthusiasm within the settings which come across in this thesis are, again, not my doing.

Thanks to Professor John Swain, for believing in me and this project right from the very start, and for his guidance throughout, and to Dr Toby Brandon for his support and guidance. Thanks also to Dr Tina Cook for stepping in, and persevering, with the R and D approval process.

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Declaration I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work

Name:

Signature:

Date:

PART ONE:
Laying the foundations of Mutual Support

The purpose of Part One of this thesis is to lay down the foundations on which the rock of Mutual Support is built. This is done by establishing the background to the project, including the people who took part, the aims and objectives of the research, and a review of relevant literature.

Section One, the introduction, begins by stating the overall aim of the research and the research question that underpinned the process, before defining the key terms used. This is followed by an account of how the idea for Mutual Support was first conceived. It then outlines the contexts within which the research is set, including an outline of the two settings which are central to Mutual Support, and the people who took part from these settings. This includes a profile of the people who took part. This is followed by a section introducing the perspectives which I have brought to the research interaction, and a brief explanation of the use of terminology in this thesis.

In Part One Section Two, a statement of the overall aim of Mutual Support is followed by a brief discussion of each objective and its significance within the research process and/or the emerging model of peer support and people with learning difficulties.

Part One Section Three is an outline of literature relevant to the research. This includes a background to the topic of peer support and people with learning difficulties, including previous research into this, and related, areas. A background of literature which is relevant to the methodology used in Mutual Support forms the second half of the literature review.

PART ONE SECTION ONE: Introduction

This introduction is an outline of the origins of Mutual Support. It begins by briefly defining the key terms within the research process before outlining the way in which the idea of peer support and people with learning difficulties evolved. It then provides an overview of the thesis, explaining the purpose of each of the three main parts of the thesis. The context for the research is then set, outlining the two main settings within which the research took place and the people who were involved in the research.

Overall aim and research question

The overall aim of the research was to construct and critique the Mutual Support model of peer support and people with learning difficulties. The research question underpinning the construction of Mutual Support was: *How do people with learning difficulties perceive the support which they give and receive from others with learning difficulties? How might this be developed further in a way that promotes inclusion, autonomy and choice?*

Definitions

Throughout the research, and therefore this thesis, the following key concepts have been defined as follows:

Model

Within the context of Social Research, Uhrmacher (2006 p181) defines modelling as "*the process of organizing knowledge about a given system".* A model is a way of organising large amounts of information about a specific system into a format which allows a presentation of understanding of the different aspects of that system. A model also enables the different aspects of information about the topic to be considered in relation to how they interact with each other. For example a model railway shows a whole system of trains, track and stations in a way which standing beside a life-size train would not. Within Mutual Support, the system being modelled was the varied and diverse ways in which people with learning difficulties were supporting one another within the specific contexts which were central to the research (see pages 7-11 for outline of the two settings). Thus, modelling Mutual Support has allowed for an overview of a whole picture of peer support to emerge at the same time as considering in detail the many different aspects of that support and how they relate to other aspects

of the model. It is important to recognise, however, that a model does not claim an in depth explanation of causality in the way that a theory would do.

Peer Support

The concept of a 'peer' is grounded in commonality of experience or circumstance. It can relate to many different aspects of people's identities and experiences. The people who took part in Mutual Support are defined as peers in two related ways. Firstly, all those who took part in Mutual Support have been labelled as having a learning difficulty. Secondly, the context in which Mutual Support is grounded is also relevant to the conceptualisation of peer. The focus on projects where people with learning difficulties were already working together meant that within each setting there was a commonality of experience upon which participants were reflecting. The picture of support which emerged from within the settings evolved within the research process and was defined by the participants themselves, but the focus was on the varied and diverse ways in which peers within those settings supported one another within the activity which was central to those settings.

Learning Difficulties

The issues surrounding the terminology used to describe the group of people whose experiences are central to Mutual Support could, potentially, fill a whole thesis. A detailed discussion would detract from the focus of this thesis, and is outside of its scope. I have chosen to use the term "people with learning difficulties". This reflects a theme which emerges from the research, articulated by Grace[1], one of The Lawnmowers actors, during one of my meetings with her:

> *Grace: we may not catch up on things straight away........but that doesn't mean that we won't catch up on them. It just takes us time......I'm very slow at learning things – but I eventually catch up on them. Just give us time, and you'll see that we do. It's like anything, really, it's like anything in life, just give us time.....*

The preference of terminology also builds on the idea that having a learning *difficulty* does not mean that someone can't learn, and that everybody has things which they find hard to learn or understand:

> *"the term 'learning difficulties' implies that people want to learn and recognizes that all people have some learning difficulty one way or another"* (Goodley 2000 p123).

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[1] All names used for participants are pseudonyms.

It also reflects the terminology preferred by self advocacy and People First groups (People First website, accessed 17/02/2009). When citing literature which uses different terminology, direct quotations will use the exact terminology used in that literature.

Mutual Support

The term "Mutual Support" has also been used throughout this thesis. It was originally conceived as part of the title for this project, as it reflected the ethos of the exploration of peer support and people with learning difficulties. Thus, when referring to the research project which is outlined within this thesis, I have often referred to the project as "Mutual Support". This has allowed for distinction between this specific project and other research being referred to and reflects the life which this project has taken as its own. As the project developed, and in particular the co-construction of the model of peer support and people with learning difficulties, that model also naturally took on the title of "Mutual Support". Thus, particularly in the aspects of the thesis relating to the nature and scope of that model, references to "Mutual Support" are also direct references to the accounts of participants and the emerging model.

Having defined the key terms within Mutual Support, this introduction now outlines the origins of the ideas behind Mutual Support.

The origins of the ideas behind Mutual Support

My original proposal for a self-funded PhD project was based on a reading of Barnes and Mercer's (2006) *Independent Futures: creating user led disability services in a disabling society.* Barnes and Mercer's work was a presentation of an extensive research project that involved evaluating nine user-led services in the UK, based on the philosophy of the independent living movement. The original "seven needs for independent living" for disabled people outlined in 1990 were: information, counselling and peer support, housing, technical aids and equipment, transport and an accessible environment (Davis 1990).

My proposal was to focus on one of these seven aspects of independent living by developing a model of peer counselling for disabled people, exploring concepts raised by a social model approach to counselling (building on work done, for example by Reeve 2004, 2006 and Swain, Griffiths and French 2006). The provision of a studentship from Northumbria University focused the proposal, and people with learning difficulties became central to the project. The shift away from support in the

specific form of counselling to the varied and diverse forms of support which have become known as Mutual Support has been led by the research process as it has evolved.

In their report on the Independent Futures project, Barnes and Mercer (2006 p100) stated that "*peer support is a primary activity for all the organisations visited*". This led my thinking towards an exploration of how peer support might be introduced into a wide range of services, wherever these services are along the continuum of user involvement. This spans from services where users have absolutely no control to those which are, at all levels of organisation, user-led. The concept of user involvement is also applicable to the methodological stance in Mutual Support which locates participants' views as central and views them as experts on their own experiences.

Thus, the idea of peer support for people with learning difficulties also builds on the principles behind both self advocacy and inclusive research. Mutual Support is about gathering evidence from the point of view of people with learning difficulties about positive experiences: supporting one another to overcome barriers in society.

Outline of thesis

The inspiration for the outline of this thesis came from one of the participants who referred to people as "rocks" of support within his group. The idea of a "rock of support" is also reflected by other participants when speaking about Mutual Support. Alongside this, the whole project has been a process of co-construction of knowledge with participation from those whose views are central. Thus, the idea of the research being based on the theoretical perspective of the co-construction of knowledge through an inclusive approach to the research process is reflected in the outline of the thesis.

<u>Part One</u> lays the foundations on which the rock has been built. This introduction explains the ideas behind Mutual Support, introducing the settings and the people involved and the structure of the thesis. It is followed in Part One Section Two by a statement of the aims and objectives of the research. The aims and objectives relate to the inclusive approach to research and the construction of knowledge in the interaction between myself and the participants. The expected outputs of the project, and their contribution to knowledge, are also outlined.

Part One Section Three, the literature review, outlines the understanding of the experiences of people with learning difficulties which underpins the project, based on breaking down barriers to inclusion and the ethos of the self advocacy movement. It

then explores literature which is relevant to peer support and people with learning difficulties, including previous research which has informed Mutual Support, thus justifying the importance of this study. The second half of the literature locates the methodology of Mutual Support within a background to research and people with learning difficulties, and disability studies research.

The foundations laid in Part One are built on in **Part Two**, which focuses on how the rock of Mutual Support was built. This begins in Part Two Section One with an outline of how the research was carried out. The methodological principles are outlined as well as the methods used in the research process. This includes the methods used in making contact with participants as well as methods used for data collection, analysis and validation of findings.

Part Two Section Two outlines the findings as they emerged, based on the construction process outlined previously. Without them there would be no rock at all. At this stage, the findings will be presented using the words of participants as much as possible and without detailed discussion. Similarly, the section which outlines the methodology provides the reader with the information needed to understand the findings section. Both the findings and the methodology will be discussed in much more detail in Part Three.

Part Three will take a step back from the "rock" which has been built in previous sections. It will ask the question: how firm is the rock? This will include detailed discussion on the methodology and findings, and my personal reflections on the process.

In Part Three Section One, the evaluation of Mutual Support begins with an evaluation of the findings from the perspectives of some of the people who had taken part. It is based on three feedback and evaluation meetings which took place within the settings that have been central to this project. Part Three Section Two then discusses the findings further, building the model of peer support based on critiquing the What? Who? When? How? and the effect, of Mutual Support. This section also considers Mutual Support in comparison with peer support in other settings, and conceptualises the findings within disability studies theory. Part Three Section Three continues to critique Mutual Support by discussing the methodology and methods used. This section includes an evaluation of the research in the light of the aims of inclusive research and people with learning difficulties. It also considers the complex ethical issues which

arose within the project, as well as the limitations of the research process. It leads to an evaluation of the research process

The **<u>Conclusion</u>** returns to the aims and objectives of the research, evaluating how far they have been attained and the implications of the outputs of Mutual Support before outlining the vision of inclusion which has emerged from Mutual Support.

The **<u>Appendices</u>** are far more than a gathering of material which did not fit into the main thesis but could not be left out. They are an integral part of the inclusive nature of the research process, and include an accessible summary as well as material used during data collection. They include a picture of a still image in which some of the participants express what supporting one another means to them.

THE CONTEXT

This section introduces the settings and the people who were central to Mutual Support. There are two distinct contexts in which the exploration of peer support has taken place: The Understanding Research Course and The Lawnmowers Independent Theatre Company.

<u>The Understanding Research course</u>

<u>The setting</u>

This course took place within the forensic services at a local long stay hospital. The course, which involved men with learning difficulties who are residents from the hospital, ran over six sessions in 2007-2008. The course piloted material that was central to the outputs of a detailed research project which had previously taken place within the hospital: The Understanding Research Project (Cook and Inglis 2007). This research was aimed at exploring how a group of men with learning difficulties perceive and understand the complex issues involved in participating in research, with an emphasis on the consent process. These men were co-researchers alongside Dr. Tina Cook and Dr. Pamela Inglis from Northumbria University. There were six interactive group sessions that formed part of the outputs of the research and were aimed at supporting other people with learning difficulties to understand research processes. The course in which the piloting of materials took place was the focus of peer support within Mutual Support.

The People

Advisory/reference group

Four of the men who had been part of the original Understanding Research project formed an advisory group to Mutual Support. These men had also been very involved in the Understanding Research pilot course as facilitators, supporting the students in the learning process. They advised me as to the best ways of going about the research process. The fact that they had completed the detailed work exploring research meant that they provided invaluable insight as to how I could make the research accessible to the people who they had supported in learning about research. They were always enthusiastic and their ideas and constructive criticism were both insightful and useful. I met with them four times over the course of the research.

The first time I was introduced to this group of men, I was still in the process of getting approval for the project at Research and Development (R and D) level within the NHS Trust. It was their enthusiasm on this occasion which inspired me to persevere with the approval process. A recording of their discussing "Becoming Educators", which took place during this meeting, also forms part of the data within Mutual Support. These men were also central to the brief physical crossing of paths between the two settings which is outlined at the end of Part Two Section Two: Findings section of this thesis.

I also met with three of them in October 2009 as part of the feedback and evaluation process. This meeting involved a discussion based on the findings which had emerged from the aspect of the project which involved the Understanding Research course. Again, their insight into the role of peer support within the course has added value to the development of the model of Mutual Support.

Participants

The six men who were students on the course when the outputs of the research were piloted were asked if they would meet with me individually and speak about their experiences of support, both given and received, within this learning context. Three of those men chose to take part. Like the advisory group, they were ready and willing to engage with thinking about their experiences within the course, even though it had been some time since the course had finished. The nature of the setup for my meetings with these men meant that I did not get to know them as well as others who have been involved in the research. Two of the men came across as more confident, one of them adding cheeky asides to the nurse who was with us. The other seemed quieter yet still

provided insight into the teamwork and interpersonal interactions which had taken place on the course, in particular the importance of respect within the group situation.

The Lawnmowers Independent Theatre Company

The setting

The Lawnmowers Independent Theatre Company (referred to throughout this thesis as "The Lawnmowers") is run by and for people with learning difficulties. Based in Gateshead, Tyne and Wear, it is a registered charity and has been running for over 20 years. The company's activity is based around providing *"solid foundations for people with learning disabilities to participate fully in their own society, shape their own environment and control their own futures"* (The Lawnmowers Business plan 2008-2011 (The Lawnmowers 2007)).

There are three main areas of activity within the company:

- *The Lawnmowers Actors* consider issues of importance to people with learning difficulties using Theatre for Change, also referred to as Theatre of the Oppressed. The productions are aimed at empowering people with learning difficulties to take control of issues that are important to them. The Lawnmowers actors' workshops and presentations are also aimed at provoking discussion which will lead to positive changes in policy and service provision.
- *The Krokodile Krew,* who run nightclubs that are accessible to people with learning difficulties, and also support others in holding their own social events.
- *The School for Fools* project uses the Commedia Dell Arte approach to comedy, enabling development of clowning skills. The ethos behind these high energy workshops, which have led to performances in Ireland and France, is empowerment through challenging entrenched attitudes to people with learning difficulties. The actors invite the audience to laugh at them by creating comic sketches. This contrasts with being laughed at in a derogatory fashion, which is the experience of so many people with learning difficulties.

At the time of completing this thesis, the Company is working on developing training programmes aimed at equipping the core members of the group to formalise and develop their skills, going on to mentor other people in the future. This has meant a

temporary cutting back of running workshops and performances. The data collection within Mutual Support, which took place during 2008, focussed on the period of time prior to these courses.

The people

The four people who were part of the formal data collection for Mutual Support were the core actors at that time. There is an overlap of people who take part in all aspects of the Company, so they make reference to all areas of activity, including the Krokodile Klubs. The Lawnmowers are a fun and inspiring group of people to be around. Spending time with them has been a breath of fresh air amidst the inevitable ups and downs of a PhD project.

One of those actors has been part of the group since its beginning 24 years ago. As well as his key roles in numerous productions over that time, he has been an Outreach Worker for the company. His dry sense of humour alongside his focus on tasks at hand is central to the efficient running of the group. He is also considered a role model amongst other groups of people with learning difficulties, in the local area and beyond.

Two other actors who took part in Mutual Support have not been part of the company for as long, but are equally central to the group's current success. One actor's singing talents, alongside another's first class music mixing, is central to the Krokodile Krew's music. One of these actors enjoys playing with words, adding quirky meaning to phrases, and writing poetry, the other has an amazing singing voice. During the data analysis and writing up phase of Mutual Support, the fourth actor has moved on from The Lawnmowers. She is pursuing her interest in presenting the views of people with learning difficulties in discussion forums. In particular, she has been working on developing and delivering Disability Equality Training.

Three of these actors were present at the feedback meetings in October 2009. These meetings also involved others who had a more central role within the group by this stage in Mutual Support.

The insight into peer support that has emerged from the two very different settings outlined above has enabled a depth of exploration into peer support. As opposed to comparing and contrasting the examples of support given by people from the two settings, the accounts of support within each of the settings have been brought together in the construction of Mutual Support. The different focus within the two settings has enabled varied aspects of peer support to be part of that construction.

Researcher perspectives

This project has been a journey for me. Through this journey, I have learnt so much more about myself and other people than could ever be conveyed within this thesis. With this in mind, I have no reservations in using "I/me" within this thesis when referring to decisions which I made throughout the research process. I have also included my reflections from that journey in the thesis where appropriate.

My experiences of disability stem from both physical impairment and mental illness within my immediate family. My own health struggles have also shaped who I am, as have my experiences of support within relationships, both formal and informal.

I have been a student at Northumbria University for the last six and a half years, beginning with a degree in disability studies and advice, guidance and counselling. My passion for inclusive approaches to research is firmly rooted in the disability studies part-route of that degree. A significant appeal of disability studies for me has been the applied learning situation. I have found an academic field which captures my passion for people, and an approach to understanding the experiences of people who have experienced far more oppression than I could ever imagine, and it makes sense to me.

My stumbling across disability studies began with a desire to "catch up" with the education I had missed out on because of illness. At that time I viewed education as an intellectual activity leading to formal qualifications. The education which I have received has been so much more meaningful and has taught me so much about valuing people in the truest sense. Personally, the PhD process has pushed me to the nth degree in terms of overcoming anxieties around people, and I am so grateful for the opportunity which this has afforded me to become more confident and back on my feet in the world.

Though I do not claim a commonality of experience with any of the participants in Mutual Support, my own experiences have shaped the process within this research project. Many people who I consider "rocks" in my life have been with me through the tough times in life, as well as sharing in happier times. I have grown a lot through relationships where there has been a mutuality of experience, including people I have met through the disability studies course. Outside of the context of disability studies, one close friendship in particular would not have existed at all if it were not for an impairment specific pen-pal initiative.

I am a firm believer in always knowing that the way people are is so often shaped by life experiences. I find joy in getting to know people and understanding what "makes them tick": not in order to analyse but in order to build mutual support and understanding. It is this endeavour to be non-judgemental within relationships that are built on empathy and compassion, added to my academic background in disability studies leading to an interest in inclusive research, which underpinned my approach to Mutual Support.

As the project has progressed, it has been the people with learning difficulties who have been central to the Mutual Support project who have most inspired me to keep going with it. Their enthusiasm has been such an encouragement. Reflecting on this, I believe that this is because their whole ethos is centred on accepting people without a need to delve into the past. There have been a few quiet moments within the informal contact with The Lawnmowers when they have shared, or alluded to, the dark times of personal oppression they have experienced in the past. This makes the work they and the men from the Understanding Research Course are doing now even more inspirational.

Looking back on the journey of this project, and its significance within the last four years of my own life, I can categorically state that peer support and people with learning difficulties, when based on a model of inclusion, is something which I am passionate about. I hope the reasons for this will become evident to the reader when following the process outlined in this thesis.

PART ONE SECTION TWO:
Aims and Objectives

Below is a statement of the aims and objectives of Mutual Support. It is followed by a discussion of these aims and objectives. This discussion seeks to highlight the significance of the aims and objectives and explore how they underpin the research process, and the topic being researched.

The overall aim of this thesis is to construct and critique the Mutual Support model of peer support for people with learning difficulties. The construction of this model is symbolised in the co-construction of the "rock" of Mutual Support. This rock will then be discussed and evaluated through discussion, including feedback and evaluation from participants.

The overall aim has been met through:

1. A research situation in which knowledge is created in the interaction between the researcher and participants.
2. An opportunity for people with learning difficulties to reflect on their relationships with one another and the potential that supporting one another has for empowerment, and ultimately inclusion.

The expected outputs are:

1. A contribution to current debate surrounding user involvement and inclusion.
2. A contribution to the growing field of discussion on inclusive research with people with learning difficulties.
3. A contribution to current conceptual debate in the field of disability studies.

1. <u>The creation of knowledge</u>

Whatever form it takes, research is about producing, or creating, knowledge (Gustavsson 2007). Throughout the history of academic research, philosophers have sought to explain how this knowledge is produced. This discussion has been based on debate surrounding ontology (what exists) and epistemology (understanding of what exists) (Guba and Lincoln 2005). In exploring these concepts, it is useful to ask the following questions: where does the knowledge which is created in a research process lie? does it exist somewhere awaiting discovery? is there a gap in current knowledge

waiting to be filled? will the research process fill a gap in knowledge? if so, how has that gap been constructed?

Mutual Support is based on a model of knowledge creation as a mutual construction between participants and researcher. That construction has taken place in the interaction between myself and participants. Within Mutual Support, the most significant contribution to the construction has come from firsthand experiences of people with learning difficulties, with an emphasis on valuing their accounts of their experiences without questioning. Beresford (2003 p4) describes this relationship between knowledge and experience:

> *"the greater the distance between direct experience and its interpretation, then the more likely resulting knowledge is to be inaccurate, unreliable and distorted"*

The inclusive approach to the research process, as outlined in Part Two Section One, has sought to find out about the direct experience of participants, basing the construction of knowledge on their views.

Background literature has also contributed to knowledge construction. This has included literature relevant to both the topic being explored and also accounts of, and debates around, inclusive research and people with learning difficulties. The research was shaped in a way which meant that participants engaged with the themes as they emerged within the process. My own perspectives, outlined in the introduction to the thesis (Part One Section One), have also contributed to the construction of the rock of Mutual Support.

Reflexivity has also been a significant element of this project. No matter how impartial a researcher sets out to be, all research is influenced by the perspective which the participants and the researcher bring to the process (Bishop 2005). Many researchers have aspired to be objective, with the elimination of bias. Mutual Support acknowledges that all research is, in some way, subjective, embracing the perspectives of all involved as opposed to seeking to eliminate them. The dynamic perspectives and complex interactions within Mutual Support have contributed to the depth of insight which has emerged from the project.

2. <u>Prioritising the views of people with learning difficulties on their own experiences</u>

The way knowledge is produced in the interaction between researcher and participant, valuing the views of participants as central, means that the research process within

Mutual Support has also been an opportunity for people with learning difficulties to reflect on their relationships with others with learning difficulties. This is set within a background of research on people with learning difficulties in which the stance of professionals' assessments have been viewed as the only accurate and rigorous evaluation of experience (Parmenter 2004). It reflects the recent move, in particular within self advocacy settings, towards research *with* people with learning difficulties.

The literature review (Part One Section Three) explores relevant research that has looked at peer support and people with learning difficulties. It also discusses the self advocacy movement and people with learning difficulties, which provides evidence for the potential of people with learning difficulties to support one another in overcoming barriers to inclusion.

The aim of providing this opportunity for reflection is therefore linked to both the methodology, based on prioritising participants' views, and the concept being researched (peer support for people with learning difficulties), both of which relate to inclusion and the breaking down of barriers which affect the lives of people with learning difficulties.

Contribution to debate surrounding service user involvement

Service user involvement is a concept which has become increasingly significant, even within statutory services including mainstream Health and Social Care. However, it is important to retain the distinction between user involvement and user-led organisations. As stated in the introduction, one of the aims of Centres for Independent Living is peer support. The idea of exploring peer support within Mutual Support was based on the idea of researching whether it might be possible to introduce this concept, which was based within user-led services, into many different contexts of service provision.

A specific contribution to the debate on service user involvement follows from Mutual Support being based on the experiences of people with learning difficulties: the group perhaps least acknowledged in wider debates around service user involvement. Service user involvement is, rhetorically, high on the Government agenda, yet the potential that people with learning difficulties have to make decisions about the services which they receive is often underrated, if not dismissed. Thus, one thread which runs throughout this project, and which again links back to the chosen methodology, is a contribution to current debates surrounding service user involvement.

Contribution to discussion on inclusive research

The previous sections have outlined the ultimate ideal behind this project: inclusion. This is, again, reflected in the approach taken to the research process in Mutual Support. Walmsley and Johnson (2003 p95) define inclusive research with people with learning difficulties as having: "*a research question owned by disabled people, which furthers the interests of disabled people, and is collaborative – disabled people involved in the doing of the work, and in which there is some control exercised by disabled people over process and outcomes and where questions, reports and outcomes must be accessible to people with learning disabilities*".

The methodology section (Part Two Section One) outlines in more detail the principles of inclusive research. The discussion on methodology section, Part Three Section Three, which follows the presentation and discussion of findings, explores in more detail if and how these principles have been met in Mutual Support. This will lead to a practical evaluation of the implementation of inclusive research within this setting, and thus a contribution to discussion on inclusive research and people with learning difficulties.

Developing the social model of disability

Mutual Support is set within the field of disability studies. The fifth objective of the research relates to contributing to current conceptual debate within the academic field, based on the issues raised and the outputs of the Mutual Support model of peer support and people with learning difficulties. Goodley and Van Hove (2005 p15) state that "disability studies aims to interrogate – and change - elements of the disabling world, including the political, economic, social, cultural, interpersonal, relational and discursive". Within the academic field there is an emphasis on the need for theory to be "policy relevant". This includes research which holds "emancipatory values" (Dowse 2009 p141), with an emphasis on research as social and political.

Within this relatively new academic field, the social model of disability has been widely accepted as the basis on which theory is conceptualised (Barnes 2004a). It emphasises the barriers to meaningful inclusion in society experienced by people who have an impairment (Oliver 1996). The experiences of people with learning difficulties have not always been considered by the wider community of disabled people when theorising about their experience of disability (Goodley and Van Hove 2005). They have been marginalised from the marginalised (Chappell 2000a). Mutual Support has sought to redress this imbalance.

The contribution to current debate within the academic field of disability studies took place once the Mutual Support model of peer support for people with learning difficulties had been constructed through the research process outlined in this thesis. The social model of disability was used as a tool to explore the potential within Mutual Support for barriers faced by many people with learning difficulties to be broken down by peer support.

Having outlined the aims and objectives of Mutual Support, briefly relating them to their significance within the research process, and signposting the reader to applicable sections of this thesis, the literature review section which follows now further establishes the background to Mutual Support.

PART ONE SECTION THREE:
Review of Background Literature

A literature review is far more than a summary of the literature which surrounds the issue which is being researched (Dunleavy 2003). It is about engaging critically with the work of others in the field that the research is based in (Ridley 2008). This enables the researcher to both define the knowledge which already exists surrounding their research, and also to define the "gap" in knowledge which their research is seeking to fill (Gustavsson 2007).

Critical reading leads to critical writing, meaning that the process surrounding the literature review enables the researcher to engage more critically with their own work (Wallace and Wray 2006). In a critical literature review, the following questions are answered:

- Why is the topic important?

- Who else thinks that the topic is important?

- Who has explored this topic before?

- Who has done similar research to the current project?

- How can previous findings be linked and/or adapted to the current study?

- What are the gaps in the research?

- Who is going to use the outputs of this project?

- What contribution will the project make?

- What specific questions will be answered in the research?

(Adapted from Murray 2006 p115).

The exploration of literature within Mutual Support is central to its theoretical and methodological stance, and the idea of knowledge being constructed in the interaction between myself and the participants. In addition to both my background from a degree in disability studies, and my own life experiences, the literature review forms my perspective within the research process.

When engaging with the literature, the key has been to draw out the contribution each book, book section or article makes to the emerging picture of both peer support and people with learning difficulties and inclusive research. Each paper or book section has been evaluated in the light of the contribution it makes to the topics underpinning the whole thesis. Therefore, each section of the review will link the literature which is being

cited to the areas which the Mutual Support research project, and therefore this thesis, addresses.

The point in any research project at which the literature review takes place influences the role which the literature plays in shaping theory (Potter 2006). Different approaches to qualitative research advocate differing ideal times for this to happen (Corbin and Strauss 2008). Throughout this project, gathering and searching for literature has been an ongoing process. As the project has evolved, the background literature has played different roles. The aim of the sections which follow are to build a picture of what has shaped the ideas behind this inclusive exploration of peer support and people with learning difficulties. Wherever possible, the discussion will be rooted in research which has prioritised the views of people with learning difficulties themselves.

The discussion begins by locating within relevant literature the position taken within Mutual Support to understanding the experiences of people with learning difficulties. This leads to a section which locates peer support and people with learning difficulties within the self advocacy movement and service user involvement. This is followed by a section on interpersonal relationships and peer support, beginning with relevant issues regarding friendship followed by a section on previous research involving peer support and people with learning difficulties.

Following this, the literature review looks at literature which has explored research and people with learning difficulties. This includes an exploration of oral history research, narrative research and participatory and emancipatory research. The review of relevant literature highlights the discussion surrounding inclusive research and people with learning difficulties, in particular drawing upon the importance of partnership in research. The summary of the literature review, which can be found on pages 45-48, seeks to draw together relevant literature with direct reference to the questions, (adapted from Murray (2006 p115)) outlined above.

Understanding the experiences of people with learning difficulties

Understanding history is not solely about recriminations or highlighting past mistakes: it is about understanding why we are at where we are today (Atkinson 2004, Thomson 2003). Both collectively and individually, human experience builds upon the history of people and/or groups of people in similar situations (Giddens 2008). Understandings of the experiences of people with learning difficulties have been massively influenced by policy and attitudes within British society (Barton 2001), and by the resulting

segregation of people with learning difficulties in institutions (Barclay 1999, Borsay 2005).

Historically, much of the understanding of the experiences of people with learning difficulties has been based on official documentation: professionals' assessments, medical records and official documents. Roets, Goodley and Van Hove refer to this as "*the cult of professional expertise*" (2007 p324). The dominant understanding of the experiences of people with learning difficulties is therefore based on this, arguably biased, documentation (Atkinson et al 1997, Clegg 2006). The focus of this thesis is the exploration of the experiences of people with learning difficulties from their own perspective, placing their accounts of their experiences at the centre.

Perceptions of learning difficulty

The philosophical discussion surrounding what it means to be human is central to understanding how learning difficulty is perceived (Judge 1987). Often, people with learning difficulties have been viewed as "not human" (Parmenter 2001), with emphasis on biological differences (French 1999), and a medical approach which views people with learning difficulties as sick and in need of medical treatment (Johnson and Traustadottir 2000 p14), emphasising deficiency (Hamilton and Atkinson 2009).

The lack of opportunities available to people with learning difficulties has exacerbated this, leading to marginalisation and oppression (Stainton 1998, Learning Disability Coalition 2008). This is significant to the ideas behind Mutual Support, as one result of this marginalisation and oppression has been the assumptions which have been made about the extent to which people with learning difficulties can and should be forming meaningful interpersonal relationships (Firth and Rapley 1990). Goodley and Van Hove (2005 p19) posit that "*learning difficulties is a socio-cultural artefact, which says more about the society we live in than it does about the individual to which the label is pinned.*" This idea is central to the social model of disability.

The social model of disability

The academic field of disability studies, the social model of disability which is central to the building of theory within that field, and the disability movement in the UK which has campaigned for a society which breaks down the barriers faced by disabled people using the social model, are inextricably linked (Charlton 1998, Albrecht Seelman and Bury 2001). This section of the literature review defines the social model of disability, locating the development of that model within the context of the disability movement's

campaign. The fact that the social model of disability is based upon collective resistance to individual experiences of oppression is relevant to the collective nature of peer support and people with learning difficulties within Mutual Support.

The social model was developed in response to the The Union of the Physically Impaired Against Segregation (UPIAS) campaign which began in the mid 1970s (Zarb 2004). Central to the campaign was the aim of highlighting the basis on which people with impairments were excluded from society: through the way society had responded to their impairments as opposed to the existence of their impairments per se (UPIAS 1976 pp14-15). The social model of disability was developed by disability studies academics, for example Oliver (1983). The model separates the individual's medical condition – *impairment* - and the barriers within society to full and meaningful inclusion – *disability* (French 1994, Brechin 1999).

It is important to recognise, especially in the light of recent criticism of the social model of disability, that the original purpose of the model was not a comprehensive explanation of the causes of impairment, but a vehicle through which disabled people could communicate the significance of social barriers to others (Barnes 1998), especially service providers and policy makers. The emphasis was on the oppression faced by disabled people (Sheldon 2007). It was formed against a background ethos, particularly within professional circles, that disability is an individual condition which needs curing, or at least treating (Oliver 2009). It is also important to emphasise that the social model does not ignore or trivialise impairment, it is about locating and breaking down the social barriers that people experience "*because of and on top of impairments*" (Barnes, Mercer and Shakespeare 1999 p2).

Thus, there is a contrast between the medical, or individual, model of disability and the social model of disability. Goodley (1997 p373) defines the individual and social models in relation to people with learning difficulties:

> "*Whereas the individual model gives rise to discourses of personal pathology, of individual difficulties and of dependency in the face of care, the social model navigates notions of social problems, of societal/environmental difficulties and of independence in the face of self advocacy*".

Similarly, in recently published work relating the social model to the experiences of people with learning difficulties, Stalker and Lerpienier (2009) explore access issues which people with learning difficulties continue to face in the light of the Disability Discrimination Act (DDA), in particular in relation to Part Three: the provision of goods, services and facilities. Their evidence demonstrated that people with learning

difficulties are "*often treated unfairly and differently from others*" (p840) and that positive public attitude towards people with learning difficulties needs to be promoted.

Similarly, Docherty et al (2005 p35-38) outline the barriers which disable them as people with learning difficulties:

- *information which isn't accessible*
- *jargon and offensive terminology*
- *people's negative attitudes*
- *people not listening to us*
- *people being patronising*
- *people who don't want to know and just walk away*
- *people who want to know you but just drop you afterwards*

This directly relates to the ethos of inclusion behind Mutual Support, justifying the use of the social model within the discussion of findings and building of theory. It will be followed up further in Part Three Section Two: Discussion on Findings (see pages 177-181).

<u>The Disability Movement</u>

As stated above, the disability movement developed alongside the social model of disability. However, people with learning difficulties have not always been central to the disability movement. The original Union of the Physically Impaired Against Segregation (UPIAS) definition of disability, formulated in 1976 and acknowledged as the statement on which the social model of disability was founded, did not include people with learning difficulties at all. It was not until the addition of "*sensory and intellectual examples*" in a later version that the wider movement of disabled people even acknowledged people with learning difficulties as similar to themselves in any way (Boxall 2007 p225). However, the fact that the wider collective movement of disabled people was formed alongside the social model is significant to the building of theory within Mutual Support and, potentially, the contribution of Mutual Support to debate within that wider movement. The self advocacy movement has been more central to people with learning difficulties collectively speaking out for social change (Aspis 2002).

<u>Self advocacy</u>

Self advocacy is about speaking up for oneself or others (Mitchell et al 2006). Although not exclusively involving people with learning difficulties, the group of people who are most often associated with self advocacy has been people with learning difficulties

(French and Swain 1999). Primarily associated with opportunities for people with learning difficulties to tell others about their experiences (Stefansdottir and Traustadottir 2006), the self advocacy movement has reflected the way in which some have taken control of and spoken up for changes which matter to them in their lives. It has also supported people with learning difficulties in making decisions about issues which are important to them, and to influence policy-making for the future (Servian 1999, Savage et al 2006).

As well as opening more opportunities in everyday life for people with learning difficulties, the self advocacy movement has given people with learning difficulties supportive environments where they have been able to speak about their own experiences (Hoy et al 2006). This has been particularly significant for people who spent many years in long-stay institutions (Atkinson 1999). The self advocacy movement also shifted the power imbalance within research situations, questioning who should be in control of the research process (Goodley et al 2000). It gave rise to people with learning difficulties themselves being more involved in the research, sometimes doing the research themselves (Williams 1999).

Within the UK, the origins of self advocacy as it is understood today can be traced back to the 1970s, with People First London being formed in 1984 (Atkinson, Cooper and Ferris 2006). In 1997, Mitchell estimated that 5000 people with learning difficulties were involved in the self advocacy movement, and this did not necessarily include individual self advocacy, people on courses which were built around the principles of self advocacy or those involved in user involvement initiatives (Mitchell 1997 p44). Goodley (2000 p3) highlights self advocacy as groups in which people with learning difficulties "*conspicuously support one another*" in speaking out against discrimination.

The ideas behind Mutual Support build on the success and growth of the self advocacy movement, in particular this "*conspicuous support*". The way in which many self advocacy groups have developed has meant that those involved have built relationships with other people with learning difficulties, and supporting one another has been a central part of this (Goodley 2000). Research has been done exploring what being part of a self advocacy group meant to eight people with learning difficulties (Beart et al 2004). However, there has not been research done which specifically looks at the nature and impact of this support from the point of view of those directly involved. Mutual Support has been about exploring this support, using the emerging evidence to build a model of peer support which can be used by other groups.

As the self advocacy movement has grown, to the point of recognition at Government level, a tension has developed between the role of self advocacy groups in enabling individuals to grow in confidence and develop skills and the collective campaign for change within the self advocacy movement (Buchanan and Walmsley 2006). Mutual Support emphasises the first of these aspects (individual growth through interpersonal interaction) though also remaining open to the role of the resulting empowerment in collective campaigning for positive change.

However, neither of the settings which are explored in Mutual Support are primarily self advocacy groups, and it is important to acknowledge the differences between both self advocacy and brokerage and peer support (Bott 2008). In their account of experiences within the self advocacy movement, Mitchell et al (2006) refer to individual and collective "*Testimonies of Resistance*". These testimonies are accounts of ways in which people with learning difficulties have resisted and overcome barriers to inclusion (Atkinson et al 2006). Mutual Support seeks to explore the role and impact of peer support within existing projects which aim to resist and overcome such barriers, and the possibility for this support to be developed further.

In this way, Mutual Support seeks to focus on the principles of self advocacy, building on lessons learnt, but shifting the focus away from the "speaking up for ourselves" aspects of self-advocacy. Goodley's (2000 p178-195) work on relating approaches of support to models of disability is relevant to the conceptualisation of the Mutual Support model of peer support and people with learning difficulties, and will be explored further in the discussion on findings section, Part Three Section Two. The commonalities and differences between self advocacy and Mutual Support will also be explored further in this section (see pages 182-183).

Legislative Theatre

Of particular relevance to Mutual Support, and The Lawnmowers' work, is Legislative Theatre, also known as Theatre of the Oppressed, and described as Theatre for Change. It links with the self advocacy movement as it is about a group of people with learning difficulties using this powerful way of communicating the barriers which they face. Goodley and Moore (2002) outline the positive effects of people with learning difficulties being part of the performing arts. The benefits go far beyond a stereotypical view of drama as therapy for individuals (Reynolds 1999): "*participation in performing arts, as a forum for maximising participation and bringing about change, is rarely mentioned*" (Goodley and Moore 2002 p9). The techniques of Forum Theatre have also

been used in a research context by people with learning difficulties, being defined as "an interactive method in which an engaged audience are encouraged to suggest alternative strategies to a social dilemma facing the main protagonists of the role play and ultimately induced to stand in their place and act out those suggestions" (Hopkins 2009 p331).

This, and the Lawnmowers work, is located within a worldwide movement of theatre groups which use Forum Drama to communicate their experiences of oppression and to campaign for changes, both within society and in relevant policy (Boal 1998). As a result, the inclusion of The Lawnmowers in Mutual Support has added to the emerging picture of peer support the experience of a group whose work is aimed at facilitating positive change in the lives of people with learning difficulties. Previous research involving The Lawnmowers and Northumbria University (Price and Barron 1999) highlighted the opportunities for social contact that being part of the group brings, within the context of a group which is effective on a number of levels: personal skills development amongst core members and other people with learning difficulties; a participatory arts project which forms links *"between the largely disenfranchised world of the learning disabled and policy makers"* (Price and Barron 1999 p822). Matarasso (1997) also links the social impact of participation in the arts to personal development, social cohesion and community empowerment and self determination.

This link between the activity of groups of people with learning difficulties and policy makers is applicable to service user involvement, in particular in empowerment through participation.

<u>User involvement</u>

As outlined in the previous section, the self advocacy movement is viewed by many as "*the most significant development for people with learning difficulties*" (French and Swain 1999 p2). It "*challenges professional dominance and top-down policy making*" (Goodley et al 2004 p188). The service user involvement movement is a similar challenge to service providers seeking to allow service users to have a say in the decisions that are made, and the future development of services (Beresford 1994), presenting a social model approach to service development (Swain French and Cameron 2003 p 138). As such, the independent living movement can be viewed as an "*analytic paradigm*" (De Jong 1979). Literature from user-led organisations, and research into service user involvement, is clear that peer support is an integral part of those organisations (Social Care Institute for Excellence 2007). The focus of this

section of the literature review is to locate Mutual Support within the development of service user involvement.

It is important to emphasise the difference which exists between user-*led* services (services/organisations in which the decisions and day-to-day running of the organisation is controlled by disabled people) and service user *involvement* (which takes place in services/organisations in which people who use the service are given an opportunity to have an influence over the services which they receive). The extent of this influence varies between different organisations. Indeed, "*there is a big difference between feeding into someone else's ideas and organisations and developing your own"* (Branfield et al 2006 pg x).

Mercer (2004 p177) highlights the fact that "too often, user participation in public service provision has turned out to be little more than 'cosmetic'". He also highlights the issues surrounding exclusion of people with learning difficulties in user participation due to "presumed incapacity" (p177). Participation is a concept which should be seen as a continuum as opposed to a dichotomy: at one end of the scale lie initiatives in which power is exerted from above and at the other end are initiatives in which service users are in control of decisions. Most initiatives lie somewhere in between the two, though it is important that tokenistic references to participation are not assumed to be giving more power to those involved than is inferred (Turner and Beresford 2005).

The aspect of the service user involvement movement which relates specifically to Mutual Support is that of empowerment through participation. It is important to clarify that true empowerment is not something that can be done to someone or for someone, but has to come from within the person themselves (Barnes and Mercer 2006 p190). When mapping the capacity of user-led organisations and considering the key characteristics of local user-led organisations, Campbell et al (2007) link peer support and mentoring with empowerment. The Discussion on Findings Section (Part Three Section Two) will link the outputs of Mutual Support with empowerment through participation.

The concept of empowerment through participation is also applicable to the methodological stance in Mutual Support which locates participants' views as central and acknowledges them as experts on their own experiences. Many user-led organisations have been involved in the development of research which promotes public and service user involvement in research (Staley 2009). Branfield et al (2006 p viii) highlight two fundamental aspects to making participation a reality: people working

together, supporting one another in order to work for change; and the need for voices to be heard. Mutual Support seeks to address the first of these tenets in relation to people with learning difficulties.

Service user involvement is the current ideal underpinning (at least rhetorically) some health and social care policy, thus directly affecting the lives of people with learning difficulties in the UK in the 21st Century (Darzi 2008, Department of Health 2007: Putting People First; Department of Health 2009: Valuing People Now). The relevance of service user involvement to Mutual Support is in relation to ways in which the outputs of the project might be applicable in a wider range of settings. This will be addressed in Part Three Section Two and the Conclusion.

Having outlined the background on which Mutual Support bases its understanding of the experiences of people with learning difficulties, and subsequent approaches to developing services, literature which explores specifically relevant research and theory on relationships and people with learning difficulties will now be outlined. This begins with an outline of interpersonal relationships and peer support, including research which focuses on friendship and peer support for people with learning difficulties.

Interpersonal relationships and peer support

> *"Relationships with other people have an important role in shaping our personalities, our experiences and how we feel about ourselves. In the past, relatively little attention was paid to the relationships of people with learning difficulties"* (Shepherd 2003 p110).

This section of the literature review focuses on the literature that is relevant to the discussion on peer support and people with learning difficulties. It begins with an exploration of research which has been done with people looking at learning difficulties and relationships in general, including friendship and other social interaction. This includes the role of relationships within the self advocacy movement. It then moves on to consider literature which directly relates to peer support and people with learning difficulties. As before, the views and first-hand experiences of people with learning difficulties will be prioritised.

Discussion around relationships and people with learning difficulties relates to how learning difficulty is conceptualised. Much of the theorising and subsequent service provision which has surrounded the experiences of people with learning difficulties and interpersonal relationships has centred around "humanness." It follows that, as relating to others is an integral part of "humanness", exploring relationships and people with learning difficulties also results in an exploration of how learning difficulty is perceived

in a wider context (Bogdan and Taylor 1982, 1998). Bogdan and Taylor (1998 p246-247) propose four dimensions to humanness; attributing thinking to the other, seeing individuality in the other, viewing the other as reciprocating, and defining social place for the other. These four dimensions will be returned to in the discussion on findings section of this thesis (Part Three Section Two) in relation to the themes which emerge on peer support from the data analysis (in particular see pages 167-168).

As with so many other areas of literature which are relevant to this thesis, the way in which people have been viewed has dictated both expectations and also opportunities available to people with learning difficulties. The case is no different with regard to interpersonal relationships, whatever their form. Chappell (1994) states that:

> *"the question of the relationships of people with learning difficulties is important to a social theory of disability and, therefore, must take account of the significance of material and ideological constraints on people with learning difficulties"* (p419).

Kristiansen (2000 p111) also acknowledges that "*historically, people with intellectual disabilities have not been perceived as adults capable of having intimate relationships*". Evidence for the current importance of relationships to people with learning difficulties comes from an extensive research project in which researchers from the Norah Fry Research Centre (one of the leading centres on researching issues of importance to people with learning difficulties in the UK) worked together with people with learning difficulties, their carers and professionals to outline priorities for research in the next ten years (Williams et al 2008). The "right to relationships" was one of the six key priority areas that emerged from this consultation.

Counselling and people with learning difficulties

When considering the conceptualisation of the interpersonal relationships of people with learning difficulties, it would be possible to get bogged down in evidence from within the vast field of psychology. As an alternative, this section focuses on evidence from literature which explores counselling and people with learning difficulties. Of particular note is literature which explores the aim of counselling and people with learning difficulties in the light of barriers to inclusion: is it the individual person who needs changing, or are the issues they face rooted in barriers to inclusion in society? Peer support and peer counselling are often grouped together within documentation from or about user-led support groups, though not so often in relation to people with learning difficulties.

Although the support which is being conceptualised within Mutual Support is not solely around the idea of counselling, there is evidence from the literature suggesting that people with learning difficulties can and do understand the complexities of relating to others and understanding themselves (Brandon 1989, Hodges 2003). Within her work on person-centred approaches and people with learning difficulties, Hawkins (2002) notes the barriers to change which people with learning difficulties face. She posits that, more than many other groups of people, people with learning difficulties face challenges due to reliance on other people and barriers to inclusion in society. Reeve (2004) also highlights the need for counselling and disabled people to acknowledge the changes which need to be made in breaking down the barriers to inclusion as opposed to seeking individual adjustment of disabled people. Mason (1998) also questions the ethics underlying therapy which seeks to change individual thinking and/or behaviour.

In the same way that Mutual Support is seeking to explore peer support as a way of people with learning difficulties breaking down barriers to social inclusion, BJ Oliver (the co-director of an independent residential provider for people with learning difficulties) reflects:

> "*when I started off working therapeutically with people with learning difficulties, I found over and over again that very often the obstacle wasn't the person themselves, it was what they were contending with in the outside world that was making it impossible for personal growth to take place*" (Hawkins 2002 p16).

It is this focus on social barriers limiting opportunities for people with learning difficulties to engage in meaningful interpersonal interaction which is central to Mutual Support.

Friendships and people with learning difficulties

Some of the earliest work around the importance of friendships and people with learning difficulties includes research done by Richardson and Ritchie (1989, 1990). They acknowledged the fact that, though people with learning difficulties have as much need as anybody else for friendship, making and maintaining friends is not always as easy, for a variety of reasons. However, their approach to researching friendships and people with learning difficulties is based on the premise that this does not need to be the case. They also write about the functions of friendship: intimacy, company and practical help (Richardson and Ritchie 1989). Their work is based around an exploration of deeper relationships, which is not directly within the remit of the exploration of peer support within Mutual Support as defined within the views expressed by those taking part. However, their statement that

> *"the quality of people's lives is fundamentally affected by the quality of their relationships. Among people with learning difficulties, this issue is only beginning to be addressed"* (1989 p1).

is relevant when thinking about the development of peer support within situations where people with learning difficulties are working together.

In their article in which "self-advocates have the last say on friendship", McVilly et al (2006a p705) state that friendship was "*a topic that was of importance to them*". McVilly et al (2006b) also state that, in the area of personal relationships of adults with an intellectual disability, "*considerable work is yet to be done (*p201)" and that work in this area could be more meaningful if family and professionals who have influence over the lives of people with learning difficulties had a greater understanding of their experiences and aspirations.

Knox and Hickson (2001), using a participatory approach to researching what close friendship means with four people with "intellectual disabilities", highlighted the fact that it is important to evaluate friendship in the terms which participants used, as opposed to in what the researcher might think as being valuable in friendship. Thus demonstrating that research which focuses on relationships *among* people with "Intellectual Disabilities" is both valuable and needed (Knox and Hickson 2001 p289). This is significant to the process of data analysis within Mutual Support: it has been crucial that themes which were drawn up were based directly on values concerning peer support expressed by participants.

The concepts found in the literature exploring friendship and how it relates to Mutual Support are complex. The questions raised include: is support the same as friendship? Are there situations, maybe in learning, where it is more effective to be supported by someone who is not a "friend"? The definition of how friendship/support is defined has been part of the exploration within Mutual Support and something which has been explored during the project in the process of constructing knowledge between myself and participants.

Holman, (2008) explores the loneliness which many people with learning difficulties experience. He also states the Government's response: "promoting personal relationships is not something that central government has a direct role in". (Department of Health 2007). However, he goes on to explore the priority which developing friendships is given, by service providers:

> *"It may help if support with friendships was seen as one of those services that falls into the preventative category. There is a lot of energy being put into this*

> *area at the moment and, with more and more people not qualifying for a service, local authorities should support and signpost people to friendship agencies as one option to at least get people out of the house and meet others"* (Holman 2008 p13).

Having considered work which explores friendship and people with learning difficulties from their point of view, this literature review now moves on to outline research which relates directly to peer support and people with learning difficulties.

Peer Support: current activity

There has been some research published which explores the idea of peer support and people with learning difficulties. This section outlines literature which describes current peer support activity and disabled people, specifically people with learning difficulties. The discussion on findings section of the thesis (Part Three Section One) will explore further the complex issues around definitions and purposes of peer support. That discussion will also explore and critique issues arising from work done on peer support in other contexts (see pages 171-176).

The most relevant study relating to peer support and people with learning difficulties was carried out by Values into Action (the UK-wide campaign with people who have learning difficulties), supported by the Joseph Rowntree Foundation (JRF 2004, Bewley and McCulloch 2004a, 2004b). The report focussed on the '*importance and availability of peer support for people with learning difficulties accessing direct payments.*' It cites the Department of Health Guidance (2003), which states that those seeking advice over direct payments should be offered the opportunity to be "*put in touch with a support group or a local centre for independent living, or a peer support group of people who already manage direct payments*" (Bewley and McCulloch 2004a p1).

Though it is not relevant to focus on the detail of direct payments, as funding policy has changed since 2003 when the report was written, the role of peer support in choice, control and inclusion remains highly relevant. This study raises the question as to why such a "logical step" (Bewley and McCulloch 2004a p4) has been met with limited support and funding. The report also highlights the fact that people with learning difficulties need exactly the same information, support and advice as other people accessing direct payments, but that the support might need to be given in a different way (Bewley and McCulloch 2004a p2). However, the idea of this support coming from peers was not always responded to positively by local authorities.

The reference to peer support as

> "*creating a local and national community of disabled people, including people with learning difficulties, who are experienced and expert in direct payments........who can inspire others to see that choice, control and opportunity in their own lives is possible*" (Bewley and McCulloch 2004b p4)

suggests that it is an area which might also be developed in other aspects of people's lives, increasing choice, control and opportunities that are available to them. However, even among groups of disabled people supporting one another to access direct payments, people with learning difficulties were less involved than people with other impairments (Federation of Local Supported Living Groups, 2005).

Work on peer support and disabled people supported by the Joseph Rowntree Foundation has also included a good practice guide to young disabled people's peer mentoring/support (Bethell and Harrison 2003) and "Something to do. The development of peer support groups for young black and minority ethnic disabled people" (Bignall et al 2002). The focus of these groups was emotional and practical support.

Within the grey literature, an online search found examples of peer support and disabled people. These included Action for Kids in which disabled volunteers with younger disabled people are placed in a peer mentoring role, the emphasis being on positive role models within work tasks (Action for Kids website, 2006). For example, "Karen's story" highlights the positive aspects of peer support for the person who is giving the support. Karen speaks about how rewarding she has found being a peer mentor, and the confidence it has given her to go on to formal employment. Similarly, The East Lothian Centre for Inclusive Living has also formed a peer support group for people who employ Personal Assistants (East Lothian Centre for Inclusive Living 2008). The group meets five times a year, and topics which have come up have included pay rates, relations with employees, rotas, recruitment and training.

There is also a growing bank of accessible resources available aimed at enabling people with learning difficulties to lead group activities. For example "We are the strongest link" (Jefferson et al 2006, The Foundation for People with Learning Disabilities) is a resource enabling young people with learning disabilities to explore feelings, friendships and support in the context of growing up as people with learning difficulties. This evidence suggests that people with learning difficulties within independent groups are supporting one another. Mutual Support seeks to explore in depth the processes behind this support in the context of two specific settings.

The significance of peer support and people with learning difficulties

The idea of peer support for people with learning difficulties builds on the principles behind both self advocacy and service user involvement. It is about gathering evidence from the point of view of people with learning difficulties about positive things which they have been doing: supporting one another to overcome barriers in society. The National Centre for Independent Living's report on peer support and personalisation (Bott 2008) states that, in addition to sharing good practice,

> *"it is hoped that the review's relevance will go beyond the adult social care agenda and also be of interest to those generally concerned with social policy and social inclusion" (p3).*

This reinforces the conceptualisation of Mutual Support building a model of peer support which prioritises inclusion.

The range of purposes within Centres for Independent Living (CILs) highlight the wide scope of peer support initiatives, moving the focus of the discussion away from "friendship" and onto the potential for breaking down barriers to inclusion which is central to Mutual Support. These purposes will be discussed further in Part Three Section Two, as part of the Discussion and Evaluation of Findings. However, it is also important not to lose sight of the personal value of peer support: "the really important people, the ones that really understand, are the people who have been through it themselves" (Slattery with Johnson 2000 p 101).

Support networks

When seeking to explore the history of people with learning difficulties, it is important to think about others who have been a major part of their lives (Traustadottir and Johnson 2000). An issue which needs to be addressed when exploring the ideas behind Mutual Support is that of whether focussing exclusively on *peer* support is, in fact, drawing a line which does not acknowledge the role of non-disabled supporters of people with learning difficulties who are striving to give support which is empowering and emancipatory.

Non-disabled supporters within groups of disabled people have been referred to as allies by disabled people themselves (Tregaskis 2004). It has been argued that these alliances have had a significant role to play in breaking down barriers to inclusion (Evans 2008). These include allies who work in the field of disability studies research, developing research practice which has placed the views of people with learning difficulties at the centre, leading to a higher profile within some areas of academia. Allies have also had a role in the growth of the self advocacy movement. The role of

non-disabled supporters has been considered in the light of the data which has been collected, and will be discussed further in the discussion on findings section of this thesis (Part Three Section One, see pages 160-162). Similarly, it does not automatically follow that just because someone is disabled they will support other disabled people sensitively and appropriately (Barnes and Mercer 2006 p168)

Literature which is relevant to the support networks of people with learning difficulties includes Atkinson's (1986) paper on support networks which involves "engaging competent others" in supporting people moving out of long stay institutions into the community. Gold (1994) explores a support group which centred on non-disabled friends supporting someone with learning difficulties. The purpose of the group was emotional support and problem solving. Both Gold and Atkinson raise issues of degrees of formality/informality within support networks, and the role of non-disabled supporters. This issue will be discussed further in the light of the analysis of data in Mutual Support.

Another question which arises is that of the formality/informality of the support which is being conceptualised within Mutual Support: does/can genuine peer support happen when it is planned by non-disabled supporters or professionals or is it only an autonomous relationship when it is initiated by the people themselves? Emerson and McVilly (2004), emphasising the significant effect of setting on relationship opportunities available to people with learning difficulties, highlight the fact that it is often more necessary for meetings to be arranged, at least initially, in order to address the barriers to socialising which many people with learning difficulties face, for example lack of transport facilities and resulting isolation.

<u>The influence of context and setting</u>

The opportunities for relationships which are open to any person are greatly influenced by their day-to-day surroundings and situation, including who they live with, their place of work and other activities (Duck 1988, Atkinson and Ward 1986). When considering relationships and people with learning difficulties, their social context is just as, if not more, significant (Chappell 1994, Jobling et al 2000). The social context is also greatly influenced by attitudes and expectations in society, and can be related to Goffman's work on stigma and interpersonal relationships (Goffman 1959, 1961, 1968).

Despite all the criticisms which could be made of institutional life and the resulting denial of rights for people who lived in them, perhaps the most consistently cited positive aspect was the relationships, often in the form of camaraderie, which took

place (Wall 1998). This sense of community amongst "patients" is reflected in the collective voice echoed in the "songs of resistance" which emerged from many institutions (Ledger and Shufflebotham 2006).

Similarly, the move towards community care, and more recently the closing down of day centres, has affected the format of interpersonal relationships in the lives of many people with learning difficulties (Welshman and Walmsley 2006). It has been suggested that peer relationships should be discouraged (Chappell 1994). Knox and Hickson refer to a "*lack of regard for the significance or worth of friendships between people with disabilities*" (2001 p287). Emerson and McVilly further highlight the "limited number of friendship activities", linking this to the social context of people with learning difficulties (2004 p195).

When considering the development of service provision and people with learning difficulties, it is important to note the influence of normalisation/social role valorisation (SRV) (Chappell 1992). Normalisation was based on the premise that integration based on making the patterns of living available to people with learning difficulties as close as possible to "regular patterns of everyday life" would be the most effective way of people with learning difficulties being accepted by "ordinary citizens" (Nirje 1999). Following on from this, Social Role Valorisation, referring to the roles that people have within society, advocated the development of roles for people with learning difficulties that were considered valuable by others, with the assumption that this would lead to more favourable treatment (Race 2003, Wolfensberger 1985 in Race 2003).

The relevance of Social Role Valorisation to Mutual Support is that it raises questions around the implications of whether relationships are more (or less) valuable when they involve people with learning difficulties and non-disabled people. The idea behind normalisation/SRV devalues relationships amongst disabled people (Flynn and Aubry 1999). However, both the disabled people's movement and, more specifically for people with learning difficulties the self advocacy movement, demonstrate the potential for overcoming barriers by uniting with others who, according to normalisation/SRV, are "devalued" (Thomas and Wolfensberger 1999) and forming a positive collective identity which responds to discrimination (Charlton 1998, Morris 1991).

So far, this literature review has considered publications which relate to the topic of Mutual Support and the issues raised within relevant literature. The discussion now moves on to outline literature which is relevant to the methodology of Mutual Support.

Review of literature relating to the methodology

This section of the literature review seeks to explore how research and people with learning difficulties has evolved in relation to the approach used in Mutual Support. An understanding of what has gone on before is best used to form a clearer picture of current practice, which in turn leads to new ways forward. This section of the literature review begins by introducing oral history research, followed by an outline of narrative research. It then outlines the development of research within the field of disability studies, which has led to participatory and emancipatory research paradigms, and how this has influenced research which prioritises the views and opinions of people with learning difficulties. The review of relevant literature then moves on to explore the role of non-disabled researchers, and collaboration in research.

By exploring these significant developments in research with people with learning difficulties, a background and rationale is provided for the fourth aim within Mutual Support: to use an inclusive approach to the research process. This background also provides firmer grounds on which to base a contribution to debate surrounding inclusive research and people with learning difficulties.

<u>Background to research and people with learning difficulties</u>

Research which is taking place often reflects practices and dominant views within wider society (Walmsley and Johnson 2003). The issues which are central to the conceptualisation of disability and the barriers to inclusion faced by many people with learning difficulties are also applicable to the way in which research and people with learning difficulties is carried out (Sample 1996). At its worst, research can exploit people with learning difficulties (Balandin 2003; Swain, Heyman and Gillman 1998), becoming part of the problem of inequality as opposed to solving it (Oliver 1992). Traditional approaches to research and learning disability have been centred around a positivist measuring of deficiency, with the goal of minimalising and preventing impairment (Rioux and Bach 1994). Traditional "objective" approaches to research also discount the idea of the value of the insight into their own circumstances which people bring to the research situation (Chappell 1999).

However, as will be explored in the following sections, new approaches to research *with* people with learning difficulties (as opposed to *on* them) have developed. Research in this area which is particularly relevant to Mutual Support will be outlined in the following sections.

<u>Background to research approaches</u>

The changes which have taken place within the field of qualitative social science research, away from a positivist approach, and towards the valuing of an in depth analysis of people's views and opinions, can be placed alongside the recent developments within the field of inclusive research and people with learning difficulties (Chappell 1999), in which the "expertise" of people with learning difficulties are valued (Duckett and Fryer 1998). There have been many steps along the way, and many more need to be taken, but the recognition of the value of people's accounts of their own experiences was needed prior to any further involvement (Jackson 2000). This development was led by oral history research.

<u>Oral History Research</u>

> "*....people with learning difficulties do have stories to tell*" (Atkinson 1993 p61).

Alongside the self advocacy movement, auto/biographical approaches to understanding the experiences of people with learning difficulties have evolved (Fido and Potts 1997). Together, these movements have been an influence in the ongoing inclusion of people with learning difficulties in society (Goodley 2000). Both have challenged dominant perceptions of people with learning difficulties as unable to make sense of their own experiences (Mitchell 2006), and have promoted active involvement in research (Atkinson 1997).

The first significant group which formed specifically to explore the history of learning difficulties from the perspective of the real life accounts of people with learning difficulties was led by Dorothy Atkinson at the Open University (Atkinson 2004). Atkinson (1997) writes of how the process of people being given the opportunity to tell their stories about their lives from their point of view can impact at both a personal and a social level.

The most obvious benefit of oral history research might be the "cathartic" effect which being listened to and given space to reflect on experiences provides (Angus and McLeod 2004), but the individual and collective accounts which have emerged from groups of people with learning difficulties have provided an understanding of experiences and situations which otherwise had only been documented by professionals (Rolph 2000, Parmenter 2004). In the same way, the emergence of accounts from several people who have lived in the same or similar contexts can contribute to an affirmation of the accounts, and a clearer picture of those settings and

contexts (Bornat and Walmsley 1994). Oral history research has always involved collaboration between non-disabled researchers and people with learning difficulties (Traustadottir 2006).

Narrative Research

Narrative research is about seeking to understand past events from the perspective of the person recounting that event or series of events (Corvellec 2007). Narratives have been defined as "*storied ways of knowing and communicating*" (Reissman 2006 p186). They allow people to make sense of their experiences (Reissman 2002) and, especially when used in the context of a research interview, are vehicles for "retrospective meaning making" (Chase 2005 p656). Squire (2008b) explores the reasons for the "narrative turn" of the last 20 years, associating it with other "turns", many of which are relevant to the theoretical and methodological stance behind Mutual Support: "turns to qualitative methods, to language, to the biographical, to the unconscious, to participant-centred research, to ecological research, to the social (in psychology), to the visual (in sociology and anthropology), to power, to culture, to reflexivity" (p6).

Booth (1996b p237) refers to the "excluded voice thesis" which promotes the use of narrative methods in exploring the perspectives of oppressed groups. By using people's accounts of their own experiences, in their own words, narratives can be used to relate personal experiences to social and cultural issues (Smith and Sparkes 2008), enabling insight into those issues from the viewpoint of people who have directly experienced them (Elliott 2005).

Narratives also give opportunities for the voices of marginalized or excluded people to be heard. Roets, Goodley and Van Hove (2007) explore the theoretical issues and debates surrounding the use of the narratives of self advocates in challenging the deficit model and pathological thinking. This thinking has dominated perceptions of the experiences of people with learning difficulties, which has been based on a pathological approach to measuring difference (Goodley et al 2004).

There are many different approaches to narrative research, and the boundaries between them are not necessarily straightforward (Riesseman 2002). However, the idea of "experience-centred narrative research" is the most relevant to the current exploration of the accounts of people with learning difficulties of instances where they have or have not given or received support from others. Patterson (2008) explores the phenomenological assumption that, through stories, experience becomes part of consciousness, and the hermeneutic approach that the use of narratives from an

experience-centred approach is centred on interpretation, as opposed to an analysis, of structure.

The way in which the experiences of people with learning difficulties have been evaluated has often been caught up in the dominant theories at a given time as to what it means to be human. In the age of biography, often dominated by celebrities, narratives can be viewed as an essential part of what makes us human (Squires 2008a), and how people understand their experiences (Czarniawska 2004). In this way, the use of narratives to explore the experiences of people with learning difficulties can be seen as redressing the unbalanced view that they are in any way less than human (Roets, Goodley and Van Hove 2007).

<u>Approaches to research: control, participation and inclusion</u>

The above sections on oral history and narrative research have outlined how approaches to gathering information from participants by listening to their accounts of their experiences have evolved. The focus now shifts onto the research process itself, in particular with reference to how involved participants are in the research process and the effect which the outputs of that process have on their lives. The role of the researcher is also significant and will be discussed in the light of existing literature.

<u>Disability Research</u>

Developments in disability research are part of the development of a wider body of approaches to research that prioritises a human rights approach within social research (Witkin 2000). The following section outlines the development of approaches to research that have evolved alongside the disabled people's movement and the academic field of disability studies. Zarb, Oliver and Morris (1992), and other contributors to a special issue of *Disability, Handicap and Society* in 1992, were particularly influential in the development of research which was based on the social model of disability, arguing that disabled people should not only be involved in research about their experiences but should be in control of every aspect of the research process. Disability research is specifically focussed on redressing the "sustained contradiction" in the lives of disabled people (Munford et al 2008 p339): disabled people's live are, on the whole, subject to more scrutiny than non-disabled people's, yet they remain invisible and lack power in relation to changing the practices in society that disable them.

Emancipatory research, which has emerged alongside the field of disability studies, and has been guided by the disabled people's movement, has at its heart the freedom from oppression of disabled people (Barnes 2004b). Its purpose should be to improve the lives of Disabled People (Chappell 2000). As such, the dominant view within the field of disability studies is that, whether the consequences of a research project has a positive or negative (or no) impact, it is a "social act" (Barton 2005 p317). Barnes (2004b p48) outlines the main elements of emancipatory research: accountability, the social model of disability, data collection and empowerment.

Participatory research puts the participants and their views at the centre of the research process, aiming to involve them at every stage: planning, implementation and dissemination (Swain and French 2004). It seeks to challenge the dichotomy which traditionally exists between "the researcher" and "the researched" (Williamson and Smyth, 2004), with an emphasis on dialogue (Lopes 2006). It is about researching "with" people as opposed to "on" people (Swain and French 2006). Chapell (2000 p38), referring to the growth of participatory methodology as an "exciting development in learning difficulty research", welcomes the opportunity for involvement in the research process. Participatory research and people with learning difficulties has most often taken place within the context of self advocacy groups (Chapman and McNulty 2004). It challenges the status of those who have assumed power over people with learning difficulties, including researchers (Dockery 2000).

It is important to note that, though emancipatory and participatory research have evolved and been developed alongside one another, it does not automatically follow that all participatory research is emancipatory, neither does research have to be participatory in order for it to be emancipatory (French and Swain 1997). Differences in the emphasis within these approaches include the profile which the social model of disability is given within the research and the role of non-disabled researchers (Chappell 2000 p40).

When thinking about research and people with learning difficulties, issues of accessibility arise which may not be applicable to all groups of disabled people (Kiernan 1999). Walmsley and Johnson (2003) highlight the complexities of applying an emancipatory approach to research with people with learning difficulties. Consequently, Walmsley and Johnson developed the framework of an inclusive approach to research and people with learning difficulties. As outlined in the aims and objectives section, and again in Part Two Section One as part of the outline of methods used, inclusive research is the preferred approach to research within Mutual Support.

Writing in 2001, Walmsley also spoke of the potential pitfall that inclusive research and people with learning difficulties might be marginalised, fitting neither within the emancipatory/disability studies research paradigm (due to complexities of accessibility and participation) nor within traditional mainstream learning disability research. However, people with learning difficulties themselves were also expressing their need to be involved in research which could or would influence their futures (for example Aspis 2000, Townson et al 2004). Inclusive research and people with learning difficulties bridges the gap that Walmsley (2001) identified and enables the desires to be involved in research expressed by people with learning difficulties to be realised. Johnson (2009 p255) outlines the link between inclusive research and community participation by people with learning difficulties: "Many of the policies and practices which frame the rights of people with intellectual disabilities are based on research. Inclusive research processes provide a number of different ways for people to have a voice".

Cook and Inglis highlight the fact that excluding the voice of people with learning difficulties when doing research into their life and experiences "challenges our notion of ethical practice" (2009 p55). Thus, an inclusive approach to research is part of an ethical approach to research. Researchers seeking to promote meaningful participation in research with people with learning difficulties, at the same time as acknowledging the barriers to accessing research, have emphasised the role of the researcher, and the need for continual reflection and evaluation (Moore, Beazely and Maezler 1998).

The role of the researcher

The approach to understanding people with learning difficulties and interpreting their experiences taken by any researcher directly influences the nature of their research at all stages of the research process (Duckett and Fryer 1998). Whatever the realities of research and people with learning difficulties, it is essential that the researcher remains aware of the implications of any decision, no matter how insignificant it may seem, on the locus of control within the research project (Rodgers 1999). It is also important to consider the relationship between the researcher and those taking part (McClimens 1999), acknowledging the complexities of every interaction (Tregaskis and Goodley 2005).

A key value behind inclusive research is that of *partnership* between researcher and participant. Partnership in the research process bridges the gap between academic research and theory and the experiences of the people who the research is seeking to find out about. This relates back to the theoretical stance which underpins Mutual Support, which seeks to dispel the "them and us" dichotomy which has been created in society throughout history between disabled and non-disabled people, emphasising the co-construction of the model of peer support.

Writing in 2004, Walmsley explored the role of the (often non-disabled) researcher in inclusive learning disability research, which is also complex. However, the non-disabled researcher can also have a role in breaking down barriers to access for people with learning difficulties:

> *"Arguably for people with learning difficulties a skilled supporter is as vital as a wheelchair is to a person who is unable to walk, or a BSL interpreter is to a deaf person taking part in a hearing person's event"* Walmsley 2004 p66.

Thus, it is essential for any researcher involved in inclusive research and people with learning difficulties to remain aware of their role in, and influence over, each and every stage of the research process.

Collaboration in Research

The epistemological and methodological complexities of applying emancipatory and participatory ideals to research and people with learning difficulties are dominant within a PhD project (Bjornsdottir and Svensdottir 2008). By definition, a PhD project is an original and unique contribution to knowledge within an epistemic community (Trafford and Lesham 2008). In her exploration of the issues surrounding collaborative research, Dowse (2009) highlights the importance of collaboration in developing research outputs that prioritise the views of those taking part.

Dowse (2009) outlines the issues which new paradigms in disability research raise when applied to people with learning difficulties. She defines her work, which formed the basis of a PhD project, as "Collaborative Action Research Based on Critical Reflection." By looking at the research situation as an interaction between "the researcher" and "the participants," she sought to challenge the *"broad assumption that researchers and people with intellectual disability are oppositional, homogenous and unequal groups"* (p150). The research process was one of "*integrated inquiry and reflection"* as the skills of "the researcher" and "the researched" were merged (Dowse 2009 p151). This approach highlights the significance of the processes used at every

stage of the research process. It again emphasises the role of reflexivity on the part of the researcher, which includes the researcher acknowledging the social and political context(s) which influence their thinking throughout the process.

The locus of power within a project at any given time also needs to be explored and acknowledged – this will be discussed in relation to Mutual Support in the ethics section of the discussion on the methodology, Part Three Section Three. Dowse (2009 p144) refers to the researcher as a "*catalyst for transformation*". Similarly, Duckett and Fryer (1998) outline the lengthy process which they took in which the role of both the researcher and participants changed through three stages. The researcher became a "newcomer-learner" as he sought to work in collaboration with people with learning difficulties as co-researchers. By the end of stage three, the co-researchers took on more of an "expert-teacher" role.

Another way in which people with learning difficulties, and users of other health and social care services, have become involved in inclusive research projects has been through an advisory role (Rhodes et al 2002). This was an approach which was used within Mutual Support.

The Understanding Research Project

As referred to in the introduction, the outputs of Cook and Inglis' (2007) project have been important to the Mutual Support research project. This is not just because the participants within Mutual Support were people who had been involved either as facilitators or as students in the course where the outputs of the research had been piloted. The original research project involved people with learning difficulties as co-researchers in exploring how the complex ideas surrounding taking part in research can be made accessible to people with learning difficulties. By drawing on the outputs of Cook and Inglis' research, Mutual Support became more participatory in the sense that what emerged (from people with learning difficulties being involved in a Collaborative Action Research Project) about how to make the process more accessible would be incorporated throughout. Within their outputs, the key processes to understanding were:

- cyclical nature of the sessions (the recursive process),
- the multiple ways of presenting and engaging with the information,
- the use of collaborative discussions,
- fun,
- facilitation,

- time to think between sessions supported by staff

(Cook and Inglis 2007).

The materials which were the outputs of this project, especially the participant booklet and picture dictionary, were central to Mutual Support. In addition, one of the aspects of Mutual Support, specifically met by the study which took place around the Understanding Research Course, has been to raise and explore the idea that the people who are best placed to support people with learning difficulties in learning processes are people who also have a learning difficulty themselves.

Walmsley and Johnson (2003 p9) state that

> "*many researchers struggle to resolve the tension that exists between research which is academically rigorous, acceptable to funding organisations and publishable, and research which is of use to the people who are subject to it, which is relevant to their needs and can inform and promote needed social change. A resolution of this tension is probably not possible. Rather it is met anew with each study and involves a continual process of balancing and compromise.*"

Having outlined the context of approaches to research in which Mutual Support is set, I feel it is now time to move on to the specific detail of those "tensions" within this specific research, discussing the process of balancing and compromise which have been part of Mutual Support. This will be done in Part Two of the thesis, which follows the summary of the literature review.

SUMMARY OF LITERATURE REVIEW.

In order to summarise the literature review, the discussion now returns to the questions outlined in the introduction (based on Murray (2006 p115)). Although these questions might also be applied to other areas of the thesis, such as the findings and discussion, this section refers solely to evidence from the literature.

<u>Why is the topic important?</u>

- The positive impact of people with learning difficulties having the opportunity to speak about their own experiences in a situation which prioritises and respects their views is evident in literature.

- Mutual Support builds on literature which has challenged the dominant assumptions that people with learning difficulties are unable to engage in meaningful relationships, building on work which has been done on friendships to look at the idea of peer support being used in the struggle for an inclusive society.

- The topic of peer support and people with learning difficulties leading to choice and control has been researched within specific contexts, but not within an in depth exploration of accounts and views.

- It challenges assumptions that people with learning difficulties lack insight into their own interpersonal interactions, and also assumptions that peer relationships are less valuable.

- The collective nature of peer support and people with learning difficulties builds on both the disability movement and self advocacy.

- It focuses on one of the tenets of the independent living movement, but does so with a group of people whose experiences have not always been fully acknowledged within the movement.

Who else thinks the topic is important?

- Work which has been done on friendship from the point of view of self advocates states that this is an area which needs more exploration, with specific reference to the need for work to be done which communicates the opinions of people with learning difficulties to service providers.

- The report from the National Centre for Independent Living produced for the Department of Health (Bott 2008) identifies a lack of evidence on peer support and people with learning difficulties. Anecdotal evidence and the grey literature suggests that it does happen. Mutual Support seeks to conceptualise this support within an inclusive approach to collecting evidence.

Who has explored this topic before?

- The idea of peer support and accessing direct payments was found to be effective and meaningful. This would suggest that the development of this idea to other areas of experience should be explored.

- Work has been done on the role of friendship within self advocacy groups. Again, this suggests the potential for a wider application of the idea.

- Evidence from literature on counselling and people with learning difficulties shows that they are capable of understanding other people's feelings, and also have the capacity for self reflection.

Who has done similar research to Mutual Support?

- Within the field of collaborative research, Dowse (2009) has worked on conceptualising the co-construction of knowledge, with specific reference to practical implications.

- There has been a study (Bewley and McCulloch 2004a 2004b) which looks at the positive impact of peer support for people with learning difficulties accessing direct payments.

- A significant amount of research has been done which looks at the value of peer support within other groups of people. These projects will be outlined further in Part Three section Three: Discussion on Findings Section of this thesis.

How can previous findings be linked and/or adapted to the current study?

- The literature which addresses issues, both theoretical and practical which participatory and emancipatory research pose, especially in research with people with learning difficulties, has been used as a resource to develop the methodology of Mutual Support.

- In particular, work which has been done around dispelling the conventional "research" and "researched" dichotomy has contributed to the development of the methodology.

What are the gaps in the research?

- There is no evidence of research having been done which specifically explores the in depth narratives about their experiences of giving and receiving support within a pre-existing context where people with learning difficulties are working together.

Who is going to use the outputs of Mutual Support?

- The groups of people who have taken part in this research, and other groups of people with learning difficulties.

- The contribution to debates surrounding user involvement and inclusive research, and current debate within the academic fields of disability studies, are intended outputs of this research.

What contribution will the project make?

- It will add to the discussion surrounding inclusive research and people with learning difficulties.

- It bridges the gap between the independent living movement and traditional services that have been grounded in a medical model understanding of people with learning difficulties.

- It will add to current conceptual debate within the field of disability studies, raising the profile of the experiences of people with learning difficulties within the wider community of disabled people.

- Mutual Support builds links between the practical experience of local groups and academia, strengthening links both within the geographical area where the research has taken place and within the wider community of people with learning difficulties, and within the wider research community.

What specific questions will be answered in the research?

- How do people with learning difficulties perceive the support which they give and receive? How might this be developed further in a way that promotes inclusion, autonomy and choice?

Having located the methodology of Mutual Support within relevant literature, the foundations on which Mutual Support is built have been outlined. The thesis now moves on to Part Two: how the rock was built. This includes the methods which were used and a presentation of the findings.

PART TWO:
Constructing Mutual Support

Having laid the foundations on which Mutual Support has been built, the thesis now moves to Part Two: Constructing Mutual Support. This part of the thesis focuses on the aspects of the construction within Mutual Support that involved direct contact between myself and people from the settings who were central to the project.

Part Two Section One is a description of the research process itself. It locates the methods used in the project within the methodological framework. It includes details of the input from advisory groups as the project evolved, as well as comments from participants about the research process. It covers the consent process and data collection and analysis. The section ends by conceptualising the ways in which data from the two contrasting settings can be brought together in order to shed more light on the topic being explored.

Part Two Section Two is a presentation of the findings. The themes which emerged from the research process which was described in Section One will be presented. This section prioritises direct quotations from participants, ending with an account of a brief crossing of paths between people who had taken part from the two settings.

PART TWO SECTION ONE:
How the research was carried out

The literature review provided a background to developments within the field of research and people with learning difficulties, and their contributions to the choice of methodology within Mutual Support. This section, which is an outline of how the research was carried out, moves on to relate this to the methodological stance and methods used within Mutual Support. The reader should have sufficient detail on which to understand Part Two Section Two, which is a presentation of findings. Complex issues relating to the methodology and methods used will be discussed in Part Three Section Three.

Methodological Stance

As stated in Part One Section Two, the philosophical approach to how knowledge is created is central to any research process (Guba and Lincoln 2005). The methodological stance taken by any researcher accounts for both ontology (what exists) and epistemology (how understandings of what exists are created), though the interactions between ontology and epistemology in social research are complex and the boundaries not necessarily clear cut (Williams and May 1996). The philosophical stance behind Mutual Support was that the peer support that formed the basis of the model of Mutual Support was already taking place within the two settings. The approach to finding out about that support was through co-constructing a model of that support, with an emphasis on narrative accounts from participants. The methodological stance of Mutual Support also accounted for the fact that it was a PhD project, in which a researcher is required to produce their own original contribution to knowledge (Trafford and Lesham 2008).

The co-construction of knowledge (with 'knowledge' being defined as the Mutual Support model of peer support and people with learning difficulties) embraced an approach to social research that emphasises the ontological perspective of reality being specific to the social context. The epistemological implications for this are that research findings are co-created and subjective. Within my approach to the co-creation of knowledge, sound ethical principles were intrinsic. The emphasis on research that was based on participatory and emancipatory disability research (as outlined in the literature review) reflected this. The use of narratives also allowed for those taking part to give their accounts of their experiences from their own perspectives, emphasising the value of the views expressed by participants (see Part Three Section Three pages

205-209 for a further discussion on the use of narratives within Mutual Support). The emphasis on an approach to the research process which emphasised accessibility for people with learning difficulties was also central to the co-creation of knowledge.

A co-constructionist approach to knowledge creation also embraces the role and perspective of the researcher: rather than seeking to objectify knowledge and eliminate researcher bias, the researcher's perspective within research encounters is valued. The perspective I brought to the research process, as outlined elsewhere in this thesis, was also part of the co-construction of knowledge. Guba and Lincoln (2005 p196) refer to the role of the inquirer as a "*passionate participant*". I was passionate about making sure that the views of participants were what drove the research process, and that I accurately represented their accounts of peer support within the two settings. Again, the use of experience-based narrative accounts as central within data collection allowed for people's views about their own lives to be the central contribution to the construction of the model of Mutual Support. As a researcher, I then used these accounts, and the process of validation of findings through multiple opportunities for participants to interact with emerging themes, in the construction of knowledge which this thesis reflects.

Methods Used

Having considered the topic being explored within Mutual Support and the complexities of applying emancipatory and participatory ideals to research with people with learning difficulties, particularly within the context of a PhD project, I decided to make inclusive research the ideal standard on which the methods used within this project were based. Walmsley and Johnson (2003 p 64) define inclusive research with people with learning disabilities as follows:

- *the research question must be one that is owned (not necessarily initiated) by disabled people,*

- *it should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities,*

- *it should be collaborative – people with learning disabilities should be involved in the process of doing the research,*

- *people with learning disabilities should be able to exert some control over process and outcomes*

- *the research question, process and reports must be accessible to people with learning disabilities* (Walmsley and Johnson 2003 p64).

The implementation of an inclusive approach to research and people with learning difficulties relates directly to the co-construction of knowledge which is central to Mutual Support: the more included participants are within the research process, the more central their views and, consequently, the stronger the model of peer support that is constructed. A detailed evaluation of the extent to which the ideals of inclusive research were realised can be found in Part Three Section Three.

Ethical Principles

In order for any research project proposal to be approved, it must satisfy the ethical standards of beneficence; non maleficence; respect for autonomy; respect for persons and justice (Sim 1997). These oft-quoted principles relate to promoting the interests of others, ensuring that they come to no harm, respecting the right of participants to self-determination, valuing each individual participant, and treating others fairly in every decision which is made (Israel and Hay 2006). These ethical principles have been central to every stage of the research process in Mutual Support. However, as Lawthorn and Goodley state:

> *"Ethically sound research is not simply about following professional guidelines on anonymity, confidentiality, withdrawal and the avoidance of distress in research. Ethical research is also about promoting an ethically sustainable vision of disability" (2006 p203).*

The literature review and other sections of this thesis have outlined the vision of learning difficulty which is central to Mutual Support. As it has evolved, the research design has been based on this vision. Section Three and the Conclusion of the thesis will evaluate how ethically sustainable that vision is.

Carrying out inclusive research with people with learning difficulties raises many ethical issues. These issues arose at every stage of the research process. When describing the process which took place, I have sought to write about issues that arose and how they were addressed. This means that the ethics of Mutual Support cannot be covered in one stand-alone sub-section of the methodology section. It is hoped that, throughout this account of the research design and implementation, the adherence to high ethical standards within an inclusive approach to the research is evident.

When discussing the ethics of research in relation to any one project, it is necessary to distinguish between getting ethical approval for the project and carrying out the research in an ethical way (Swain, Heyman and Gillman 1998). Of course the two are interlinked, but the discussion around ethics in this section of the thesis centres around

ways in which the research was carried out in an ethical way. Again, this will be expanded further in Part Three Section Three alongside a discussion on the ethical approval process and the issues it raised.

Research Design

This section outlines the research design used within the project. It includes an outline of the approaches used as well as describing the shape which the project took. It also includes views expressed by the advisory groups and direct quotations in which participants talk about their experiences within the research process.

The way that Mutual Support proceeded as a project evolved throughout the months of the active research (the initial proposal for the project hardly resembles the final shape of the project). This reflects the ideal of research design being an ongoing process (Maxwell 2005). This section on research design mirrors the 'snowballing' within the research design, which took place in response to the views of participants and the way in which my thinking developed as a result. Thus, the shape which this project has taken has been a complex process, influenced and shaped by many factors. It is not possible to discuss at length all of the decisions which were made. The following discussion provides insight into the factors which have had most significant influence in the project as a whole.

As the shape of the research process was different within the two, very different, settings, each section of the account of methods used will begin with an outline of the principles on which the aspect of the project was based. This will be followed by a more specific account of how and if the principles were realised within the specific settings. The aim of this section of the thesis is to provide an outline of the processes which took place. This account begins with an account of meetings with the two advisory groups, presenting the themes emerging from those meetings and the way they influenced the shape which the research took. The account of the research process then describes the sampling process followed by consent, data collection and data analysis. A justification of how the two settings have been brought together within the construction of the Mutual Support model of peer support and people with learning difficulties is followed by a description of the feedback meetings which took place in October 2009.

The flowchart overleaf is a chronological outline of the research process. Colour has been used to distinguish the different settings, with different shapes signifying the different stages of the research process. The way in which the colours and shapes

intermingle with each other reflects the way in which the research process intertwined research interactions and analysis. The diagram includes page numbers in each stage, signposting the reader to the relevant descriptions within this methods chapter of the thesis.

Figure 1: A chronological overview of the research process

Advisory meeting at Skills for People: what makes good/bad research? (Pgs 56+57)

Sampling/ Consent Process at Lawnmowers (Pgs 62 +67)

Initial interviews with four Lawnmowers' actors (pg 69-71)

First advisory meeting with facilitators from Und Res Course (pgs 58-60) "Becoming Educators" was recorded (pg 72)

Second advisory meeting at Skills for People (pg 56-57)

Analysis of initial Lawnmower interviews (pg73-75)

Lawnmowers performance at Coach Lane: interviews 2 days after (pg71 and Appendix E pg 264)

Second meeting with facilitators/advisory group from UR Course (pg 59-60)

Consent Process with students from UR course (pg 62-64 and 69)

2nd interview with students from UR Course (pg 72)

Analysis / accessible presentation of 1st interviews with students (pg72 + 78 + Appendix C pg 259)

First interview with students from UR Course (pg 72)

Feedback at Skills for People (pg 81-82 and Appendix F pg 270)

Comprehensive data analysis (pgs 75-78)

Feedback and Evaluation Meetings: facilitators and Lawnmowers (pgs 81-82 + Appendix F

Key:

Advisory grps:

Selection/consent

Interviews:

Data Analysis

Feedback/evaluation

-------- **Skills for People**

------- **Lawnmowers**

--------**Understanding Research Course**

Page nos refer to relevant section of methods chapter

Advisory/ reference groups

As stated in the literature review, people with learning difficulties have become more involved in research as advisors to projects, especially alongside researchers who are aiming at inclusivity as an ideal (Ward 1998 p129). Walmsley and Johnson (2003 p146) also refer to these groups as reference groups. A significant aspect of the role of people with learning difficulties in Mutual Support was through advisory/reference groups. There were two such groups: the Programme Committee at Skills for People, and the advisory group from the Understanding Research Course. These two groups of people were advisors to the project, but their advisory role did not mean they were participants in the project. It was important to make this distinction during the ethical approval process. The meetings I had with them influenced my thinking and the shape which the project took but were not recorded. In contrast with the direct quotations from the individual interviews which are integral to this thesis, accounts of these meetings within this thesis are based on notes taken at the meetings and are not direct quotations of things said at the meetings.

Skills for People

Skills for People is an Independent organisation supporting disabled people to speak up and take more control over their own lives. It has been running for over 25 years, with an emphasis on support for and by people with learning difficulties. It seeks to support disabled people and their families through advocacy, information, awareness raising, consultancy and training. Skills for People also works with services, enabling them to better meet the needs of service users and their families.

I met three times with the Programme Committee. This committee is central to planning and monitoring the activities throughout the organisation. With the exception of the Chief Executive who was facilitating the meeting, all the people on the committee had learning difficulties and/or physical impairments. I was told when arranging the third of these meetings that the Programme Committee would no longer be meeting in that format from September 2009.

Advice from the Programme Committee

The first meeting with Skills for People Programme Committee took place in November 2007. The previous week, I had sent letters and information sheets (see Appendix B, page 232-236) asking to call in at their drop in sessions. It transpired that the drop-in sessions were no longer running, but I was invited to attend this Committee meeting

instead. The half hour discussion centred on their ideas as to how to approach doing research. Their advice provided very practical guidance on how to proceed, reflecting the ethical principles which I had set out to follow.

They said that good research:

- *involves people,*

- *listens to people,*

- *takes in what they say.*

It is important that the researcher really gets to know people, meeting them and talking with them.

They also stated that it is important to listen to individual stories, to give a few days' notice and not just turn up. Practical advice was also given: it is important to find out before the day who will be available and not just assume that you can talk to people (it is their decision if and when they take part, you are not a school teacher or jailer).

We also reflected on what makes bad research, and this was significant to many who recounted examples from the past. They said that, in bad research the researcher:

doesn't listen to what people are saying,

doesn't meet with people,

and doesn't consider people's feelings.

The word "research" triggered thoughts of past bad experience: being wired up, tested, and having their behaviour measured. They suggested that I should introduce myself as wanting to find out about what they think about.... as opposed to a researcher.

(my notes from Skills for People Programme Committee meeting 13.11.07).

The views and opinions expressed at this point in the project, based on the advisory group's response to my introduction of myself and the project, reflected the definition of inclusive research which I had sought to implement (see above – Walmsley and Johnson 2003 p64). In particular their references to what makes good and bad research, including insight from negative past experiences, gave a personal dimension to the theoretical stance I had adopted, thus justifying my approach. The input from this group of people with learning difficulties was invaluable at this stage, as it provided me

with practical pointers and advice on which to pin the future of the project. They also encouraged me that the project was worthwhile, and meaningful to them.

Advisory/reference group: Four facilitators from Understanding Research project

Within the local hospital, four of the men who had taken part in the original Understanding Research Facilitated Collaborative Action Research Project, and who had been facilitators when the materials had been piloted, became advisors to Mutual Support. Their role as facilitators on this course meant that they had supported other men with learning difficulties in thinking about research, ethics and consent. The fact that these men had spent considerable time thinking about and exploring research and the complex issues surrounding taking part in research, added to the fact that they knew the setup within which this aspect of Mutual Support was taking place, made them ideal advisors to Mutual Support.

During the first meeting, in September 2008, I asked for their advice about how to go about the research. We spent time focussing on the information sheet which was accompanied by an audio CD; the notes below focus on their suggestions based on listening to the CD during the meeting. The Research and Development (R and D) committee had not yet approved the project, meaning that this was an opportunity to pilot the information sheets. A copy of this information sheet can be found in Appendix B page 237-241. I have included both this information sheet which I took to the group to critique and develop and the information sheet which was finally used in the appendices to this thesis. This allows the reader to directly compare the two and see how the sheet was changed based on the input from this group.

The input and ideas which they had were summarised in the notes which Dr. Tina Cook took at the meeting:

Timings: Is an hour going to be long enough for the interview (or too long for some)?

Jargon: don't use it, or if you do explain it – e.g. use agree or disagree rather than asking do you consent.

Presentation: put questions and answers in different colours

Presence of staff: make sure the people know that the staff are there to help them and support them, not to tell them off

Treatment and Research: make sure they know this is research and the difference between treatment and research – they don't have to participate in research if they don't want to.

Don't have to do it: and they can change their mind about their participation at any time even if they say yes and then decide they don't want to do it, it will not have any consequences on their treatment etc.

Tips for supporting participants: approach them through someone they know and trust; make what they do interesting for them; use "concrete" things to help them understand ideas (example of the use of Lego to help understand notions in research); use simple pictures and signs to help aid understanding (thumbs up/thumbs down signs given as example).

This advice played an important role in shaping the proposal which was approved by the R and D committee, both in terms of the revised information sheet and consent form, and also in highlighting some of the ethical issues which may arise and how I would deal with them. The revised information sheet can be found on pages 246-250, Appendix B.

Similar meetings took place in January and March 2009, prior to the individual interviews with people who had been students on the Understanding Research course. The following account of the meeting in January 2009 is based on the notes taken by Prof. John Swain at that meeting.

<u>*Themes/advice which emerged from the discussion (08.01.2009)*</u>

They had looked/listened to the info sheet and CD which I had left behind and made the following points:

- *It's important to sound really confident on the CD. This will put potential participants at ease.*
- *Also important to speak slowly.*
- *It is useful to use the pictures which they used in the course. Again, no jargon.*

I asked them what they thought people would want to know when deciding whether or not to take part:

- *What would being involved mean?*
- *What will they get out of it?*

- *What will happen to the information?*
- *How will people benefit?*

They said it's important for people to know that:

- *they can say no*
- *staff are there to support them*
- *there is no right or wrong answer*

I also asked for input about the research process. They gave the following advice:

- *The men who took part in the course will remember taking part and what they did. It would be useful to use concrete examples, for example taking a copy of the student work books along.*
- *Body language is important in getting a message across.*
- *It's important to stick to one topic.*
- *If people don't want to be pushed, don't push them. You will know when people don't want to be pushed.*
- *Ground rules are important.*
- *It's important to go in with an open mind.*

They spoke about the qualification which they have got from the work they have done, and the presentation of their work at conferences. One of the men gave an example of someone at a conference "picking his brains", he commented that it was strange that someone was coming to someone with learning difficulties to do this, but it has happened since they've been going to places and speaking about the project.

Porter et al (2006) define two roles of advisory groups: firstly as sounding boards for inclusive practices and secondly in ensuring that the rights of individuals taking part are recognised by the researchers. Within Mutual Support, the advice given by two groups of people with learning difficulties covered both of these areas and was a valuable tool as the project progressed. However, I did not take specific issues relating to my interactions with participants to the groups, largely due to ethical issues and difficulties in arranging the meetings at specific times. Nevertheless, their advice made the research more meaningful and accessible for those taking part. Their advice included general pointers as well as specific guidance. It reflected the ethos of inclusive research and enabled me to more fully apply its principles to the research process as it evolved.

Sampling: who took part and how were they approached?

The emphasis within qualitative research is on gathering a richness of data, focussing on a small number of participants and spending considerable time eliciting their views on the topic being researched (Miles and Huberman 1994). This is reflected in the methods used for identifying potential participants, also referred to as sampling.

Sampling within Mutual Support has been based on a non-probability purposive sample. Tuckett (2004 p53) states that: "*Purposeful/theoretical sampling attempts to select research participants according to criteria determined by the research purpose, but also as guided by the unfolding theorising*". Purposive sampling also builds in variety and acknowledges opportunity for intensive study (Stake 2005 p451). It involves conscious judgement on the part of the researcher as to who is and is not included in a project (Crookes and Davis 1998).

Purposive sampling also prioritises the element of choice by those who take part as to whether they get involved. Probability, random or quota sampling is much more rigid, which is not desirable within an inclusive approach to research in which participation should be by informed choice (French, Reynolds and Swain 2001). The people who were asked if they would like to take part in Mutual Support were not identified randomly, but in order for the emerging data to be focussed, shedding light on the topic being explored. The decisions surrounding sampling were based on potential participants having had experience of being in a group with other people with learning difficulties where there had been potential for instances of peer support.

The settings which became the focus of the exploration of peer support existed prior to the Mutual Support project, and were considered, by others, to be innovative in their purpose and outputs. All those who took part came from the settings which were outlined in the introduction to settings (see Section One pages 7-11). Once the specific groups had been identified, all individuals within those groups were asked if they would like to take part.

Within an ethical, inclusive approach to research with people with learning difficulties, it is important to acknowledge that sampling leads into the consent process, and therefore needs to be transparent and accessible. Issues within the process of identifying and recruiting participants also include gate-keeping. Linked to this has been the very different ways in which I introduced myself and the project to potential participants. This process within the Understanding Research Course was very formal and rigid compared to a much more personal approach within The Lawnmowers.

Issues surrounding the way in which sampling influenced the outputs of this project are discussed in Part Three Section Three. The following two sections outline the sampling processes which took place within The Lawnmowers and within the Understanding Research Course.

Sampling within The Lawnmowers

I first came into contact with The Lawnmowers when I attended their "Real Project" conference at The Sage Gateshead in March 2008. This conference was centred on people with learning difficulties and employment. Following this, I made contact with the Artistic Director. She invited me to call at their base at a time when most of the actors would be around. This meeting took the form of my explaining briefly what I was wanting to find out, and centred around a discussion about friendships. I then continued the conversation with two of the actors over a coffee in a local cafe.

Following this, I made an audio recording of the information sheet (see Appendix B, page 253-255) and left several copies of the CDs and information sheets with actors. I had given the Project Manager a list of times which were possible for me, stating that I wanted the arrangements to be made without me being there. This limited the potential for coercion by myself within the sampling process. Out of the six core actors who were part of the group at that time, four said they would like to meet with me. The reasons for the other two actors not taking part were based on the physical health of one actor, and the need for routine without unusual demands being placed on the other. In fact, though, the second of these people has, informally, been part of the recorded discussions, giving insight into the way in which The Lawnmowers have supported an individual who has complex social needs.

Sampling within the hospital

The way potential participants were approached at the hospital was very different. It became obvious that not going through conventional routes (i.e. through staff) to make contact with participants would mean that this part of the project would not happen at all.

Originally, it had been proposed that I, as part of the first phase of research, would spend time on the villas (wards) within the hospital, getting to know people and recording short interviews with those who were interested, asking them about how they support one another. I proposed that I would then identify a smaller number of people who would be willing to speak with me in more detail about times when they had or had

not felt supported. This proposal, which had been approved by the University's School Research Ethics Committee, was rejected by the Research and Development (R and D) Committee at the hospital.

It became evident that a much more focussed proposal would be needed, and it was at this stage that the focus within the hospital became the pilot of the training materials within the Understanding Research course. As outlined above, the four men who had been facilitators within this project formed an advisory group, and potential participants were identified as the six men with learning difficulties who had taken part in the project as students. This provided a focus for the project, and a concrete example of activity which had involved people with learning difficulties supporting one another.

Within a project which needs to be approved by an NHS LREC (Local Research Ethics Committee), sampling is based on inclusion/exclusion criteria. Within research and people with learning difficulties, this is often based on levels on a scale, e.g. IQ or SSRS (Social Skills Rating System). Again, this specific statement was needed in order for the project to proceed at all.

The inclusion/exclusion criteria within the NHS setting, as stated on the NRES form, were:

Inclusion Criteria

1. Has completed the six training sessions on Understanding Research, which developed participants' understanding of the processes involved in taking part in research, in particular informed consent. This means that potential participants have specific knowledge on which to base their decision about participating, and subsequent participation.
2. Is able to give informed consent to taking part (capacity will be assessed by senior clinical staff).
3. Is considered by Service Manager, Forensic Services, and/or relevant Ward Manager to be suitable for this particular research project.

Exclusion criteria

1. Has not yet taken part in the six week training on Understanding Research
2. Is considered unable to give informed consent.
3. Is considered unsuitable to take part by Service Manager, Forensic Services, and/or relevant Ward Manager.

Once it had been established that potential participants from the hospital had been students on the Understanding Research course, the process which had been approved by LREC was followed. Firstly, names of those who took part in training sessions were confirmed with Service Manager. The Service Manager then identified relevant staff as contacts for each potential participant and gave me contact details for those staff who then received a "letter to staff" with information sheet and audio CD for potential participants (see Appendix B page 243-250 for letters and information sheets). These staff supported potential participants in accessing the information sheet/audio CD and deciding whether to take part.

Out of the six people who had been students on the course, one had moved on from the hospital so was not asked to take part because of practicalities. Another chose not to take part, and there was a mix up over another (see Discussion on Methodology page 202-203 for a full account of this). This meant that three students from the Understanding Research course took part, telling me about their experiences of peer support, given and received, within the course.

Having outlined the sampling process which led to identification and recruitment of participants, the outline of research design now addresses issues surrounding the consent process. Again, the complex issues surrounding this process will be explored further in the Discussion on Methodology and Methods Used section of the thesis.

Informed Consent

"informed consent is not as straightforward as it may at first seem" (French, Reynolds and Swain 2001 p43).

Informed consent is an issue which is particularly significant in research with people with learning difficulties (McCarthy, 1998). Within an inclusive approach to research, informed consent must be far more than simply asking participants to sign a consent form, which is invariably full of jargon (Walmsley and Johnson 2003 p158). Rather than seeing capacity to consent and act as a fixed, measurable attribute, the influence of the context and the environment need to be considered (Stone and Priestley 1996).

The process within the different contexts within Mutual Support ended up with very different approaches to the consent process. This section on informed consent begins with an outline of the ideals of the consent process and people with learning difficulties within an inclusive approach to research. This is followed by an account of what actually happened within the two contexts. The positive and negative aspects of the

process within each of the settings will be discussed further in Part Three Section Three, highlighting the fact that it is hard to generalise a "right" or "wrong" way of going about the process.

<u>The process of informed consent</u>

As part of the process of informed consent, it is necessary to present the information to potential participants in a way which will tell them what the project is about. Within this, it is important that their decision as to whether or not to take part is based on knowing what would happen if they did take part. This should be accompanied by an opportunity to ask questions about what would happen if they did decide to take part.

Paper versions of all information sheets can be found in Appendix B. The information sheets were also modelled on the outputs of the Understanding Research project. This meant that the way issues were tackled was based on the views of a group of people with learning difficulties who had spent considerable time thinking about how to present information about research to other people with learning difficulties.

Apart from the very first information sheet which was sent to Skills for People, all information sheets were accompanied with a word for word audio CD. Practical issues in getting someone with learning difficulties to do this recording meant that this was my voice reading the information. The advantage of using my own voice within the hospital setting meant that potential participants were able to put a voice to a name, even if not a face at this stage.

McLeod (1994 p169) states that "*genuine informed consent depends on the fulfilment of three criteria: "competence, provision of adequate information and voluntariness"*". Applying these criteria to people with learning disabilities raises complex issues (Arskott et al 1998). Significant work within this area comes from Cook and Inglis' work in collaboration with co-researchers who were people with learning difficulties around Understanding Research. The following themes emerged from this work:

- Ability to consent is not necessarily fixed, or congruent with cognitive ability. The way in which the researcher presents the research process is particularly important, and it is a researcher's responsibility to ensure that the research process has been consented to with an understanding of the process which both the participant and the researcher are comfortable with.

- The process of gaining informed consent is continual throughout the research, and should be re-visited as many times as is needed by each participant.

- Information about the process should be presented in multiple formats.

- Traditional methods are not necessarily the most effective way of getting informed consent. The use of information sheets and consent forms has meant that some people with learning difficulties have been excluded from the research process by barriers in the system as it stands rather than by their own abilities to understand and respond (Cook and Inglis 2007).

Conventionally, informed consent is obtained by the participant signing a form which has been written by the researcher prior to the interaction (French, Reynolds and Swain, 2001). This form states the participants' rights and responsibilities and should outline everything that will happen within the research. However, issues arise as to the accessibility of the written word to people with learning difficulties, and also the fact that signing forms may be associated with authority and coercion. It could also be argued that gaining consent verbally is more conducive to tailoring explanations of the process to each individual participant. Again, these issues will be discussed further in the Discussion on Methodology section of the thesis, Part Three Section Three.

It is also important to apply the principle of consent not being a one-off interaction (Department of Health 2001: Valuing People), and that the issues surrounding informed consent are re-visited as many times and in as many ways as is appropriate. Based on the above issues and careful consideration, my proposal stated that it is crucial for the following points to be covered in the interaction between myself and participants:

- Answer any questions the participant might have about the research, including what research is in general and what a particular research project is about.

- Check that the participant understands what I want to ask them about, and find out about any assistance which might be needed in order to facilitate communication.

- Ask for permission for the interaction to be digitally recorded, so that I can remember what was said, but emphasise that no-one else will be able to listen to the recording and it will be destroyed after what was said has been written up. Explain that the recording will be kept safe and only I will have access to it.

- Check that the participant understands that what they say may be used as part of a research project, but that anything they say will remain confidential, and their contribution will be anonymous.

- Check that participants understand that they can withdraw at any time, with no consequences, and that any data already collected will be destroyed.

Having outlined the principles behind the process of informed consent within Mutual Support, the specific processes which took place in the two settings are now outlined.

<u>The consent process with The Lawnmowers</u>

Within The Lawnmowers, a relatively informal approach was taken to the official consent process. This involved a recording of the conversation. In order for clear evidence of informed consent to be '"documented" (in this case digitally recorded) I made sure that I had a recording (at a minimum) of the participant communicating the fact that they have asked about anything which (at that time, more questions may arise at a later date) they want to know about and that they are happy to take part in the project.

The following is an extract from an interview with a Lawnmowers actor which illustrates a typical recording of consent to take part. This interaction followed a more in-depth discussion about the research and how to approach it.

> *Sarah: Just before we start, I want to make sure that everything I do is based on your views and your opinions.*
>
> *Chris: Sure, yeah,*
>
> *Sarah: Um, is there anything that you don't understand about what I'm doing, or anything that you'd like to ask me about?*
>
> *Chris: No.*
>
> *Sarah: No?*
>
> *Chris: No.*
>
> *Sarah: Um, obviously I'm asking your permission to record what we say today?*
>
> *Chris: By all means, yes.*

> *Sarah: But the recording will be kept safe, and if I quote anything that is said I won't say your name.*

> *Chris: Yep.*

> *Sarah: Um, and you know that I'm not setting out to trick you?*

> *Chris: Yeah.*

> *Sarah: I'm just wanting to straightforwardly find out about your views.*

> *Chris: Sure.*

> *Sarah: About how The Lawnmowers support each other.*

> *Chris: Yeah.*

> *Sarah: So just for my official files, we just need to record me asking: Chris, are you happy about taking part in this research.*

> *Chris: Sure.*

> *Sarah: um, you're happy with me recording it?*

> *Chris: Sure.*

> *Sarah: You know that you can withdraw at any time.*

> *Chris: Sure.*

> *Sarah: And you know that if there's something I ask you that you don't want to say, just say "don't want to answer that".*

> *Sarah: Is that OK?*

> *Chris: That's perfectly OK (June 2008).*

In practice, most participants were not too concerned with the process and wanted to get on with the interviews:

> *Sarah: so does that make sense, is there anything you want to ask me before we start?*

> *Laura: I don't mind, I just wanna get on and get started.*

The consent process with students from the Understanding Research Course

As outlined above, staff contacts for each potential participant were given an information sheet along with an audio CD and asked to look at it with them. It is not possible to know what happened at this stage in the process: how long did staff spend with each potential participant? Were participants able to listen to the audio CD in their own time? How much was the fact that taking part or not was a choice emphasised, and how was the research presented to potential participants?

Following this, I then met with those who were still interested in taking part and a member of staff. These meetings, in the end, were relatively brief, though also informal and an opportunity for both myself and participants to meet each other. When making initial contact with staff through meeting with ward managers and letters to the specific staff they had identified, I had been clear that I was asking staff to take an active role in this meeting. I contrasted this with the interviews when I asked that the interaction would be between myself and the participant. As far as was possible, I began the meeting with an informal chat, aiming to cover all the points on the consent form, before covering the questions on the form more formally. A copy of the consent form can be found in Appendix B pages 251-252.

This allowed for the potential participant to ask questions before referring to the consent form and making sure that both myself and the staff member were satisfied that all the points on the form had been covered. At this point, the participant, myself and the staff member who was present each had to sign both pages of the form, adding to the formality of the meeting.

Data Collection and Analysis

The above sections outlined the processes used to identify and recruit participants, and the creation of a situation in which deciding whether or not to take part was based on information being presented in an accessible format, emphasising individual choice. This section describing how the Mutual Support model of peer support and people with learning difficulties was constructed now moves on to describe the processes used for data collection and analysis.

Garwood (2006 p57) defines data as "*observations about the social world*". As such, there have been many situations, formal and informal, that have influenced this exploration of peer support and people with learning difficulties. However, it has been ethically important to be specific about situations in which formal data collection and analysis took place, because this in turn influences the conversations that I do, or do

not, have permission to quote directly in this thesis. The emphasis within these crucial stages has been on the co-construction of knowledge in which participants' accounts and views of their experiences are central. As well as describing what took place during data collection and analysis, this section outlines ways in which that co-construction occurred, including an outline of ways in which the emerging findings were validated.

As stated above, formal data collection took the form of individual interviews. As with every aspect of the Mutual Support project, advice was sought from people with learning difficulties as to the best way of approaching interactions with people. In the following case, I asked the first person who I interviewed at The Lawnmowers about how to make the interview process as accessible and comfortable as possible:

> *Sarah: wanted to ask your advice about how I go about the chats that I'm having with individual people....... what's the best way of getting people – I'm aware that I'm talking a lot at the moment, and you're not talking very much, but, um, that'll hopefully change in a couple of minutes, but, um, do you have any advice as to how I might go about the interviews?*

> *Chris: Um, just explain what you're wanting them to say, or say "I'm going to ask you some questions, just tell us[2] in your own words". It might take a bit of time for someone, for some people to say what you need them to say, and some people you'll have to say "thank you that's enough on that one, can we move on?" Cos the odd one might just go overboard!*

> *Sarah: ...how can I get over to people that I want it to be their views, and there's not a wrong or a right answer?*

> *Chris: Just say "look," like you just told me, just say to them "look, there's no right or wrong answer," but if you say one thing, someone might say, the same question, something totally different, but just cos they've said something different to you. None of uus[3] are wrong, and they're both, just say whatever you say, what you think of there's no right way or wrong way to answer it* (June 2008).

It was encouraging for me to see participants' confidence in the process growing. This is illustrated in the two quotations from first and second interviews with the same actor:

> *Sarah: Is there anything you'd like to ask me before we finish?*

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[2] Geordie pronoun: me.
[3] Geordie pronoun referring to second person plural.

> *Grace: Um, just wanna thank you for making this easy for me.*

> *(end of first interview).*

> *Sarah: Like before, just say if you're unhappy.*

> *Grace: Unlike last time, I don't have a problem any more.*

> *Sarah: Ah, that's good (both laugh) but you'll tell me if you do have a problem?*

> *Grace: Oh yes (beginning of second interview).*

As outlined in the review of literature relating to the methodology and methods used, the interviews were based on the idea of experience-based narratives: people were being asked to tell their stories about real life experiences. A further discussion around narrative research and how its principles were and were not realised within Mutual Support can be found in Part Three Section Three (see pages 205-209).

Data Collection within The Lawnmowers

The first stage of formal data collection within The Lawnmowers took place in June-July 2008, involving one-to-one interviews with the four core members who had agreed to take part. The interviews centred on instances of support given and received within day-to-day life in The Lawnmowers.

Following these interviews, I was involved in organising a performance by the Lawnmowers at Coach Lane Campus, Northumbria University. This took place in November 2008, attended by an audience of ninety people, including other groups of people with learning difficulties and also staff and students from the University. Significantly, those in the audience from the University included lecturers and students from Education, Nursing and Social Work courses. The event, which has been used as an example of inclusive practice, drew out the theme which had been begun to emerge of people with learning difficulties as educators (see Appendix E, pages 264-269 for more details of this event). I visited The Lawnmowers' base two days after this event and interviewed three of the actors, specifically about the event and how they had supported one another throughout the day.

The Twisting Ducks.

One of the groups in the audience at the November performance was The Twisting Ducks Theatre group. I visited them at their base in February 2009. The rationale for this visit was to find out how watching The Lawnmowers' performance at The

University had inspired them, thus exploring further the theme of The Lawnmowers supporting other people with learning difficulties.

As I introduced myself and the project, they were keen to speak about their own experiences of supporting one another. I visited them two more times and had brief (recorded) conversations with 8 "ducks". A summary of the themes emerging from the brief conversations with this group can be found in Appendix D (pages 262-263).

<u>Data Collection within the Understanding Research course</u>

Within the hospital, I met twice with each of the three students from the Understanding Research course who had agreed to take part. There was always a member of staff there. During the first interview, I asked them about times when they had and had not been supported, and supported others, within the Understanding Research course. We also explored the role of the facilitators in supporting students to learn. The purpose of the second interview was to check out what had been said during the first interview. In between the interviews, I worked on an accessible summary of the first interview, along with questions to ask which would enable the themes to be followed up. An example of one of these summaries can be found in Appendix C (pages 259-261). I also made use of the Workshop Evaluation Sheet which had been used during the course. This facilitated participants' thinking about how they had joined in, which led to thinking about how they and others had supported one another. A copy of this sheet is also in Appendix C (pages 256-258).

A further source of data came from an audio recording made in September 2008. It involved the four men who had been facilitators on the Understanding Research Course talking about their experiences of "Becoming Educators". This recording was made on the same occasion as I was first introduced to the men, prior to their looking at the information sheet and audio CD. I was not involved in this discussion at all, but was there throughout. The discussion was led by the Director of the Centre for Excellence in Teacher Training for Inclusive Learning (CETTIL), based at Northumbria University. It was to be used on the CETTIL website as an example of innovative practice. I asked the men's permission to use this recording as data in my project. Their reflections have added dimensions to the discussion around peer mentoring which forms part of this thesis.

Data Analysis

Each interview was transcribed as soon as feasible after it was recorded. As with every aspect of Mutual Support, data analysis was based on an inclusive approach to research. The issues raised when applying the principle of inclusive research to this complex stage of the research process are discussed further in Part Three Section Three of this thesis. The purpose of data analysis within Mutual Support has been to organise the relatively large amount of data collected within the research into a format which presents the reader with the views expressed by participants, remaining as true as possible to those views. A secondary purpose of data analysis was to begin to make sense of the emerging model of peer support – this is pursued further in the Discussion on Findings section, Part Three Section Two.

The basic principles behind the detailed data analysis within this project, based on a constructivist approach to interpreting data were:

- the views that were expressed by participants were the tools which drove and guided the analysis of data;
- the methods used created an opportunity for participants to express their views and opinions on emerging issues on more than one occasion, and from different angles;
- emerging themes are presented in a way which is faithful to the views expressed by participants.

Some of the data analysis took place alongside the formal data collection, meaning that I was basing each point of contact on the views that had previously been expressed. Within The Lawnmowers, this took place after the June 2008 interviews and before the performance at Coach Lane. Within the Understanding Research course, this took place in between the two interviews with each student, resulting in the accessible summary and follow up questions which I took along to the next interview (see Appendix C, pages 259-261). The comprehensive data analysis, which resulted in the themes presented in the next section of this thesis, took place in August 2009, after all the data had been collected and before the feedback and evaluation meetings. The feedback meetings allowed for further input from participants on the emerging themes prior the presentation of this thesis.

Finally, once the main body of this thesis had been drawn up, I listened back over the recordings of all of the interviews and group meetings. This enabled me to return to the data in the purest form possible and identify discrepancies in the way I had presented

the participants' views. This was especially important given the time I had spent away from the raw data by this stage in the PhD process.

<u>Tools Used</u>

Tools used for data analysis included NVivo8 (a Computer Assisted Qualitative Data Analysis Software (CAQDAS) package) and mindmaps. NVivo8 allows for vast quantities of data to be stored and retrieved (Gibbs et al 2002). The tools I used within the software were the facility to import transcripts and the facility which enables sections of those transcripts to be coded according to themes within them. The software then gathers all the data at any one code. The concept of a code is directly related to the conceptualisation of a "theme" within qualitative data analysis and allows data to be gathered according to the themes which are emerging. My main reason for using NVivo8 (as opposed to manual "cutting and sticking" of chunks of text) was to ensure that everything that had been said by participants had been accounted for as I built the Mutual Support model of peer support.

NVivo8 is based in grounded theory, a methodological approach to qualitative research in which theory is built by detailed data analysis and sampling involving a gradual development of theoretical concepts grounded in the data (Gibson and Brown 2009). Though Mutual Support did not use grounded theory in data analysis, the tools which allow for a gradual building of ideas based in the data were ideal for the process of data analysis in Mutual Support. It is important to emphasise, however, that the tools of NVivo8 did not analyse the data: the way in which the software stores and retrieves data enables a more efficient system for recording, sorting, matching and linking data (Bazeley 2007 p2). It is a tool which can aid project management, something particularly useful in a project as detailed as a PhD project. A more detailed discussion on the positive and negative aspects of using software such as NVivo8 can be found in the Discussion on Methodology (see pages 209-211).

The use of mindmaps alongside NVivo8 meant that I was not getting too constrained by Nvivo8 and enabled a standing back from the coding system at regular intervals throughout the process. Mindmapping has allowed the emerging themes to be presented in a way which demonstrated the links they had with one another. This has been useful in my own thinking around the data, providing a format for presenting the work to others. It has also allowed for a presentation of the ways in which the data coded at the main themes has been broken up in more detail. Both NVivo8 and Mindmap use the symbols of "trees" and "branches" within the way concepts are

broken down, enabling further consistency between data analysis and the way it has been presented in this thesis.

<u>The Process of analysing data</u>

As stated above, in addition to the data analysis that took place concurrently with data collection, a comprehensive analysis of all data collected throughout the project took place in August 2009, after data collection but before the feedback and evaluation group meetings. Throughout this process, the data from each of the two settings was kept separate.

Within this process of comprehensive data analysis, a process of inductive coding took place. Coding is about developing concepts and categories from data (Kelle 2004). Inductive coding involves "bottom-up" generation of codes leading to a theory, driven by the data as opposed to pre-existing concepts (Gibbs 2007). That is, the emerging codes are created from the data and the coding system is developed based on the data as opposed to existing theory (Lewins and Silver 2007). The coding system which was created was non-hierarchical: codes were not assigned different levels of significance/importance. The development of the themes, which are presented in Part Two Section Two, took place in four main stages. Appendix H (pages 280-282) is a summary of the codes created during the different stages of data collection.

In stage one, the development of the coding scheme was done through a descriptive content analysis. The question which drove the analysis and the themes which were created was: what is this participant talking about? The description was either of the activity which they were talking about, the point they were making and/or the issue which the participant was raising. At this stage, it was important to remain focussed on the issues participants were raising and not stray into linking back to my own thinking or the literature. This process was done relatively quickly, answering the question outlined above without deliberating for too long over each transcript. Of the three elements of narrative analysis - structure, content and context (Squire 2008b) – it was the content of what had been said by participants that was prioritised. The context was also significant, but the structure (syntax) of the accounts was not relevant to the analysis of data within Mutual Support, as the structure of people's accounts was not being considered.

Following this, stage two involved a more detailed analysis. This began with use of the basic tools of mindmapping, creating mindmaps which represented the codes that had been drawn up. This was followed by printing out all of the data which had been

collected within each setting at the codes which I had assigned to each section of the data. This was done using the "export" facility within Nvivo8, meaning that data could be viewed in the codes which had previously been created. At this point, each of the codes was read through more carefully, and changes were made within Nvivo8 to alter the way some of the data was coded so that coding was consistent within my understanding of what was being said in the data. Some of the codes which had already been created overlapped so I merged them. This work meant that data was now represented more consistently and at, what seemed to me at the time, the most appropriate code.

Stage three involved an evaluation of coding and development of a thematic framework. I realised at this stage that the original coding system was fragmented and began to look for more general themes within the codes. For example, within The Lawnmowers and taking the concept of "Practical Support", I drew out examples of practical support from each of the codes which had originally been created. The themes which emerged from this process allowed for a more overall picture of support within each setting to emerge. Subsequently, the examples of practical support given within The Lawnmowers span every area of their activities. This process was repeated many times, and the coding system which emerged at this stage began to resemble the themes which are presented in the final thesis.

At this stage in developing the codes from the Understanding Research course, the quotations from the Becoming Educators discussion (the facilitators) and the individual interviews with students were not separate. I decided to separate them in order to demonstrate the distinct roles which the two groups had within the course, especially as the two perspectives revealed different insight into the peer mentored learning process. I also realised the distinction between comments relating to teamwork and comments relating to the teaching and learning process and altered the coding system accordingly.

Following this, the tools of mindmap were again used in order to map out the data at each code and the relationships between codes, breaking down each of the main themes into the codes relating to it. Firstly, a mindmap was produced which presented all of the themes which had been created relating to the transcripts within each of the two settings. The exact wording used within the coding tools of Nvivo8 were used for the branches of the mindmap, resulting in a more direct translation of the codes within the detailed tools available within Nvivo8 into the more visual and straightforward tools

of mindmapping. Mindmaps which broke down each code represented in the mindmaps in more detail were also produced.

Stage four involved checking for consistency between coding within NVivo8 and the mindmaps, ensuring that the codes in Nvivo8 were consistent with the diagrammatic representation within the mindmaps. Before presenting all of this in a word document, colour was used on the printout in order to clarify the relationship between the coding in Nvivo8 and the mindmaps. The data represented at each code was also read through again at this stage in order to uncover any obvious inconsistencies. This process of data analysis using Nvivo8 alongside representation of themes in mindmaps has allowed for consistency in the coding of data and the way it is represented in the final thesis.

Participants' role in interpreting data

In addition to this detailed writing up and reflecting done by myself, three focus groups were held during October 2009. The purpose of these groups was to ask people who had taken part, either as advisors or participants, what they thought about the findings. These discussions form the basis of Part Three Section One of this thesis, where the evaluation and feedback from participants begins the process of evaluating and critiquing the emerging model of peer support.

I had initially set out on the process of data analysis intending to draw the themes emerging from the different settings together. However, it became clear that due to the obvious differences in the situations being considered, a direct merging of findings was not feasible or desirable. The discussion which follows in the section of this outline of methods used focuses on bringing the settings together. It explores the difference in the settings, and how the emerging themes have shed light on the same topic by approaching it from different angles.

Validation

Within a constructivist approach to interpreting data, there is an emphasis on credibility, transferability, dependability and confirmability of the findings (Denzin and Lincoln 2005). Within Mutual Support, the emphasis was not on "testing out" what people had said and meticulously comparing this with what that person had said elsewhere or what another participant had said about the same incident or idea. The process of validation of findings was based on the principle of ensuring that as the findings were constructed into the emerging model of peer support, each part of that rock was firm. It was also

important that each section of the rock was placed within the context of other parts of that rock. There were several points in the data collection and analysis which allowed for the findings to be validated as the themes emerged and were built on. These points differed between the two contexts.

Within The Lawnmowers, the interviews in June 2008 focussed on asking the actors to tell me about times when they had given or received support. These meetings were followed up in November 2008, when the focus was the specific performance at Coach Lane Campus. Thus, the accounts of support from the first interviews were built on by finding out about experiences within a specific context that was fresh in the actors' (and my) minds. The feedback and evaluation meetings at The Lawnmowers in October 2009 were also based on the principle of validating previous findings. The inclusion of three actors who had not previously been part of the research at these meetings also allowed for a further exploration of emerging themes from a fresh point of view.

Within the Understanding Research Course, my analysis of the first interview always included an accessible summary (pictures) of the first interview. This summary also included follow up questions, allowing for the ideas which emerged from the first interview to be followed up at the second. The inclusion of the "Becoming Educators" discussion also allowed for the perspectives of the four facilitators, who were reflecting on the same events as the students were interviewed about, to add to the strength of the rock which emerged.

Though the emphasis within Mutual Support is on the experiences of individual people, the findings are centred on the experiences of those individuals as part of the group situations they were reflecting upon. This is demonstrated by the way in which data analysis soon moved away from the individual transcripts to an overall thematic review. It was also demonstrated during data analysis when the data was very soon handled in relation to the theme or themes it reflected as opposed to who had said it, allowing for a firmer overall picture to emerge.

Bringing the settings together

The settings which are central to this study are very different, and this is evident in the data which has emerged from interviews. The Lawnmowers actors were reflecting on their work which has become a way of life for them: during the time when the interviews took place, the actors were spending at least three days each week either rehearsing or performing. This involved long days. The positive impact of being part of The

Lawnmowers means that the activity upon which they were reflecting in the interviews has become part of their identity.

The Understanding Research course, upon which the students who were participating in Mutual Support were reflecting, involved six half day sessions which had taken place nearly a year prior to the interviews. The length of time since the sessions, added to the fact that the course was far less central to the participants' lives, is reflected in extent of the detail of the reflections. The data which has been used from the "Becoming Educators" discussion is, again, within a different context. These men had spent more time working together through participation in the Understanding Research course prior to becoming facilitators. The course had also become a central part of their lives through the time and effort which they put into having their work accredited, and attending the conferences at which they have presented their work.

Mutuality of support

A further difference in the nature of the support which was given and received was the mutuality of the support (the extent to which the support was reciprocal or one-way). The Lawnmowers' accounts of support which was given and received suggest a very mutual, everybody supporting everybody else, situation. This differs from the data which emerged from the Understanding Research course, where the students spoke about working as a team with the other students, or about receiving support from the facilitators. The facilitators' accounts suggest that they were working as a team with one another and within this team the support was mutual. The facilitators also spoke about supporting the students to learn, though this support was not entirely one way: during the feedback session (October 2009) the facilitators highlighted ways in which the students had supported them by the information gained from the ways in which students engaged with the course.

Language used in the two settings

The differences in settings explain the different language used within the interviews, influencing my labelling of codes. The students from the Understanding Research course focussed much more on the idea of "teamwork". This could be explained by the setting in which they were working, with a small group of men who had been recruited from the larger group of men and staff with whom they spend most of their time. This is evident in the use of teamwork and related terms within the interviews. Similarly, as the activity taking place within the teams was focussed on a learning situation, the interviews also focussed on teaching and learning within a team situation.

The difference in the activity upon which The Lawnmowers actors were reflecting has also affected the language used in their accounts. They do not use terminology which is specific to teamwork, though when the accounts are looked at in more detail it becomes evident that they are speaking about working as a team. Many of the activities which are part of everyday life for The Lawnmowers are not within the current experiences of those who took part in the Understanding Research course.

Deeper reflection

The difference between the settings does not make the data which has emerged from the different settings incompatible or incomparable. In fact, as long as the differences are acknowledged, the different angles from which the participants were considering peer support result in more light being shed on the topic, which in turn provides a firmer foundation for this thesis to be built upon. Similarly, the factor surrounding the mutuality of the support, when incorporated into the building of theory within the project, adds a further dimension to the conclusions drawn.

The following diagram outlines how the support reflected on in the different contexts are being built together to establish a model of peer support.
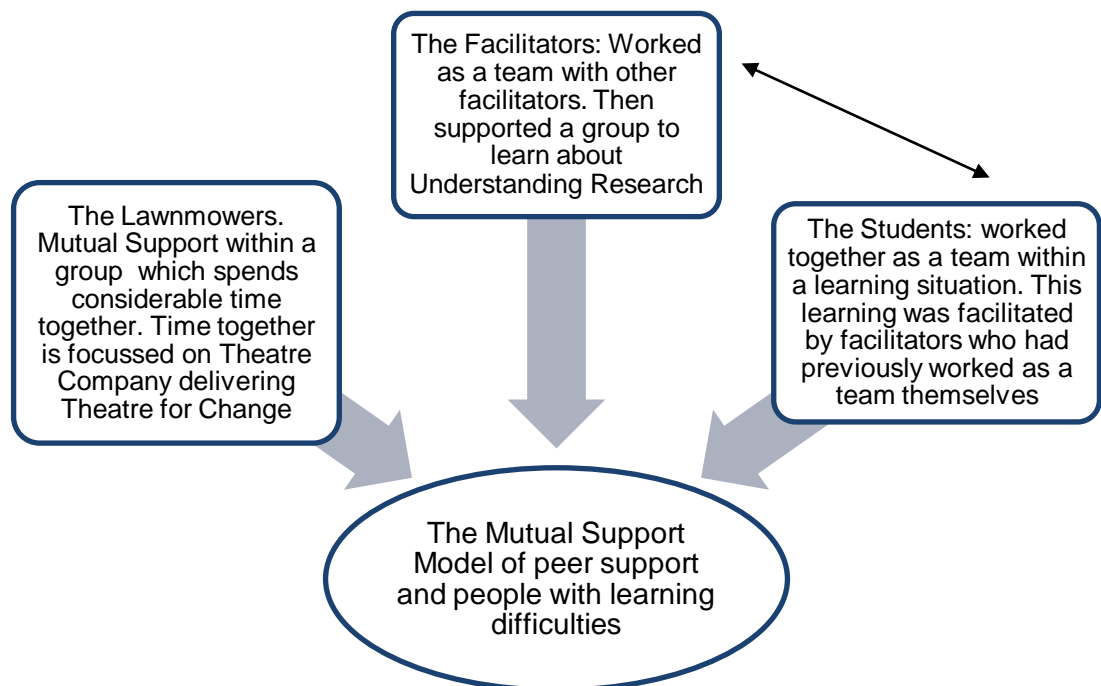
Figure two: bringing the settings together

Feedback sessions

The purpose of the feedback sessions/workshops which took place in October 2009 was to ask those taking part what they thought about the themes and ideas within Mutual Support. I met twice with The Lawnmowers as a group and once with the advisory group from the Understanding Research course. The aim was that participants interact with the themes. These meetings were also an opportunity for me to thank people for their input, and felt like a fitting way to draw the project to a close by taking the outputs back to the people whose views were at the centre of the project. I also presented the findings (as they were at that stage in the process) to the Programme Committee at Skills for People in July 2009. Their questions which followed this presentation helped form my ideas and thinking, especially around the role of non-disabled allies.

Within the meetings which took place I was asking the groups about the themes which emerged from their specific setting, though more general reflection did take place. With both of the groups, I presented the findings by adapting the mind maps which had emerged as central to the outputs of the project. This was done by presenting some of the themes in pictures. With some of the pictures, I asked the group a question based on the picture. Other pictures came with a statement, and I asked them to discuss whether they agreed or disagreed with the statement. Appendix F (page 272-277) is an outline of those statements and questions for each of the groups. The first workshop with The Lawnmowers was more interactive, and an outline for the session can be found in Appendix F (pages 272-274). The outputs of these meetings form the basis of Part Three Section One, as part of the evaluation of findings.

Dissemination

A significant aspect of an inclusive approach to research is the dissemination of views expressed by participants (Balandin 2003, Mallett et al 2007). Bewley and McCulloch and The Learning Difficulties Research Team (2006) emphasise the importance of this stage of any research project. An accessible summary, based on the feedback sessions has been produced (see Appendix A, page 224-230). The factors of time and resources have made it unrealistic to spend time in disseminating the findings of Mutual Support prior to submitting this thesis. However, I am determined that this essential element of the research process will not be neglected or allowed to simply drop off the bottom of a list. I also asked the people who were at the feedback sessions

for advice as to how to "get the information out there" (see page 148 for a summary of their ideas).

Part Two section One: Summary

This section of the thesis has outlined the methods used in the process of constructing the Mutual Support model of peer support and people with learning difficulties. It has described the methods used within an inclusive research design based on the co-construction of knowledge in the interaction between myself as a researcher and the people with learning difficulties whose views were central to the construction. The principles behind each aspect of the process have been outlined as well as specific methods used. These methods were different in each of the two settings. It is important that the outline of the methods used has been detailed, as this demonstrates the processes used in constructing the rock of Mutual Support. The following section presents the findings which have emerged from this process.

PART TWO SECTION TWO:
Findings

This section of the thesis presents the findings which emerged from the formal data collection phase of the research. Mindmaps have been used in order to present the findings in a visual format, enabling the reader to follow the thread of the findings as they read direct quotations from participants. The terms used as titles for branches are taken directly from the codes used in Nvivo8, and the quotations used have been selected from data which had been coded at that specific code. This method of presenting the findings ensures consistency between the data analysis phase of the project and the presentation of findings.

Direct quotations from participants are at the centre of this presentation of findings. Each theme is presented in relation to its place in the picture of Mutual Support which has emerged from the data. The Discussion on Findings section (Part Three Section Two) will develop these themes and discuss them further. The quotations which have been used represent the range of views expressed by participants relating to each code. Where the same view has been expressed by more than one participant, an example quotation has been given in order to avoid repetition.

The way in which the data from the two settings has been kept separate at this stage is reflected in the structure of this "findings" section. The themes which emerged from data collection within The Lawnmowers is followed by the emerging themes from the Understanding Research course.

Pseudonyms have been used for participants. Wherever possible, people chose these names themselves. Anonymity has been integral to the presentation of findings. However, it may be possible given the relatively small number of people involved combined with their in depth accounts of their experiences that readers who know those involved are able to identify who is who. I would ask that readers be sensitive to the ethos and spirit of Mutual Support and respect the anonymity of the quotations and insight from those who have taken part, maintaining confidentiality.

MUTUAL SUPPORT AT THE LAWNMOWERS

The following is a presentation of the views of four Lawnmowers actors on how they support one another within the context of an Independent Theatre Company which focuses on Theatre for Change. Mindmap one is an overall presentation of the themes which emerged from analysis of the interviews at The Lawnmowers. This is followed by the breaking down of themes from the overview and the branches of maps two to eight represent the sub-themes within each of those themes.

```
Mutual Support at The Lawnmowers
    ── Practical Support
    ── Emotional Support/Encouragement
    ── What makes a good Supporter?
    ── Improving life opportunities
    ── Support for others w learning difficulties
    ── People with learning difficulties as educators
    ── Times when not supported
    ── The role of non-disabled allies
```
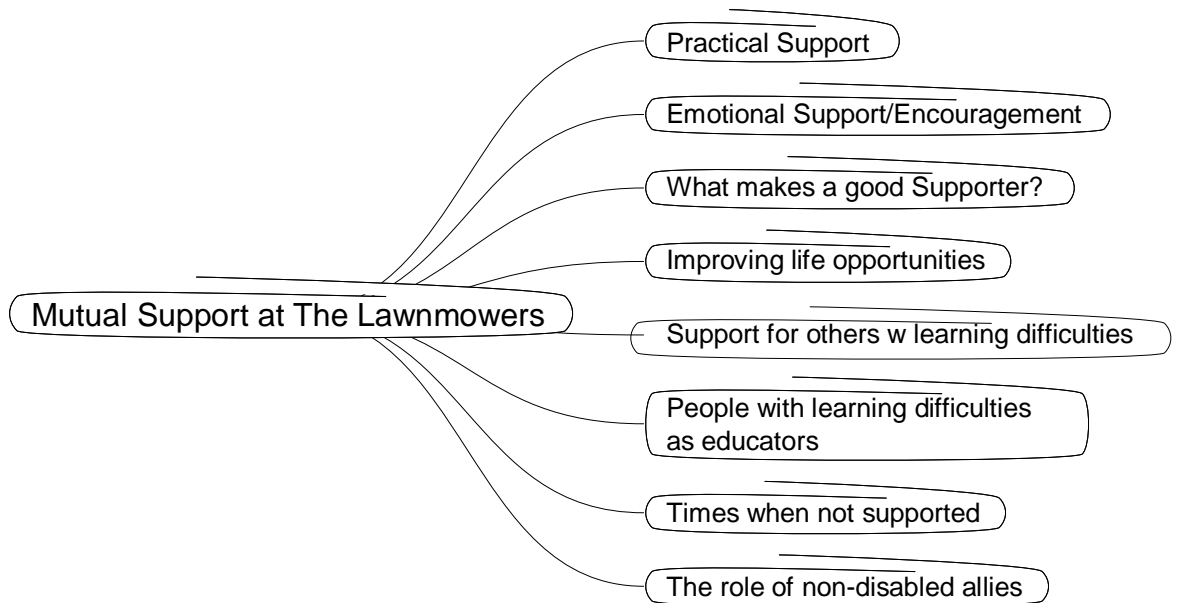
Mindmap one: overall presentation of themes from The Lawnmowers Independent Theatre Company

The above mindmap provides an overview of the themes which emerged from the analysis of data at the Lawnmowers. Beginning with Practical Support and working downwards, the following sections take each of these themes, breaking them down and using direct quotations as examples. The presentation of themes demonstrates the range of activities that are part of everyday life for the group. However, no aspect of group activity is included in this presentation of findings without having been specifically referred to with regard to peer support within the formal data collection. As each of the themes is broken down, the extent to which supporting one another is central to different aspects of activities within the group becomes evident. The thematic framework also demonstrates the different forms of Mutual Support which were appropriate within the group, reflecting versatility within different circumstances.

Practical Support
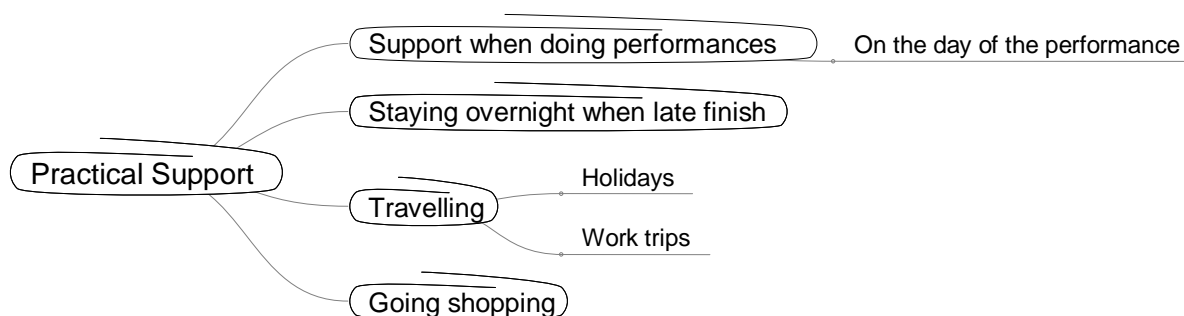
Mindmap two: Practical Support at The Lawnmowers

This section of data relates to examples of practical support spoken about by the actors in the interviews. It includes focussed support during performances but also extends to other areas of the actors' lives. It reflects practical support which is part of the routine of the company, as well as more spontaneous instances of practical support.

Support when doing performances

The most concrete examples of practical support came from days when The Lawnmowers were doing a performance. This included setting up, ready for performances. Grace speaks about the things she does routinely and a willingness to do more, as and when it is needed:

> *Grace: Um, if, say we're doing a show, with The Lawnmowers, Heroic Feets, and we need stuff setting up, um, I help L out in setting the stuff up, and if they wanted me to do anything I'd be happy for them to ask me to do anything (June 2008).*

On the two occasions when I was around whilst the sets were being put up, my experience was that it required slick work to get set up before the audience started arriving, and the "knack" to putting the flats up requires at least two people. The way in which the sets are designed to be put up and taken down for each performance demonstrates the versatility of The Lawnmowers actors, as they seek to perform in many different settings, in order to reach as many people as possible. They seldom have the luxury of dressing rooms and the fast-paced, jam-packed nature of their schedule means they have to quickly adapt to performing shows, or parts of shows, in new places to a wide range of people.

One such occasion was in November 2008, when the group performed "Heroic Feets" at Northumbria University to an audience of students and lecturers. In Dean's account of the event, he spoke about the support which the actors gave one another in preparing for the event. Preparation that morning had been interrupted by a fire drill:

Dean: and we discussed about the event that we were doing at Coach Lane, and then when we got back here we quickly had our lunch, and we all rallied together, and we did the last half of the show, we practised that, cos we'd already practised the first half (November 08).

Once they arrived at Coach Lane, the actors supported one another with getting the set ready:

Dean: We arrived at Coach Lane, and we all helped unpack the van, and we all sort of helped put the set up (November 08).

Some aspects of support in preparing for the performance were based on specific roles within the group:

Dean: and I support Chris, usually with his costume.....and he always appreciates that because, obviously to go into the man's toilet, it's obviously better if there's a man there (November 2008).

If taken in isolation, this practical support might be considered basic. However, as demonstrated in the section on "people with learning difficulties as educators", the event was significant in relation to breaking down barriers to inclusion. This follows on from the sub-section of the literature review which outlined the Theatre of the Oppressed/Theatre for Change and ways in which the Lawnmowers' activities are breaking down barriers to inclusion.

<u>Staying Overnight when late finishing</u>

The actors also referred to practical support which would be found in many groups of people who were working together:

Dean: Chris always supports me, in allowing me to stay at his flat for the night when we do late nights..... and it supports him, because it gives him company, and it supports me Mam and Dad cos they don't have to come and pick me up cos it costs too much petrol ...so Chris came up with a solution..... (June 2008).

Chris' support outside of official work, which was his idea, enables Dean to be fully involved in the group's work. The arrangement also extends to the social aspect of keeping each other company, as well as practical support for family members.

<u>Travelling</u>

The Lawnmowers travel regularly, both for pleasure and work. One such journey enabled a founding member of the group whose physical health was failing to fulfil his dream "trip of a lifetime" to Graceland:

> *Chris: Just cos, like, me and Pete shared a room, so I just was there in case he needed us during the night, and we hired a wheelchair when we were there, why we got the wheelchair was with the heat, and Pete being de-hydrated, and he collapsed. But apart from that, just making sure he was OK, pushing him in the wheelchair, just make sure he had plenty of fluids (June 2008).*

<u>Going Shopping</u>

The final aspect of practical support which was demonstrated was day-to-day support when shopping. This is done independently of non-disabled supporters:

> *Dean: And then there's another time when I've gone up to Tescos, say with (name) or Chris, I helped support them, to help them get some bits of shopping for us (July 2008).*

The independence with which the group disperses at lunchtime, each sorting out their own lunch, making use of the microwave and kettle, is something which I take for granted having been around the group over the last three years. But historically people with learning difficulties in institutions have been denied even this basic independence.

<u>Support for newcomers</u>

I was interested to find out about how a newcomer to the group would be supported, and whether the tight-knit nature of the group would make it hard for newcomers to feel welcome: an issue which can apply in any situation where people are coming to an existing group for the first time. Their responses straddle the two themes of practical support and emotional support/encouragement.

Support for newcomers would include practical direction:

> *Chris: when they come in you'd say "are you OK?", show them where they've*

got to sign in, where the toilets are, you know, and a drink (June 2008).

Chris also spoke about a two way introduction, finding out what the newcomers' interests are as well as introducing The Lawnmowers' ways of doing things:

Chris: and just talk to them, and find out what they like, tell them what we like, and then we will do games and exercises (June 2008).

It also involved making them aware of the support mechanisms which exist within the group, both formal and informal, and letting the newcomer know what to do if they were anxious or unhappy:

Chris: make them feel at home, and say "look, if you've got any problems, you can have a word with me, or you could have a word with [Project Manager]" give them the people who, if they feel they need to talk to someone, they would be told who they could talk to, if they did feel a bit anxious (June 08).

Laura spoke specifically about getting settled in from her experience, specifically referring to the "meeting people" aspect of getting settled in:

Sarah: Can you remember what, how people tret[4] you when you first came here?

Laura: the Lawnmowers tret me fairly.............which was giving me an opportunity to meet people and mix with people (June 2008).

Emotional Support and Encouragement

The next theme considers examples of emotional support and encouragement. Historically, people with learning difficulties have been considered incapable of the self awareness needed to understand their own, and other people's emotions (Beail 1989, Hodges 2003). The Lawnmowers showed that they are not only able to understand emotion, but know how to support one another when they are upset. The analysis begins with examples given by Dean and Laura of times when they had supported others when they were upset. The presentation of findings then moves on to applied situations in which The Lawnmowers encourage one another.

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[4] Geordie phrase meaning 'treated'.
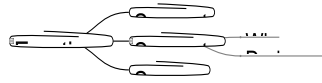
Mindmap three: Emotional Support and Encouragement at The Lawnmowers

Support for others when upset

Dean spoke about a time when another actor was upset, and what he did to support her. His insight begins with responding to her upset, and he then sought to find out what had caused it, explaining how he sought to resolve it:

> *Dean: so I went to one side with her and we discussed what was wrong with her, and sort of helped make her feel better in herself by telling her not to worry too much.... (June 2008).*

The following interaction gives specific insight into the support which takes place within The Lawnmowers when people are distressed on a day-to-day basis. It provides a glimpse into the support which The Lawnmowers extend to someone who has relatively complex needs:

> *Setting: Laura and I are recording interview (June 2008) in the main rehearsal room. Richard comes in to set up the keyboard so he can lead in singing Happy Birthday for Pete.*
>
> *Richard opens the door and looks in.*
>
> *Sarah: Hiya Richard It's alright Richard you can come in, it's fine.*
>
> *Laura: I do support people here, like I support Richard, don't I Richard, do I support you when I come here?*
>
> *Richard: Why-aye[5].*
>
> *Laura: Just to try and stop him from biting himself, I know it's a hard time for him when he's stressed.*
>
> *Richard: I haven't been biting lately though.*

---

[5] Geordie phrase meaning 'why, of course'.

> *Laura: No, you haven't, have you, but I try to support you to stop you from doing that, all of us are, aren't we Richard, as a group of us? Yeah? As a group?*

> *Richard : Yeah, (Laughs).*

> *Sarah: So do The Lawnmowers help you Richard?*

> *Richard: Pardon?*

> *Sarah: Do The Lawnmowers help you?*

> *Richard: Yes. Very much, very much. Just a bit (with sarcasm). They help me a lot.*

<u>Support (encouragement) when doing performances</u>

The actors also gave examples of encouraging support when doing performances. I have separated these from the previous section on practical support when doing performances. This is because they demonstrate a different level of support; the performances would not run smoothly without the practical support outlined above, whereas the supportive encouragement outlined in this section adds to the quality of those performances. This demonstrates the role of strong teamwork being behind the group's success. The specific examples which were given related to the performance at Coach Lane Campus, Northumbria University, in November 2008. Two of the actors in particular had felt unwell on the day of the performance:

> *Dean: Grace was a good support to me, cos behind the scenes she was, with me not feeling very well on Monday (November 2008).*

The idea of encouraging each other in "doing a great show" despite difficult circumstances came through on more than one occasion:

> *Dean: she was going "are you OK?" she was patting me on the back and telling me to just take it easy, and saying "you'll do good, and you'll do a great show" (November 2008).*

As stated above, the events of the performance at Coach Lane will be explored further in terms of The Lawnmowers' roles as educators, but the following quotation belongs in the section on encouragement as it speaks about how the group supported one another within the challenging situation. This included the question and answer session which followed the show. This session involved the actors answering questions from the audience. They had no forewarning as to what those questions might be:

> *Dean: and when the show was finished we did the general question and answer, and we all sort of supported each other by each having a go at answering the questions (November 2008).*

This was followed by some Forum Drama (part of Legislative Theatre – see literature review page 24 and Grace's description on page 156):

> *Dean: we did our sketches and we did our usual support of each other in the sketches (November 2008).*

The support which The Lawnmowers gave one another whilst delivering Forum Drama enabled audience insight into the experiences of people with learning difficulties:

> *Dean: and sort of supported the audience to sort of come up and take part in that, and, you know help people do that, and help the audience to get ideas, and sort of say what people thought could be changed (November 2008).*

<u>Fulfilling ambitions</u>

The second aspect of encouragement which became evident from the interviews was that of support in fulfilling ambitions. Dean spoke about how his ambitions had in the most part been fulfilled:

> *Dean: because one of my dreams was to have my own music video, which has happened, so I wouldn't say there's any great huge ambitions, because what we do with the nightclubs and the DJ-ing, playing music, that's what I've always wanted to be able to do.... (June 2008).*

This was set against a background of years of struggling through courses and work situations which did not appreciate Dean's talents: it did not happen instantly. He recounted experiences at college and working in a care home when he felt misunderstood and not supported to fulfil his potential:

> *Dean: although it took a long time to, well it's took from about '96, it's took all these years to get to where I want to be.... (June 2008).*

Grace also referred to Dean's love of music, and how she has supported him in this, it demonstrates the awareness of the strengths of other people and a desire to encourage one another to fulfil ambitions which exist within The Lawnmowers:

> *Grace: I've supported him, through his music, cause he writes his own music, and puts his own music together, and songs, and I support him through that*

(June 2008).

Grace also spoke about her own ambitions and the support which the group were going to give her in fulfilling these:

> *Grace: [Artistic Director] has said that she'll support me, and that The Lawnmowers will support me........There's two things, the first thing is I wanna do some more singing, cos I love singing, and, that's when I feel at home and that I can do something like that. The other thing is I want to get over me fear of water.....(June 2008).*

The way in which The Lawnmowers support people in pursuing dreams is picked up again in the section on "persuading/assuring family members", within Mindmap Five: improving life opportunities.

What makes a good supporter?

All of the examples of support which have been given demonstrate what The Lawnmowers think and feel about what makes good support. This section of the presentation of findings goes deeper into the views expressed by two actors, in particular about what makes somebody a good supporter. They reflected on a more abstract level about what makes a good supporter/friend. It is significant that they also (independently) named one another as having given and received meaningful friendship and support. This section considers their insight and reflections.

Again, this section demonstrates an immense depth of understanding both the self and other people, and an insight into interpersonal interaction.
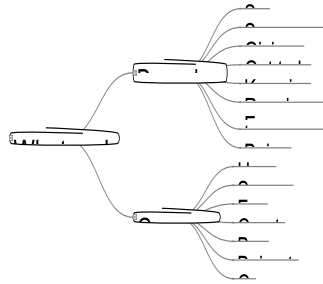
Mindmap four: what makes a good friend/supporter?

Early on in the first meeting with Dean, he spoke about how one of the artistic directors had affirmed him as a support within the group:

> *Dean: when we had my birthday party, [he] got up and said things about me, like [he] claimed that, within the School for Fools, he claimed that I was one of the group's rocks, somebody that is solid, and just is always there, supporting and helping people (June 2008).*

Later in the same interview I asked him further about this attribute:

> *Sarah: can you think of some things that have helped you to get to the point of being able to support other people....?*

Dean: Well, I've always been good at supporting people, like, I would probably say, my Mam would probably say it was a general natural thing, that I'm so supportive (June 2008).

Dean also spoke about the support he gives within groups he is involved in outside of The Lawnmowers. It shows a transferability of the support which takes place within the specific setting of the Lawnmowers, and is an example of people outside of The Lawnmowers, such as the support staff, recognising Dean's strengths in giving other people advice:

Dean: I mean like the place I go to on Saturdays, I'm a volunteer there now, and they always get me to talk about, you know if people have problems, they always come to me and ask my advice or my opinion. And, when I used to do the Newcastle College course, in productions, a performing arts course, people there used to always come to me, and if somebody had a problem, sometimes even the support staff would say "oh well, I know a man, I know Dean here, he'll be able to give you some good advice" (June 2008).

Grace described approachability within a friendship. She viewed this as a mutual interaction. Quotations from Grace used elsewhere suggest that her appreciation of trust and rapport within a relationship is set against life experiences of "*being tret like an outcast"* (a phrase she used in our meeting in November 2008).

Grace: ...and you can talk to that person, no matter what, and feel at ease with that person, that they can feel at ease with you (June 2008).

Grace also spoke about the need for trust within a friendship where people feel able to share without worrying:

Grace: and that they'll have nothing to worry about and they can tell you anything and, um, that you have a bond of trust with that person... (June 2008).

Dean related this sharing of problems to times when people have a specific need for advice:

Dean: So, I kind of, so when people have a problem they always tend to gravitate towards me, to ask my advice, or my opinions, so I suppose I'm always generally helpful in that sense (June 2008).

He reflected on the importance of getting to know people, and gaining insight into them

in order to support them:

>*Dean: But I would say one of the main things that allows me to be so supportive, is once you get to know everyone yourself, and once you have a good personal relationship with everyone within the group.......*

His reflection echoes my own thoughts in the introduction to this thesis about gaining insight into people in order to know how to support them, and using this insight in specific instances where they "have a problem":

>*Dean: .....then you have more insight into them, into each person, then that allows you, when they have a problem.........that allows you to be able to help them (June 2008).*

Grace also described this need for understanding of other people:

>*Grace: Well, what I think makes a good friend is, the fact that you can have a rapport with that person (June 2008).*

Dean spoke about working as a group when one or more of the members are struggling or with people you might not naturally get on with. This realistic evaluation that "there might be people who you might not get on with" is an important insight for anyone to take into a group situation:

>*Dean: I mean, sometimes they might be people who you might not get on with, or sometimes one of them might be having an off morning, and they might be still sort of friendly with people, to an extent, but they might be a bit, feel a bit washy or a bit wary (June 2008).*

The non- judgmental approach to supporting people which I have appreciated so much within The Lawnmowers was also significant to Dean:

>*Dean: and then, I suppose, you, the rest of us, I always feel, that it's good for you to still be supportive to them, to the best you can, and by doing that you'll sometimes make them feel a bit better about themselves, and often that helps them, whatever they're feeling mooded over (June 2008).*

Dean's insight also acknowledged that the issue which people are "mooded" over is not necessarily something which involves The Lawnmowers:

Dean: Cos often, it's not anything to do with the group, The Lawnmowers, when we feel a bit moody, but obviously that doesn't happen too often. But now and then it can occur (June 2008).

Dean also spoke about the best ways of resolving conflict:

Dean: whenever conflicts do come up, even if it's a Krew day[6], I often try to help sort it out. And then often these things sort themselves out just like that, and you think "well, why were they arguing over that, that wasn't important?" and then obviously they realise that. And so then, by doing that we stay strong (June 2008).

He spoke about the need to resolve conflict as soon as it occurs:

Dean: Because it's quite easy, if you have a little tiny conflict over something, for the whole group to then just fall apart. Or then start to fall apart (June 2008).

And the significance of resolving conflict for the strength of the group:

Dean: people then realise that they're just being arguing over nothing, then it just helps keep the group tight and strong, and I suppose things are always best, sort of, sorted out straight away (June 2008).

Dean also reflected on responsibility within a working group. The dilemma of whether to go to work or not when unwell is common to many people, especially when working with a team in which roles are defined and unique to each individual:

Dean: But then, I suppose we've got to work out the boundary of when it's appropriate to be off, when you're really seriously ill, then, if you're not too bad – obviously on Monday, I was just a bit shivery but I wasn't, I didn't feel I was bad enough that I needed to stay off, and it wasn't something that people could catch, so I just came in and did it, and felt better for doing it (November 2008).

Though not directly related to the same issue, Grace also spoke about responsibility and reliability within a supportive relationship:

Grace: and show that you are there for them. That's the most important thing, being there for them (June 2008).

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[6] A day when the activity focussed on the Krokodile Krew nightclub.

Having considered examples of practical and emotional support, and Grace and Dean's reflections on the qualities of meaningful support and friendship, the analysis of data now moves on to consider the effect that the support which The Lawnmowers give and receive in terms of inclusion and people with learning difficulties.

Improving life opportunities

The support The Lawnmowers gives to actors impacts on their whole lives and the lives of other people with learning difficulties, improving the quality and range of opportunities available to them. The next section outlines examples from the actors themselves about the opportunities, associated with being part of The Lawnmowers, that have opened up for them. The section which follows this outlines ways in which people with learning difficulties outside of the core group have been supported. During the interviews, the actors also spoke about ways in which being part of The Lawnmowers has opened up opportunities within other areas of their lives.
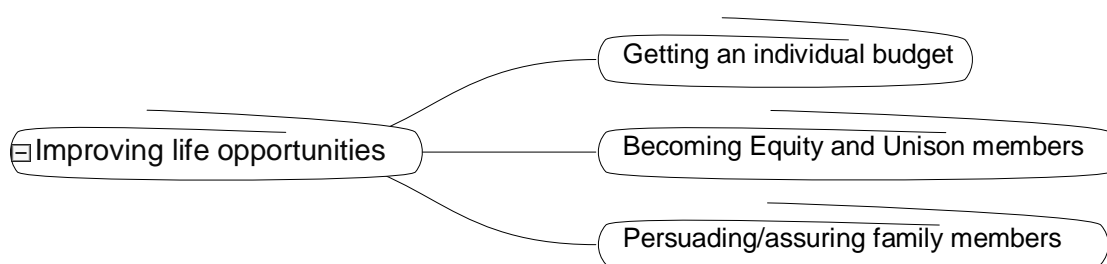
Mindmap five: The Lawnmowers – improving life opportunities

Getting an individual budget

Laura spoke about getting her first Individual Budget. This was significant at the time of the interview for two reasons. Firstly, the UK Government was promoting Individual Budgets for people with learning difficulties without providing the support which was needed in order for people to access them. Secondly, the show which The Lawnmowers were touring (Heroic Feets) was centred around the issues of accessing individual budgets.

> *Laura: Cos The Lawnmowers have done a lot for me. The Lawnmowers have given me my first individual budget, for me to like, [Artistic Director], she was the first person that got me started to do an appeal form, an individual budget, and then she had a chat with me Mam, and all those kind of things, but I really thanks [her] for all that hard work (June 2008).*

Trade union representation

The work which The Lawnmowers has done has extended to enabling people with learning difficulties to be represented at Union level. This is particularly significant in relation to representation of volunteers. The negative experiences which people with learning difficulties working as volunteers have experienced can be a barrier to employment, because voluntary work is often a way into formal employment. This work demonstrates the core value behind The Lawnmowers' work of campaigning for people with learning difficulties on a wider scale to experience the opportunities which are opening up within the core group:

> *Chris: [Artistic Director], Laura and myself are .... Unison, members, and we were asked to do a small video for the conference, cos at this moment in time, people with learning disabilities.........can't get, if they do any voluntary work, they can't be part of Unison, but the branch in Newcastle, they've started to take people with learning difficulties on board, as Union members (June 2008).*

Persuading/assuring family members

The Lawnmowers have also taken on a role in supporting family members. The specific example given was of instances when family members might need reassuring or persuading that someone with a learning difficulty might be encouraged and supported in doing something, maybe something that they have not done before. It is a concrete example of The Lawnmowers' work in challenging assumptions. Again, this reflects the theme which has emerged throughout Mutual Support: never underestimate what people with learning difficulties can do, especially with appropriate support.

A person with a learning difficulty might approach the Lawnmowers because their family is reluctant to let them do something they want to do:

> *Chris: Yeah, cos, they get support from family members.......but say if they wanted to do something, with a family member, say something different, they might come and see us, and say "'look, so and so said this, I shouldn't do this".*

As a group, The Lawnmowers would seek to explain why their family are reluctant to support them in pursuing that ambition or goal:

> *Chris: ....and we would probably talk to them and say, "right" and we'd explain to them, maybe why it would be a bit dangerous or not right for them to do that" (June 2008).*

There is also support in place to enable family members to see how important it is to the person:

> *Chris: But then, if they still want to do it, we would probably have a talk to their parents or carers and say "look, even though you don't want them to do this, they still want to do it," and we would support them to do what they want, in conjunction with the family (June 08).*

Supporting others with learning difficulties

During the 24 years since The Lawnmowers first met together, they have become a trailblazing organisation among many groups of people with learning difficulties. The nature of their work means that their support extends to people with learning difficulties outside of the core group. This support for other people and groups of people includes inspiring others to have confidence to pursue their dreams and the ever popular nightclubs and social events. The Lawnmowers' work also supports the wider community of people with learning difficulties by communicating issues which are important, and breaking down assumptions as to what people with learning difficulties can achieve. Their work has increasingly been aimed at policy-makers and service providers.
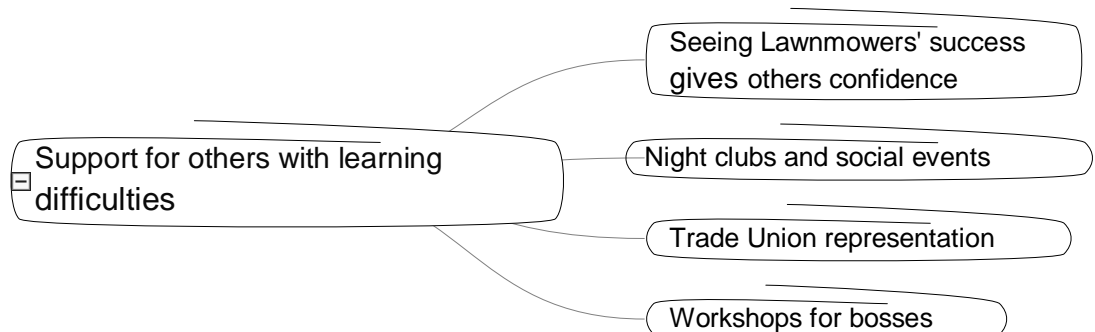
Mind- map six: The Lawnmowers. Support for other people with learning difficulties

Seeing Lawnmowers' success gives others confidence

The Lawnmowers always seek to inspire other people with learning difficulties to fulfil their potential. Whether that is through becoming actors themselves or being inspired to use their own talents and interests in different ways, the confidence which The Lawnmowers show throughout their performances is an important factor in inspiring others, and those who support them:

Laura: If there was a learning disability[7] sitting in the audience, watching a performance of Heroic Feets, they're probably saying to themselves "why can't that be me up there?" and just saying....... I would love to have an opportunity to ......to make friends and to do things with The Lawnmowers actors (June 2008).

Chris: if one person goes away from seeing our show and think "well if he or she can do that acting, well I can" If one person goes away with that attitude and goes and tries it then that's just been fantastic (June 2008).

The themes which emerged from the brief interaction with the Twisting Ducks (see Appendix D pages 262-263) also provided insight into Mutual Support outside of the immediate contexts of the research.

<u>Night clubs and social events</u>

The Krokodile Klub, a nightclub which people with learning difficulties are especially welcome at, is also organised from The Lawnmowers' base. Three of the actors who were interviewed individually are very involved in this, and spoke about these events as a way of supporting others:

Chris: we run nightclubs, for people with learning difficulties, and all the DJs have got learning difficulties....so if people come up and they're a bit shy, they want to do the singing, or they need a bit of support, the Krew members will sing with them, to give them that support (June 2008).

Dean: The Krokodile Klub is one of the biggest supports for people, cos it allows them to have an opportunity to socialise with people like themselves, and also just to meet with friends, it allows two friends to have a night together in a sociable environment...(June 2008).

It was not just the events which supported other people with learning difficulties, the "fantastic group" was significant, and recognised by others:

Dean: Like we went and did a, we went and helped with a KK2[8] disco, and when we got there the night was dead, it was dull and dead, and then when we got up, and did an open mike, the whole place just went – whoosh – the energy went up, everyone was lively, people were wanting to get up and sing, but by that time it was too late, because they had said they didn't want to, but then

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[7] Laura referred to people with learning difficulties as 'a learning disability' throughout the interviews.
[8] Krokodile Klub Two (an off-shoot of the Krokodile Klub).

they wanted to, cos they realised how good it was, and the people who run the KK2 were just like "oh, my god" and they turned, and the woman turned and said to us "you've just got such a fantastic group......." (July 2008).

In addition to the night clubs, Dean also spoke about the drama workshops as a way of supporting other people with learning difficulties, through "giving them a day out" and also through trying out new skills:

Dean: And then obviously, also through the drama work, the workshops and other things that we do and that we have going on, like the other week we had drama workshops, and people came here for the day, and we had two, a morning group and an afternoon group where we had different people, that obviously helps them – cos then that gives them a day out in a different environment, with something different to do. And something obviously new to try......(July 08).

The growing number of requests from people who would love to join the group resulted in a lengthy waiting list and many disappointed people. This led to two outreach workers, drama graduates from Northumbria University, setting up Love Drama, a rolling ten-week course introducing The Lawnmowers' techniques. These workers also run workshops in local day centres and other group settings.

<u>Trade Union Representation</u>

The trade union representation referred to above as a way of improving life opportunities has also extended to people with learning difficulties outside of the core group:

Chris: And we're going down to the conference on the 19th, as far as I know, of this month, with the DVD to show it at the conference, at the fringe..........as far as I know it's gonna be voted on, so it'll be not just Newcastle doing it, the whole of, England, as far as I know, will be doing this........ it's for the national conference of Unison (June 2008).

The creation of Union representation and support is aimed in the first instance at people with learning difficulties having mechanisms for speaking out against discrimination within voluntary placements.

<u>Workshops for employers</u>

The Lawnmowers' technique of using Theatre for Change has been extended to workshops which are aimed at employers being more sensitive and open to employing people with learning difficulties. When put together with the trade union work, these workshops are aimed at paving the way for appropriate work placements, leading to employment for people with learning difficulties within supportive workplace environments.

> *Grace: It's kind of how bosses react to people with learning difficulties, and how they can't handle being around a person with learning difficulties.....(June 2008)*

Grace's account of these workshops articulates the way in which the issue of how people with learning difficulties are perceived can be a barrier within the workplace. She also highlights the important area of how people with learning difficulties perceive employers. She speaks about how the workshops which The Lawnmowers were doing with employers could support changes in these perceptions, again leading to more supportive work environments:

> *.......and it's how we perceive a boss, so we're kind of taking on their role. So, some of us are taking on the boss' role, and some of them are taking on the employee role, so there are going to be bosses there.......so we've got to be like OK, don't make fun of we cos it's like serious kind of thing. I've just got involved in this thing now, so it's really good actually, being part of that (June 2008).*

The above quotation from Grace touches on a role which The Lawnmowers are developing: people with learning difficulties as educators.

People with learning difficulties as educators

The next section uses evidence from the actors' accounts of the performance at Northumbria University's Coach Lane Campus (November 2008) to explore the role which The Lawnmowers have as educators. Elsewhere in this project, the idea of people with learning difficulties educating one another has been explored, in particular in relation to the Understanding Research Course. This section explores the way in which The Lawnmowers saw their role in educating University students and lecturers who were in the audience about issues which were important to the actors. The accounts of how they supported each other during that day have been included in the sections on practical support or emotional support/encouragement sections.

This section focuses on the evidence from that day, in which The Lawnmowers educated people whose professional lives will involve working people with learning

difficulties about their experiences from their point of view. This is a radical shift: not only were the audience being challenged to consider the experiences of people with learning difficulties, The Lawnmowers took on the role of educating the audience about supporting people with learning difficulties. It provided a significant opportunity to break down the barriers and assumptions which often surround professional practice.
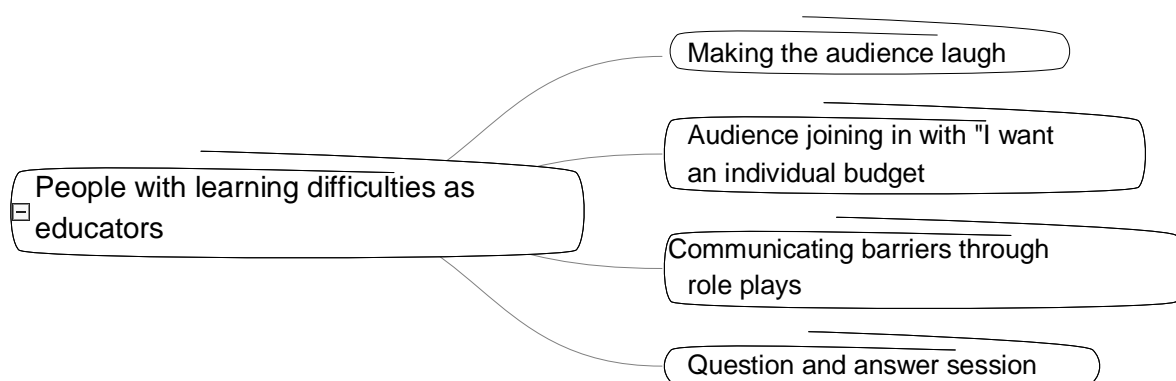
Mindmap seven: People with learning difficulties as educators (evidence from The Lawnmowers' performance at Coach Lane)

<u>Making the audience laugh</u>

One of the aims of The Lawnmowers' work is for the actors to reclaim the power which has often been taken away from people with learning difficulties through people laughing at them. Chris said that hearing the audience laugh when he came on was the best part of the afternoon:

> *Sarah: What do you think the best thing about Monday was?*

> *Chris: Listening to the audience laugh, when we, like when, not much when Grace and Laura came on in their costumes, but like when I came on you could hear them laughing, so that's just brilliant (November 2008).*

<u>The audience joining in with "I want an individual budget"</u>

This reclaiming of power was also reflected in audience participation, led by The Lawnmowers actors. As part of the show, the actors present to the audience practical suggestions for accessing Individual Budgets. Part of this involves the audience joining in saying "I want an Individual Budget". The audience is also asked to repeat the web address for In Control, an organisation which supports people with learning difficulties. Chris spoke both about the audience listening to what the actors were saying and the

audience joining in:

> *Chris: and people listening to what we were saying, and people participating, when we were saying like "I want an individual budget". Them joining in, everybody joined in, when it was their turn (November 2008).*

<u>Communicating the barriers faced by people with learning difficulties – through audience participation in role plays</u>

Following the question and answer session, there was an opportunity for the audience to take part in some Forum Drama. The actors spoke about how the use of role plays enabled a two way interaction. Grace spoke of a sense of pride when students from the University took over her part in the role play:

> *Grace: I mean, it makes you feel kind of proud, a sense of pride, watching them get up and take on your role, um, I thought it was quite cool actually (November 2008).*

It might be assumed that once an oppressed group of people reclaim power by becoming educators they assume as much power as possible over the people they are educating. However, The Lawnmowers insight extended to the need for learning to be two-way, with an exchange of views.

Grace highlighted the opportunity which the role plays provided for this exchange of views:

> *Grace: but I thought it went really well on Monday, um, I mean it's different performing in front of a group like that, cos there were different groups there, and it was nice, though, cos it was nice to see what their views were, and when we did the workshop it was nice to see the students getting up and doing things (November 2008).*

She related this to the two way interaction within the learning situation:

> *Grace: Cos it's a learning curve as well, you learn from them, and they learn from us (November 2008).*

<u>Question and answer session</u>

Following a performance of "Heroic Feets", the actors answered questions from the audience. Both the question and answer session and the Forum Drama created unstructured opportunities for the actors to communicate their views and experiences to the audience:

> *Dean: and when the show was finished we did the general question and answer giving our views, and what we thought (November 2008).*

Grace also spoke of the way in which the performance had enabled lecturers and students, many of whose work involves people with learning difficulties, to be challenged about the actors' views and experiences. She spoke about the interaction between groups of people who may not have met previously. Again, there is an acknowledgment of the need for a reciprocal acceptance:

> *Grace: Um, I think it's interesting performing to an audience of students who've never been round people with learning difficulties as well, cos, they don't know how to react towards us, and it would be the same for us, if we'd never met an audience like them, we might not know how to react towards them (Nov 2008).*

Grace viewed the learning situation as one in which The Lawnmowers were seeking to change the views of staff and students at the University. She spoke about the huge steps needing to be taken in order for views to change:

> *Grace: I do think it is a big thing, though, getting teachers to change their views, cos if they've never worked with people with learning difficulties, it's a hard thing, I think, to change their views of people with learning difficulties, but I think that would be a big step forward for them if they could learn that (November 2008).*

Grace highlighted the potential that workshops in which people with learning difficulties express their views and opinions have to change the views of people whose working lives will involve contact with people with learning difficulties. She also spoke about her own desire to see views changed:

> *Grace: Cos they are gonna come across people with learning difficulties, no matter what, and it's a very big thing for me, for people to change their views.*

She expressed her personal desire for an end to discrimination which has affected her throughout her life:

> *Grace: cos people have tret me differently all my life, and I don't like being tret like I'm an outcast (November 2008).*

The presentation within the afternoon at Coach Lane also challenged a traditional delivery and lecture style of teaching and learning by demonstrating new ways of learning based on the experiences of people with learning difficulties. This relates back to Grace's comment in the introduction (see page 3) relating to the fact that different people learn in different ways, and to how an openness to these differences would enable people with learning difficulties the freedom to tackle situations in ways which make sense to them:

> *Grace: I think that's one of the things that teachers and anyone that works with people with learning difficulties need to learn, that we would just like to be a bit free, to do what we want to do, and then see what we can do, and they can think "oh, right, that's how they do things" (November 2008).*

Times when not supported

It was important that the interviews also gave participants an opportunity to speak about times when they had not felt supported.

Chris spoke about how the loading up of the van had been left mainly to him:

> *Sarah: The Lawnmowers spend quite a bit of time together?*

> *Chris: Oh, yes.*

> *Sarah: I was just wondering if there are times when things aren't that good between people, like there would be in any group of people?*

> *Chris: At one time.......when we had any set to move, I used to be there before any of the others, and some of them weren't that enthusiastic, about moving the stuff. ....I wasn't asked to do it, I did it myself cos of the time factor, if I could get the van loaded up so I would get the stuff all ready outside, downstairs ready for when [artistic director] comes we could just hoy[9] it in the van (June 2008).*

He went on to explain how this issue had been resolved........:

> *Chris: Later on, after that, we did have a meeting and [Artistic Director] did say*

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[9] Geordie: throw.

> *to the others "look, we've all got to pull together, we can't just leave it for one person" and after that, they just pitched in (June 2008).*

An appreciation of the group, and that the group is now stronger than ever was a theme echoed throughout the interviews:

> *Chris: But otherwise, now, it's just fantastic group to work with. They were fantastic people before, but it's, we've just got something which is fantastic now (June 2008).*

Another actor was more vocal in her example of an instance of not feeling supported:

> *Laura: Um, not with walking, though, I don't get any support with walking, off the other actors.......I was OK walking across the main roads, and the traffic lights, I was fine on me own, but it would've been nice if I'd had a bit of support from them (June 2008)*

This same actor recounted how another actor had missed out on lunch during a conference at Coach Lane Campus:

> *Laura: Well, I don't know really, about the day of that conference, about our support. I don't think everybody was supporting each other. I don't think that happened, cos (name) was left on his own in that main conference hall, he didn't know where we went – cos it was time to go off for lunch, and he didn't know where everybody disappeared to.*

The role of non-disabled allies

It became evident as soon as the interviews started, that The Lawnmowers actors do not necessarily see as clear a distinction as I had assumed at the outset of Mutual Support between support from others with learning difficulties and non-disabled people who are part of the group. Some examples were given of direct support from non-disabled allies. However, it has also been evident that the ethos of support within The Lawnmowers is based upon enabling people with learning difficulties to support one another as much as possible, with an emphasis on empowerment and choice within autonomous relationships.

This is reflected in the following quotation, which refers to how the layers of support needed were constructed when embarking on a trip abroad. Chris refers to the same trip to Graceland which was used as an example of practical support earlier in this

presentation of findings (see page 87). The support was centred on Pete's physical impairment:

> *Chris: Well, um, when Pete, who is a mad Elvis fan, eventually got some money to go to Graceland, I was asked to go to support him, with him not being well, he couldn't have went off on his own, so I was asked would I go as his support, so I supported Pete in fulfilling his ambition....*

Chris was supported himself in order to support Pete, by a non-disabled ally:

> *Chris: plus, I was supported by J [non-disabled ally] , cos I felt, with Pete not being well, it was a big responsibility for me, to bear myself, so we got some more money so J could come to support Pete as well as support me to support him...(June 2008).*

This "layering" of support is an example of a non-disabled ally supporting someone with a learning difficulty (Chris) in a way which enabled him to then support another person with a learning difficulty, highlighting the issues surrounding the uniqueness of a peer to peer relationship. This quotation, which involves the relationship between the same two people as the previous two quotations, sheds light on the uniqueness of the relationships between two Lawnmowers actors. It highlights the right which Chris has to speak to Pete in ways which would not be acceptable to Chris if coming from someone else.

> *Chris: me and Pete go back years, right, I call him worse than muck, right, but if anyone else calls him, I'll smash their face in. So that's it, it's just the way I feel, like about Pete, cos at times I could throttle him, but, in saying that, I wouldn't let anyone else hurt him, cos he's a really good friend (June 2008).*

What The Lawnmowers want others to know about how they support each other

This final section of the presentation of themes emerging from the interviews with The Lawnmowers focuses on what the actors who were interviewed want other people to know about how they support one another. This section brings together the previous sections and is of particular relevance in the context of the Mutual Support Research project as it reflects an aim of the project: telling other people what people with learning difficulties want them to know about how they support one another.
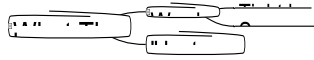
Mind map eight: What The Lawnmowers want others to know

We do support each other

The Lawnmowers want others to know that they work well together as a group. Within Chris' quote there is an emphasis on the fact that the people within this working group all have learning difficulties:

> *Chris: Just, as a good working group, cos all of us have got learning difficulties (June 2008).*

Dean develops this idea further, referring to the strength of the group which stems from the supportiveness within it:

> *Dean: I would want them to know that The Lawnmowers are a very tight-knit group, and that The Lawnmowers, throughout the whole company, we're all now very supportive of each other.... (June 2008).*

Chris highlights the fact that people might think that is not possible. His evaluation of this prejudice is two-fold: thinking it can't happen and thinking people with learning difficulties wouldn't know how to support each other:

> *Chris: and if they might think "oh, people with learning difficulties can't support each other, or might not know how to support each other" .....(June 2008).*

This quotation relates to two aspects of Mutual Support which this project has demonstrated: people with learning difficulties have both the potential (can support one another) and have also applied that potential (they know how to support one another) in complex settings and in varied ways.

The Lawnmowers are evidence that people with learning difficulties can and do support one another. Chris recognises that people from outside seeing The Lawnmowers' support for each other might be challenged to re-think assumptions around capability and confidence:

Chris: but then once they see us supporting each other, they might change their attitude, and think "eee, I didn't think they could do that," or "I didn't think they would have the, is it whereforeall?, or the confidence to do that" (June 2008).

Dean recognises that not all groups experience the support The Lawnmowers enjoy, appreciating the group and also recognising the future of support within the group must not be taken for granted:

Dean: And obviously not all groups are like this, so we're lucky to have the group that we have, and you've just gotta kind of, I suppose cross your fingers that we'll stay this ways for quite a while (June 2008).

<u>"Just a general day" involves supporting each other</u>

Dean stated that:

in a general day of doing The Lawnmowers and doing the show, you always support each other and support everyone (June 2008).

He also stated that this is evident to others looking on from outside, including the support given to others outside of the core group:

Dean: the way that we support each other comes across to people, and we think "oh, they are a very strong group together," cos they're so supportive to each other, and obviously others (November 2008).

Peer Mentoring at The Lawnmowers

From September 2009, the focus of The Lawnmowers' daily activities has shifted. They have streamlined the number of performances on their schedule with the aim of consolidating the work which they have done through developing training courses. During 2009-2010, the core actors are formalising their skills through courses which reflect the organisation's activities, such as filming and planning a celebration. The actors who have completed all ten courses and also an ambassador's course will become ambassadors for the organisation.

The overall aim in the next three years is that these courses will be delivered by the core members themselves for people who are interested in the Lawnmowers' work. Thus, a programme of peer mentoring should evolve. This initiative was not established enough at the time of data collection to include the actors' views and accounts. I made

note of this in the thesis in order to reflect the emphasis on peer mentoring within the medium-term goals of the organisation.

Mutual Support at The Lawnmowers: Summary

The key points which emerge from conversations with four actors about support given and received within the context of an Independent Theatre Company delivering Theatre for Change begin with accounts of practical support. These include support with day-to-day activities such as preparing for performances, going shopping and staying overnight for convenience. This support sometimes extends to travelling, both within the UK and abroad. The group expect that support would be extended to newcomers, including explaining support mechanisms to the newcomer.

The presentation of findings then moved on to support on a deeper level, and ways in which The Lawnmowers support each other when upset – the data includes an example of support when someone with relatively complex needs was distressed. Examples were also given of ways in which the group encourage each other in preparing for and delivering performances – specific evidence of this happening on the day of the performance at Northumbria University were given. This encouragement has also been extended to supporting people in fulfilling ambitions.

Being part of The Lawnmowers has opened up new opportunities in life for the actors. Examples of this include getting an individual budget, union membership and support for family members. Similarly, through their activity and their ever-growing network, The Lawnmowers extend support to other people with learning difficulties. The actors spoke about this happening through other people seeing their performances, night clubs and social events, union representation, and workshops for employers.

The concept of people with learning difficulties as educators is part of the Mutual Support model of peer support and people with learning difficulties. The Lawnmowers' work also enables people with learning difficulties to become educators, through presenting their views about what matters to them. The performance at Coach Lane provided detailed evidence of this.

It must be noted that there were examples given of times when people within The Lawnmowers had not felt supported by others. This will be dealt with further in the discussion on findings section of this thesis, Part Three Section One. When considering the role of non-disabled allies within the conceptualisation of Mutual Support, the data provided evidence for a "layering" of support which enabled one actor

to support another whilst he himself received support from a non-disabled supporter of the group. The Lawnmowers who took part want other people to know that they can and do support each other, that supporting one another is central to their day-to-day activity, and that the attitudes of non-disabled people need to be challenged in this area.

The findings section of this thesis now moves on to present the themes which emerged from the data collected from people with learning difficulties who took part as students or facilitators in the Understanding Research course.

MUTUAL SUPPORT AND
THE UNDERSTANDING RESEARCH COURSE

This section is a presentation of the data collected in relation to the Understanding Research course at the hospital. It includes data from individual interviews with three students (Dan, Simon and Liam) and also data from a group discussion with the facilitators of that course entitled "Becoming Educators". There are three sub-sections to this presentation of data, beginning with a presentation of themes around teamwork. As the focus of this data collection was an educational course, participants spoke about the processes of teaching and learning. The second section draws out these themes, specifically in relation to accounts of support given and received in the teaching and learning process. The third section relates to how participants viewed what they had achieved from doing the course, and their plans for the future, providing evidence for the effectiveness of the peer mentoring/education which was a central aspect of the course.

The evidence which emerges from the interviews with the students sheds light on their experiences of teamwork within a learning situation which was facilitated by people with learning difficulties. Overall support within the course came from Dr. Tina Cook and Dr. Pamela Inglis. Hospital staff were also present at the course sessions and supported the men in between meetings. The role and purpose of this support will be explored in the discussion on support from non-disabled allies (see Discussion and Evaluation of Findings Part Three Section One, page 143 and page 160 of Part Three Section Two).
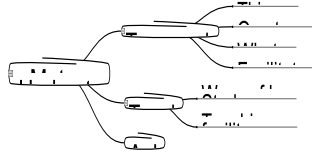
Teamwork

A strong theme which emerged from the students' accounts of the course was that of teamwork. The sub-themes which emerged relating to teamwork are divided into four sections: things that we did as teams, one-to-one support as part of the team, what makes a good team, and facilitators' reflections on teamwork. The use of team/group work created an interactive learning situation. The facilitators in particular reflected on this interaction as an ideal way for using the different strengths and weaknesses which each person brought to the learning situation, adding value to it.

A strong theme which emerged from the students' accounts of the course was that of teamwork. The sub-themes which emerged relating to teamwork are divided into four sections: things that we did as teams, one-to-one support as part of the team, what makes a good team, and facilitators' reflections on teamwork. The use of team/group work created an interactive learning situation. The facilitators in particular reflected on this interaction as an ideal way for using the different strengths and weaknesses which each person brought to the learning situation, adding value to it.

Things we did as teams

This section outlines the examples given by the students of working together as teams. The specific emphasis is on the support which being in a team provided students in relation to the interactive learning process. The three students all spoke about working

in teams. However, I do not know at what point the three students were part of the same team.

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                                          │ Explaining/discussing │
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│ ⊟ Things we did as teams  │             ╭──────────────────────────────╮
╰──────────────────────────╯             │ Working as a group: ground rules │
                                          ╰──────────────────────────────╯
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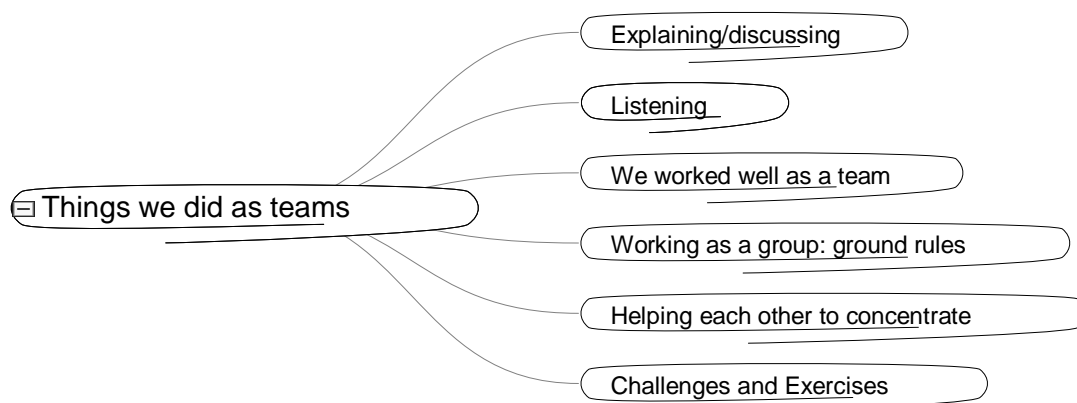
Mind map ten Understanding Research – things we did as teams

The above mind map outlines the areas in which the students spoke in relation to teamwork. The insight the students give into teamwork is significant when considered in relation to the assumptions that people with learning difficulties lack the capacity and insight needed for interpersonal interaction. The aspects of teamwork which relate to respecting and listening to one another are also significant when considered in the light of the lack of respect and voice which people with learning difficulties are often shown. The reclamation of dignity and respect through peer support will be explored further in the discussion on findings section (see page 168-169).

Explaining/discussing/talking to each other

As an example of this respect for one another, the students spoke about talking to each other, and this included explaining and discussing the tasks within the course:

> *Simon: We helped each other, write things down, people in the group saying it's like a detective, and like a jigsaw puzzle.....talking to each other (first interview).*

Listening

Simon also spoke about listening within the team context:

> *Sarah: You said you talked to each other, can you think of anything else you did to help each other?*

> *Simon Um, listening to each other.*

Sarah: You listened to each other. Can you think of a time when that happened?

Simon: All the time (first interview).

Liam related this idea of listening to joining in with activities:

Sarah: what helped you to join in?

Liam: By listening (second interview).

We worked well as a team

Within the team situation, students related the listening and respecting others within the group to turn taking within that group. This quotation also speaks about feeding back to others in the group about what they had said:

Sarah: You were saying about people respecting each other, and listening – did you feel that happened within the group?

Dan: Yes.

Sarah: Can you think of how that happened......?

Dan: If one person was speaking, then the rest of the group would stay silent until they were finished, and then they would take their turn. And tell you about what they thought about what you said, and how you'd been doing your research and things like that (first interview).

Within the account of activities, there was an emphasis on working together:

Liam: We did that one - sitting round the table...

Sarah: It sounds like you did quite a lot of that – working together?

Liam: Yes, we did a lot of working together (second interview).

It is important to counteract the natural inclination of anyone being asked about working in a group to only speak about things that worked or went well. I made sure there was an opportunity for the students to speak about times when things had not gone so well:

Sarah: Did it ever not happen, within the group situation, that people didn't respect each other?

Dan: Sometimes, but not often, it was only once in a blue moon (second interview).

<u>Working as a group: ground rules</u>

There was an emphasis on the use of ground rules within the group. Again, there was an emphasis on respect, specifically with regard to not disclosing what had gone on to others, especially within the hospital:

Sarah: You said earlier on about setting group rules and ground rules – um, can you tell me a bit about that, what the ground rules were?

Dan: Just to respect each others' wishes what was said in the room had to stay in the room – like we're doing now, um, listening to each other, one person speaking at a time, um, no swearing, no bullying, but both of them go without saying (first interview).

The facilitators told me during an advisory group meeting that clear support mechanisms were in place for instances where students needed to speak to someone about an incident outside of the time allotted for the course: this usually involved a staff member who had been there at the sessions.

<u>Helping each other to concentrate</u>

Liam spoke about how his group supported each other if people in the group were finding it hard to concentrate.

Sarah: Was there ever a time when you didn't work well as a team?

Liam: There was times when people couldn't concentrate you na[10], that was really hard..........

Sarah: What happened then?

Liam: We had to get them to concentrate...... (first interview).

I followed this up at the second interview.

Sarah: One thing that we talked about last time, which I wanted to ask you a bit more about, was how you helped each other to concentrate ....what would you do?

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[10] Geordie phrase: 'you know'.

Liam: Tell them to try and focus on what we're doing in the group, in the room, and concentrate. Cos some people they might be too busy listening to like noises outside the room, and we were just trying to get them to concentrate, just telling them to ignore the noise that was going on and to concentrate on what we were doing in the room (second interview).

The above quotation is an example of a student showing awareness of difficulties that another student had which specifically related to learning. He also had ideas of how to support the person to overcome that difficulty.

<u>Challenges and exercises</u>

The focus of the course was challenges/exercises. When asked about the activities within the course, the responses emphasised the teamwork element of activity.

Sarah: Just going back, cos it's quite a while ago that you did the course, can you tell me a bit about what it was like, what you remember?

Simon: We were like in a big room, across the canteen area, we met on a Friday, and we were all, helping each other, we were in groups, talking.

Sarah: What did you do in the groups?

Simon: Um, we did a lot of challenges, and we were doing a lot of things, exercises (first interview).

The activities involved examples of processes that are part of research activity. Liam focussed on an activity which involved making choices as a team. It is an example of making a decision when that decision is complicated by different people wanting different outcomes:

Liam: We had two teams, and one team decided on a pizza, and one team had to decide something else, I forget what.

Sarah: So were you on the pizza team, yeah?

Liam: Yes.

Sarah: What did you do?

Liam: We decided to have a pizza, but not everyone – we decided initially we'd have pepperoni, but then we decided that not that many people liked pepperoni,

so why not pick some other pizza, you know?

Sarah: So, you've got some people who like pepperoni, so you might have a bit of the pizza with pepperoni (drawing segments etc).

Liam: Some people like pepperoni, but some people might like cheese and tomato on it.

Sarah: How did you decide in the end what pizza it was that you were going to order?

Liam: We just went back and forth, seeing what the other lads wanted.

Sarah: Do you think that you decided about the pizza as a team, or do you think one person....?

Liam: No, we decided by the team really... (first interview).

Having outlined what the students said about working as a team, the presentation of data now moves on to explore instances of one-to-one support, both given and received, within that team situation.

One to one support as part of the team

There is potential for overlap between this section and the previous one. The distinction has been made between accounts of working together as a team and examples which were given of specific instances in which one person received support. Some of the accounts within the data were about giving support, others were about receiving it.
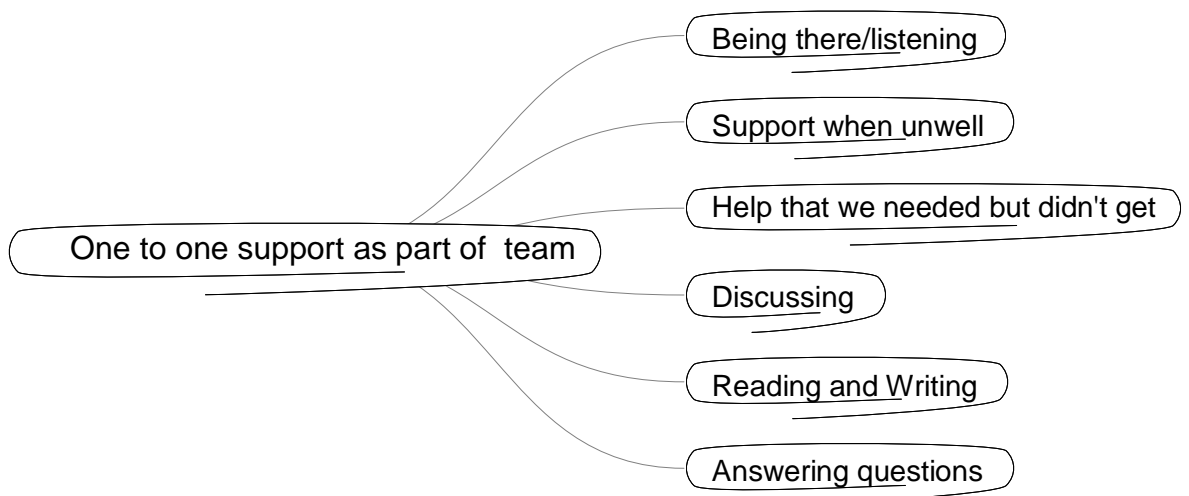
Mindmap eleven. Understanding Research: One to one support as part of a team

<center>Being there/listening</center>

Dan extended the quotations about listening to one another within a learning situation to instances when someone is finding things hard. Again, it must not be forgotten that Dan is speaking from the point of view of being part of a group of people who, historically, have not been listened to:

> *Sarah: What's the best way to support someone who is finding things hard?*

> *Dan: Just be there, for someone to listen to. Somebody to talk to, or to listen to, be there for them. That's the best way (first interview).*

<center>Support when unwell</center>

The following quotation from Dan relates a specific example of support given to an individual within the team context. I have left the conversation which took place prior to the specific account as an example of how conversations with the students often started on relatively abstract subjects but then focussed in on specific events:

> *Sarah: Can you think of other things you did as a team when you were doing the course?*

> *Dan: Um, we supported each other and like I say we respected each other's wishes.*

> *Sarah: Can you tell me about a time when you supported someone else in the group?*

> *Dan: Um, well not long after the research course started, when one of them was bad[11], I was helping him go through his things, cos he didn't understand what was happening.*

> *Sarah: So what did you do then?*

> *Dan: Just keeping him, with his temperature down and that, and we got advice off the staff and that, and just kept trying to give him plenty fluids (first interview).*

Dan recognised that his peer needed support in relation to catching up on understanding within the course as well as care for his illness. He also recognised the need for advice from staff.

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[11] Geordie phrase referring to illness.

<u>Help that we needed but didn't get</u>

I asked all participants if there had been instances of them or somebody else needing support but not getting it:

Sarah: Was there any help that you needed that you didn't get?

Dan: No.

Sarah: None at all?

Dan: No, any help I needed it was there.

Sarah: Was there any help that you think anybody else needed that they didn't get?

Dan: I don't think so.

Sarah: Was there a feeling in the group that you could ask for help if you needed it?

Dan: Yes.

Sarah: And people were asking for help?

Dan: Yes, they were (Second interview).

Sarah: Was there any help that you needed at all during the course that you didn't get?

Simon: No, not really, all the help we had was OK.

Sarah: Do you think there was anyone else doing the course that needed help they didn't get?

Simon: Everyone was OK (Second interview).

<u>Discussing</u>

I asked Liam what he had done as part of the team in order to help others. Again, discussing things within the team as part of the learning process was important:

Sarah: Can you remember something that you did to help someone in your team?

Liam: Na.

Sarah: What were you good at that maybe you could help the other people with?

Liam: Discussion – like talking to people about it and that. ...Telling people what it was about and all that ..... (first interview).

<u>Reading and Writing</u>

Within the learning process there was an emphasis on supporting one another with reading and writing. The facilitators spoke about the effectiveness of mixing up the teams with people who could and could not write. This pooling of ideas and strengths and weaknesses will be returned to later in this presentation of findings:

Sarah: Do you think there's anything we haven't talked about, to do with support that you either gave or other people gave you when you were doing the course?

Dan: Just that we supported each other, like with spellings and that, if we cocked it up, pardon the expression (First interview).

This quotation from Liam speaks about the two-way "helping each other" which took place:

Liam: Other people helped me, we helped each other really, see some people couldn't write, and spelling and that, we just helped them (second interview).

<u>Answering questions</u>

Simon had spoken earlier in the interview about asking each other questions. When I followed this up, he related it to reading and writing.

Sarah: So we talked about asking questions, did anyone ever ask you any questions?

Simon: Some, in the group.

Sarah: Can you remember what kind of questions?

Simon: They asked me to spell things (first interview).

What makes a good team?

Having outlined the students' views on working as a team and support given and

received as part of that team, the presentation of findings now moves on to outline insight and views expressed by the students about what makes a good team. This section relates to specific views of participants as to what makes a good team.
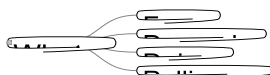
Mindmap twelve. Understanding Research: What makes a good team?

Much of this reflection was based around my mapping out on separate bits of paper what participants said as we went along about what makes a good team or a bad team and asking them to add anything we had missed.

Focussing on the task

Dan spoke about the importance of clarity in what the group is setting out to achieve.

> *Dan: Knowing what you're doing, how you're doing it and the way you're doing it...... (first interview).*

Liam also spoke about the potential efficiency of teamwork, showing an awareness that working together on a task can enable faster completion of that task:

> *Liam: Working as a team, cos you get through it quicker (first interview).*

Depends on who you are working with

Within the reflection on teamwork, both Liam and Dan highlighted the influence of who is in the team on the outputs of that team:

> *Sarah: How does a good team work together, do you think?*

> *Liam: It works alright, as long as you've got good sensible people (first interview).*

> *Dan: But it also depends who you're working with......(first interview).*

These quotations echo an insight into the complexities of interpersonal interaction within a team situation and the effects that people within the team have on the team as a whole.

A further idea which emerged was that of responsibility within the team to other people in that team:

> *Sarah: Is there anything else that's important, to be part of a group?*

> *Dan: Doing what's asked of you.*

The theme of doing what's asked of you was also relevant to Simon, who highlighted the need to "be bothered" – and turn up for meetings:

> *Simon: Not being bothered, not going over to meetings, not turning up (first interview).*

Having explored the themes of teamwork in relation to the students' accounts of their experiences, and the insight which they provided into how they worked as teams and the values that are important within a team situation, the presentation of themes now moves to the facilitators' discussion of teamwork. The quotations in this section are taken directly from a discussion which centred around the facilitators' experiences of gaining University accreditation for their work as peer mentors.

Facilitators' Insights into teamwork

The four facilitators are speaking about working as a team. Both the facilitators and the students spoke about themselves in separate teams (either one of the teams of students or the team of facilitators). Therefore, the data which is presented in this section relates to the same learning activity but not to the same teams as those spoken about above.
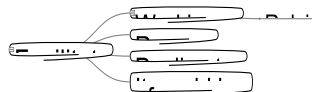
Mind map thirteen. Understanding Research: Facilitators' reflections on teamwork

The focus of the discussion was that of peer mentoring/education. This will be explored further in following sections. However, within this section of the discussion, the facilitators also spoke about working as a team.

Working as a team was most important

One facilitator stated that working as a team was the most important element of the work they did, developing trust within that team where different people worked on different elements of the tasks. The facilitators also spoke about "playing to each others' strengths", remaining aware of things that each team member finds easier or harder than others in the group:

> *Facilitator: I think that was the most important thing, working as a team, relying on each other for trust, to do one part of the research, and others like another part of the research, and working in groups...(September 2008)*

Responsibility within a team is important

The facilitators spoke about how they worked as a team when gathering the information they needed. This sharing of work was dependent on others in the team taking responsibility for their role:

> *Facilitator: Also having a good bunch and that, working with a good responsible team, to keep that information, the information that you need (September 2008).*

....and an awareness of their importance to the team:

> *Facilitator: Because if somebody could come to you with the wrong information, then it chucks the whole lot away....(September 2008).*

This relates to the above quotations from Dan and Simon about responsibility within a team.

Pooling together of ideas and information

For the facilitators, this responsibility extended to the context of supporting each other and pooling information:

Facilitator: It were also nice to know that you were in a team. And that if you didn't get a piece of information, there was somebody there that backed you up (September 2008).

Like the students, the facilitators made use of discussion within a supportive team, with the extent and range of the information resulting from the group discussion being added to as a result of that discussion:

Facilitator: And we often found that in the discussion we came up with even more than we thought of at the beginning (September 2008).

<u>It would be different if we did the same thing again with a different group</u>

The facilitators' experience of working as a team themselves and then supporting others to work in teams gave them insight into different teams working in different ways. This was emphasised in the reflection on what might happen if they were to repeat the course with a different group:

Facilitator: I would like to do this course again with a bunch of different lads, the reason I'm saying that is it would be interesting to see what they'll come up with (September 2008).

A different group would come up with different ideas:

Facilitator: And I daresay if we tried it with a different bunch of lads, maybe two or three different lads, the course would be totally different, it would be very interesting because, just to see what they would come up with (September 2008).

This would enable the facilitators to learn more themselves:

Facilitator: we could learn something from that, and we could say "maybe we could change that" (September 2008).

.......and to develop the course further:

Facilitator: and we could say "we could change it this way" and we could add bits to it, and it would give them a bit of help and it would give us a bit of help (September 2008).

Through the feedback meeting with this group of men, it became evident that part of their development as peer educators was a result of the way in which students

engaged with activities. This sensitivity to the strengths of a two-way learning process will be considered further below.

Understanding Research: Teaching and Learning

The focus of this presentation of findings now moves to the activity at the centre of the Understanding Research Course: teaching and learning. It begins by presenting the students' views on ways of learning, including a section on what the facilitators did to support students in learning. The second section draws on the facilitators' experiences of Becoming Educators and the skills which they used when supporting others to learn.

The first section of the presentation of data relates to teamwork and interpersonal interaction. This teamwork took place within a teaching and learning situation, meaning that where specific examples were given they related to the activities within the course. This section explorers further the teaching and learning within that context, exploring what the students said about how they learnt within the team situation. The ways in which the facilitators supported the students in learning is of particular relevance to the discussion within Mutual Support.

Ways of learning: students' reflections
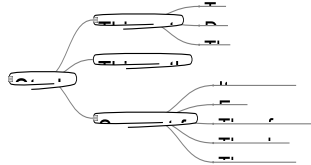
Mindmap fourteen: Understanding Research. Ways of Learning. Students Reflections

Things that helped with learning

I asked the students about the things which helped with learning within a team situation. Their responses included talking, drawing and use of the DVD which The Lawnmowers had produced.

Talking

Liam spoke about talking to one another, especially when explaining something new to someone. When I followed this up at the second interview, he spoke about being able to get the message across through talking:

> *Sarah: How you might help each other in a good team? If you were wanting to learn something new..?*
>
> *Liam: Talking. Talking about it (first interview).*
>
> *Sarah: Do you think you can help each other more when you're talking about things?*
>
> *Liam: Yes, you can put it across more clear (second interview).*

<u>Drawing</u>

Simon also said that drawing can be a useful way of explaining something to others:

> *Simon: You can draw everything. It's good, if you can't write to draw* (first interview).

I increasingly sought to make use of drawing things that we were talking about in the interviews, also making use of clip-art between sessions in order to follow up what had been talked about.

<u>The DVD</u>

The Understanding Research course also made use of a DVD in order to introduce the concepts which were being explored. This DVD used actors from The Lawnmowers Independent Theatre Company.

> *Sarah: Can we think a little bit about what helped you to learn, what helped you to join in? Cos this might be useful, if you're going to facilitate another group, to think about what helped you to learn within the group.*
>
> *Simon: Everything. Talking, discussion, different things. Definite the DVD.*
>
> *Sarah: That's really useful to know that you found that helpful.*
>
> *Simon: Yes. It helped me a lot, watching the DVDs (first interview).*

Liam also spoke about the DVD as a way of initiating thinking and discussion:

> *Sarah: You watched a DVD, didn't you, in the group? Was that a helpful way to learn?*
>
> *Liam: Aye, cos it was about getting to know the way which people act up.*
>
> *Sarah: So it was giving you a real situation.*
>
> *Liam: And then afterwards we thought about it and we had to tell them what went on and what happened (second interview).*

The use of this DVD, made by The Lawnmowers, is also significant to the overall focus

of Mutual Support. It demonstrates the way in which the strengths of one group of people with learning difficulties was used in supporting another group in this learning situation.

Things that didn't help with learning

All of the participants were asked if there was anything that didn't help them with learning. Liam spoke about the potential difficulties of listening within the inevitable instance of lots of people talking at once:

> *Liam: It is hard to listen when there's loads of people talking at one time, and that's what was happening sometimes. Everyone was talking over the top of each other.... (first interview).*

Support from the facilitators

The students were asked how the facilitators had supported them within the group situation. Their responses highlight aspects of interaction between students and facilitators which the facilitators also referred to. This section of data is highly significant as it provides evidence for the peer mentoring aspect of Mutual Support. The most significant aspects of the facilitators' support in learning were their approachability, the methods they used for explaining things and their commitment to the quality of the course. Overall, the students' perceptions of the facilitators was of them being there whenever they were needed and for whatever reason.

Dan said that it was easy to ask the facilitators for help:

> *Dan: If we weren't sure about something, then we could cut across them and ask them as they were going around and correcting mistakes (first interview).*

Liam highlighted the facilitators' role in explaining:

> *Liam: Like in the beginning, they talked about what we were going to do, in that session, so that everyone was in the room, sat down and talked about what we were gonna do. And that's how we got to know what we were gonna do that day (first interview).*

Liam also spoke about the work which the facilitators did in between sessions, finding information for the students:

> *Liam: they would go away afterwards and bring it back the next week, they'd have it typed up. So they did work in between the sessions (second interview).*

Simon also spoke about the way the facilitators mingled with the students whilst they were explaining things:

> *Simon: And they helped us with our work.*
>
> *Sarah: How did they help you with your work?*
>
> *Simon: Coming round telling us what to do (second interview).*

Dan spoke about the quality of the support which the facilitators gave:

> *Dan: whatever you needed help with they were there for......... I wouldn't have got through it if it wasn't for that group of lads (second interview).*

Teaching and Learning: facilitators' reflections

This final section on teaching and learning within the course outlines the facilitators' reflections on the skills they found useful when supporting others to learn.
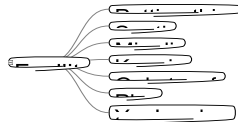
Mindmap fifteen. Understanding Research. Teaching and learning: facilitators' reflections

Putting things in a language they'd understand

The facilitators emphasised the need for accessibility of information, and the need to adapt the format in which the information was presented as the course progressed.

The following quotation tackles the issue of accessibility, with insight into the fact that accessibility issues are different for each individual:

Facilitator: Some of them couldn't read, and some of them couldn't understand what meanings and words meant. So we had to put it into a language where they would understand. And I felt that helped (September 2008).

The facilitators spoke about explaining things verbally:

Facilitator: We didn't do the thing what was suggested, was the pictures, we didn't do that. But we managed to do it in other ways, you know, which helped, you know, like words (September 2008).

They spoke about the need for students to feel comfortable with the way ideas are presented:

Facilitator: And that was really good, to help people to learn, in the way that makes it comfortable for them (September 2008).

And that it was also important that the facilitators felt comfortable as well:

Facilitator: *and it also makes it comfortable for us to understand (September 2008).*

This idea of making sure everyone was comfortable echoes what was said by the students about the approachability of the facilitators.

<div align="center">Seating Arrangement</div>

The process was one of continual reflection on the part of the facilitators. One significant aspect which developed as the course went on was the seating arrangement:

Facilitator: Cos we had one seating arrangement where one team was like where they couldn't read and write, and the other team had more of learning and what they can understand, what can read and write. So we mixed it together, so we got half and half, and that helped (September 2008).

The quotations from students about both giving and receiving help with reading and writing is evidence for the effectiveness of this mixing it together.

<u>Mingling with the groups</u>

The approachability of the facilitators has been described by the students. One of the facilitators explained how they worked as a team to enable this. They spoke about mingling with the students:

> *Facilitator: We also mixed us in with it. Whoever weren't doing the speaking, they were on the floor going round (September 2008).*

They spoke about giving the students opportunities to ask questions or ask for explanations:

> *Facilitator: anybody didn't understand the question, or didn't quite grasp it, or wasn't sure, they had the capabilities to pull us to one side and ask us about it then while the discussions were going on (September 2008).*

This was done in a sensitive way so that people asking for help did not feel too conspicuous:

> *Facilitator: Cos in some cases, we had a lad that that, he weren't very confident, so saying out loud "OK, explain this" were very hard for him to do. So we were walking round, and he had enough encouragement to just pull us to one side and say 'look can you just explain that bit to me, I don't quite get it?' And we would sit down and explain it to them (September 2008).*

The facilitators also spoke about the organisational skills needed when facilitating a structured training course such as the Understanding Research course:

> *Facilitator: One of the other problems we had was they didn't always find the stuff they wanted, in the files. We came up with a number and tagging system for that. To make it easier, so if it were that colour or that shape, it were there – dictionary terms, and we'd tell them what the words mean (September 2008).*

<u>Adjusting the level as the weeks went on</u>

As stated above, reflexivity is a vital element for anyone who is "Becoming an Educator". The facilitators spoke about the need to adjust the content of the course as the weeks went on:

> *Facilitator: Cos the first one was just like trial and error, just to get to see what they were capable of doing. Then as the weeks went on, that was when I picked up on it, as to help them gradually get on to their level, just week by week. Help*

them to understand, help them with their level, to understand, to help us as well. It gradually came into place, though the weeks (September 2008).

<u>Two facilitators going round during any one session</u>

The facilitators also commented on the need to not be too overpowering. They addressed this issue by deciding to have two facilitators present on any one week:

Facilitator: We were just in pairs going down, cos if we'd had all of us together, there'd be too many of us going round and it would just over the top, it would be just overpowering (September 2008).

<u>Planning ahead was important</u>

It was important for the facilitators to plan ahead. This planning was done as a group. This quotation specifically relates to deciding who would work with whom:

Facilitator: We talked about it, like we're here now, we talked about who was going to work with who, and we always had to get together (September 2008).

This example demonstrates how the facilitators worked as a team in between sessions, reflecting on what was and was not working and deciding on changes that needed to be made.

<u>You're always learning when you're teaching others</u>

This final quotation from one of the facilitators demonstrates the two-way interaction within a teaching/learning situation:

Facilitator: You're always learning. Especially if you're teaching other lads. The more you teach, the more you learn. And everybody comes up with different ideas (September 2008).

During the feedback session with this group of men, they emphasised the importance of the students supporting them within the learning process. They stated that the students had supported them by coming up with new ideas and new ways of looking at things. For the facilitators, this was a significant element to the process of "Becoming Educators".

Understanding Research: Achievement/ enjoyment

This final section of presentation of data from the Understanding Research Course looks at the sense of achievement and enjoyment which both facilitators and students expressed at having completed the research and/or course. The data relates to: the achievement associated with having worked as a team, the fears and anxieties which people overcame in order to take part and complete the course, seeing the final result and plans for the future.
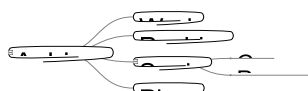
Mindmap sixteen. The Understanding Research Course: Achievement/enjoyment

<u>Working as a team</u>

When asked about the best/most enjoyable part of the course, both Dan and Simon referred to the group/team work.

> *Sarah: What was the best thing about doing the course?*

> *Dan: Getting to know people. Before I started the group there were people there that I didn't know, you na, so I was getting to know them as well (first interview).*

> *Sarah: What did you enjoy most about it?*

> *Simon: Working in a big team, cos when I did it we were like a big team, there was a canny few of we[12], on one big table (first interview).*

<u>Pushing/challenging yourself</u>

Both the facilitators and the students spoke about what they had overcome in order to complete the course. They spoke about this as an achievement.

For the facilitators, their journey included pushing the boundaries:

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[12] Geordie phrase meaning quite a few of us.

> *CETTil Director: Did you think you would be able to do it?*

> *Facilitator: No, I didn't actually in a way, because the reason I'm saying no is because it's you're pushing yourself to another further limit...(September 2008).*

And challenging themselves:

Facilitator: are you going to challenge yourself over what you expect to do? (September 2008).

This, in the end, led to a sense of achievement:

> *Facilitator: but then again, we've achieved it. It was hard, but we've done it...(September 2008).*

One of the facilitators expressed his growing confidence through the journey:

> *Facilitator: then when I realised there were bits I could do, I started to fly, and then when I moved into teaching other men like myself, I were soaring in the skies. It was just an amazing achievement to know that stuff I'd put together, stuff that I had a part of in a team, was getting used, to teach somebody else. And it was just really, really fantastic (September 2008).*

<u>Seeing the final result</u>

For Dan, a sense of achievement came from seeing the final result. This was symbolised by the certificate he was awarded:

> *Dan: cos Tina told we[13] that if we had passed the course we would get a certificate........... When I first got them, I couldn't believe I'd passed the course, the when Tina came to give us the one in the cover, I knew I had done (first interview).*

For the facilitators, part of seeing the final result has been speaking about their experiences as conferences. The opportunities they have had to tell others about their experiences have gone one step further in breaking down barriers to Inclusion:

> *Anything I think if you go to conferences and speak at conference meetings, I think you get like there's something there even bigger for you, like a goal (September 2008).*

<u>Plans for the future</u>

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[13] Geordie pronoun 'us'.

When asked about their plans for the future, all three of the students said that they would like to become facilitators themselves:

> *Sarah: What would you like to do now, with what you learnt?*

> *Simon: I asked Pam and Tina, for you know to do like a facilitator course.... A couple of us still want to do it (first interview).*

> *Sarah: It's a while since you did the course, what would you like to do now to maybe build on what you did on the course?*

> *Liam: Me?*

> *Sarah: Yes.*

> *Liam: Be a tutor (*first interview).

Mutual Support and the Understanding Research Course: Summary of findings

This section is a summary of findings from the exploration of peer support within the Understanding Research course. The students worked as teams, supporting one another to learn. This included discussion and listening to each other. Teamwork was based on ground rules which encouraged respect and support for one another. Within the team, support from individuals was both given and received. This included being there and listening, as well as support with tasks relating to the learning situation.

Students who were interviewed spoke about responsibility and focussing on the task within a team. The facilitators also drew upon the strengths of being in a team. They spoke about pooling ideas, relying on one another. The course made use of a DVD which The Lawnmowers had made. This illustrates the use of The Lawnmowers drama work in supporting other groups of people with learning difficulties to learn. The students valued the support from facilitators. In particular, they spoke about their approachability, specifically in explaining things as they mingled.

The facilitators' experiences of peer mentoring provided a framework for future peer mentoring. This included sensitivity in making the learning accessible for the students, and the need to adjust the content and the way it was delivered, as the course went on. The facilitators' reflections on what they had learnt from the experience demonstrated the two-way aspect of their teaching and learning experience. The sense of

achievement and enjoyment which students expressed was centred around the teamwork aspect of the course. All three students expressed a desire to become facilitators themselves in the future. This demonstrates the effectiveness of the venture and the potential for future peer mentored learning.

Presentation of findings: Conclusion

This section of the thesis would not be complete without an account of a presentation given at the CETTII (Centre for Excellence in Teacher Training for Inclusion) conference at Northumbria University in March 2009. Following the recording of the "*Becoming Educators*" discussion (which has been used as data in Mutual Support) audio quotations from the men had been made into a Power Point presentation. At the conference, parts of this presentation were shown. Professor Dan Goodley then presented the men with their certificates, formally recognising the University accreditation which they had worked so hard to achieve.

The most meaningful aspect of the day for myself and many others who were there then followed: other groups of people with learning difficulties, led by The Lawnmowers who had involved the audience in some Forum Drama at the beginning of the day, gathered round the men and congratulated them. For me, this symbolised the coming together of the two main settings within Mutual Support. Until that point, with the exception of the use of the DVD in the Understanding Research Course, the Mutual Support which I had found out about had been intra-setting (separately within each setting). This brief exchange was Mutual Support inter-setting (between the two settings).

A further example of inter-setting support has been The Lawnmowers' use of the facilitators' files. These files had been used by the University as evidence of the accreditation process. The Lawnmowers borrowed their files in order to view examples of good practice on which to base University recognition of their courses. This symbolism of the crossing of paths, portrayed by the coming together of people from the two settings in this way, is the point at which this thesis now moves on to Part Three. It will consider Mutual Support through the evaluation of the rock which has been constructed. A detailed discussion of the findings is followed by a discussion of the methods used in the project.

PART THREE:
Evaluating Mutual Support

Having outlined the process of the construction of the Mutual Support model of peer support and people with learning difficulties, and having presented the themes which emerged from the construction in Part Two, this thesis now moves on to evaluate 'the rock' constructed through the research process. This evaluation includes feedback and evaluation from participants, a discussion on the findings leading to the conceptualisation of Mutual Support and an evaluation of the methods which were used in the research.

Part Three Section One is an outline of the views expressed by people with learning difficulties at the feedback and evaluation sessions. These sessions involved the facilitators/advisory group from the Understanding Research course and The Lawnmowers. This section of the thesis uses the views expressed at these meetings to critique and build on the themes that emerged from data analysis. It is at this stage of the thesis that I begin to bring together the themes that emerged from the two settings.

Part Three Section Two builds on this critique, exploring the nature and impact of Mutual Support before moving on to evaluate Mutual Support in the light of research on peer support from other settings. The final section of Part Three Section Two relates the emerging model to the social model of disability.

Part Three Section Three is an evaluation of the methodology and methods used in Mutual Support. It begins by evaluating the research process in the light of the five aspects of Walmsley and Johnson's (2003) definition of inclusive research. This is followed by a detailed discussion of the ethical issues raised at each stage of the research process. These discussions lead to an outline of the limitations of the research process, and recommendations for future research.

PART THREE SECTION ONE:
Evaluation and Feedback by The Lawnmowers and the Facilitators

This section is a bridge between Parts Two and Three of this thesis. In Part Two, the focus was the construction of Mutual Support. Part Three evaluates it. This section is based on the feedback meetings which took place in October 2009. The meetings were an opportunity for participants to evaluate the findings, through discussion of the ideas I presented to the groups in the form of statements or questions. As the sessions were an important aspect of the inclusive research process, it was important that they were as accessible and interactive as possible. The statements were accompanied by pictures in order to spark discussion. Outlines of these meetings can be found in Appendix F (pages 272-277).

Purpose and Overview of meetings

I met with The Lawnmowers twice. These group sessions involved three of the actors who had been part of the formal data collection and also four other people with learning difficulties who are taking part in the courses. The Artistic Director and Krokodile Krew Project Manager were also present. I also met once with three of the facilitators from the Understanding Research Course who had also been on the advisory group within that setting.

Overall, the ideas which emerged from these sessions confirmed what had been found already, sometimes shedding more light on certain topics. I recorded all of the meetings, though only have permission to quote directly from the meeting with The Lawnmowers. In this section of the thesis, where the views expressed by the advisory group from the Understanding Research Course are cited, I have sought to represent the views expressed as accurately as possible but the views outlined are not direct quotations.

There were several related purposes for the meetings in both of the contexts:

- to feed back significant themes which had emerged from the data project so far, asking people in the groups what they thought
- to clarify aspects of the findings, such as the role of non-disabled allies
- to create an opportunity for the groups to add to anything that might have been missed (in the case of The Lawnmowers, this included my being brought up to

date with relevant developments, such as the introduction of The Round Table meeting and the first few sessions of their courses)

- to mark the end of the active research, thanking those at the meetings for all their time and effort

The meetings were an important aspect of the mutual construction of knowledge within Mutual Support, and an inclusive approach to research. By this stage, I had spent considerable time away from the people who had taken part, analysing data, conceptualising themes and writing up this thesis. It was therefore essential at this point to return to the participants, validating and developing the findings based on what they thought about the themes.

Within this section of the thesis, I have outlined the important points from all of the meetings. I have not organised them within the themes of the previous findings section as one of the purposes of this section is to begin to bring the themes from the two settings together. This will be developed much further in the discussion on findings section, Part Three Section Two.

At The Lawnmowers, the first two elements of the first feedback meeting involved general expression on views about how the members of the group support each other. An image of this expression can be found in Appendix G (page 278-279). The following quotation from the Krew Project Co-ordinator sheds light on what she thinks about how people support each other:

> *I think the group supports each other really well, and I think that yeah, when we work together, when we do a club or when we do a School for Fools show, everyone's absolutely there, and really tight, and really looks out for each other, and takes an equal role. They work, from getting the set together, to putting it up, to putting it down. People work long hours, and give a lot to The Lawnmowers, and I think...people come to each other with their problems, we always look out for each other, I think that everyone's really supportive to each other – really supportive, and always goes the extra mile, to make something really good (October 2009).*

There are several themes emerging from this quotation (from a non-disabled ally who had not previously been involved in the project) which confirm or build on ideas from the actors: working together on performances and social events. Her reference to times "when we work together" refers to a team situation in which all involved are an important part. Specifically, she refers to the "tight"-ness of the group, with everyone

looking out for each other, coming to each other with problems, people taking equal roles within the company's work schedule and working immensely hard. She also states that the support given and received directly affects the quality of the final product.

One of the group, who had not previously been part of Mutual Support, reflected the themes of improving life opportunities and fulfilling ambitions:

> *cos they help you develop your, like independence, and communication and just learning better things. Doing DJ and stuff and that, and it's really good. Definitely (October 2009).*

The above quotation refers directly to the development of independence through being part of The Lawnmowers, and also the development of new skills.

<u>Working together: playing to each other's strengths and weaknesses</u>

I asked the facilitators from the Understanding Research Course about the way in which students had worked in teams for lots of activities within the course. They picked up on the positive effect of playing to the strengths of different people within the team. They spoke about muddling the teams up according to strengths and weaknesses. An idea which I had not fully articulated prior to this was that, within the group's strengths and weaknesses, it was not a case of having a "strong" person or a "weak" person, even when the activity was the same. The men described ways that different people within the team were strong or weak in relation to the nature of the issue being tackled as well as the task being set, and that using these strengths and weaknesses required reflecting on and mixing up the groups accordingly.

The Lawnmowers also spoke about different people having different strengths:

> *Grace: I agree that we all have strengths, and I agree that we are all very supportive of each other.....(October 2009).*

Again, Grace's insight into teamwork is two-fold: the important dynamic of different people having different skills, and the need to support one another within that.

Within this, there was an emphasis on everybody being included:

> *Core member not previously involved in Mutual Support: yes, we agreed on it, in the case of like everybody should be included, it looks like everybody's included in this [picture], you're getting into the swing of joining in and stuff like*

that. So, in my view I think it's important to have that support cos everybody wants to be in it, they want to try new stuff, they want to aim for their ambition if they can get. I definitely agree with that (October 2009).

The above quotation addresses two important aspects of Mutual Support. Firstly, the actor refers to the importance of everybody being included, specifically in relation to joining in. He goes on to refer to the support needed in order to join in, to try new things and to fulfil ambitions.

Learning through discussion and reflection

The facilitators from the Understanding Research course backed up what the students said about the discussion which resulted from working in teams being a strength of the learning process. The men also spoke about one of them taking notes during the sessions so that as a team of facilitators they had a record of the meeting on which to base planning for subsequent meetings. The Lawnmowers also spoke about learning through reflection as part of their courses and the learning process which will lead to them becoming peer mentors. Within the idea of "learning through reflection" both groups highlighted this important aspect of a meaningful learning experience, especially when working as a team.

Another aspect of team dynamics which the facilitators referred to was the role of the students' ideas in supporting them to develop their ideas and approach to peer mentoring within the course: the different feedback from different groups was important. This included the team dynamics and the information the groups were coming up with. This echoes the previously quoted reflection from one of the facilitators that if doing the course again with a different group of men, different ideas would emerge, leading to new directions.

The facilitators also spoke about the way in which students often needed the facilitators' input to get going on a task, but then the facilitators took a step back, seeing what they could learn from it as well as enjoying watching the students grow in confidence. This insight from the facilitators shed more light on what the students had said about support from the facilitators. They spoke about their amazement when the teams were applying themselves to tasks: it was fantastic. It was important to the facilitators that they had given the students space in order to find answers for themselves.

The role of non-disabled supporters

An issue which I wanted to tackle with the group from the Understanding Research Course was the role which Tina Cook and Pamela Inglis had in the support mechanisms behind the course. The facilitators confirmed the significance of Tina and Pamela's role in supporting them as they developed their skills and ideas. They spoke about the importance of getting the right support, referring to the guidance and encouragement which enabled them to rise to new challenges.

They also stated that the idea of "playing to each others' strengths" had come from Tina and Pamela, bringing them together as a team. They had then applied this idea in their roles of facilitating the other teams. The men were sure the whole venture would have fallen to pieces without Tina and Pamela. I also asked them about staff support. In addition to the staff role in supporting students between sessions, they spoke about the staff being there to step in if there was anything the students didn't agree about.

Layers of support

When taken together with one of the students' statements that they would not have got through the course without the facilitators, the role of non-disabled supporters within the course fits in with the idea of layers of support which came from analysis of data within The Lawnmowers. The specific example of this came from the trip to Graceland, (see findings section page 108). In both cases, there were non-disabled supporters enabling peer support between people with learning difficulties. Within the Understanding Research course, the facilitators stated that once the groups were working well, they stepped back as far as possible, and that once the groups had got going at a task often they no longer needed support from the facilitators.

The facilitators reinforced the inter-setting support which I had previously noted. They specifically stated that they would not have got going without the support which they had received from The Lawnmowers in the first place.

Formality of support

A question raised in the literature review was that of whether peer support for people with learning difficulties requires a formal arrangement. Within both of the settings, any of the examples of support given and received could be placed along a continuum in terms of the formality of the arrangement. This will be discussed further in the Discussion on Findings section.

Examples of formal support mechanisms were given by both feedback groups. The facilitators from the Understanding Research course spoke about this in terms of those

involved in the course agreeing who they would go to if there was any aspect of the meetings they wanted to discuss. It was important that this was agreed within the context of the ground rule of respecting confidentiality within the group, so that people had support in between meetings, but, wherever possible, discussion only involved people who had been at the meeting.

When presented with the statement "we support each other when someone is finding things hard or is upset", The Lawnmowers also spoke about a more formal system:

> *Dean: First of all, we have a system, we haven't really used it yet, but we have a system where if you're feeling really upset about something you can talk to [Project Manager] about it. And she'll help you, and calm you down, and help you realise what your problem is about, and help you solve it (October 2009).*

The Lawnmowers also spoke about being understanding as a group, with an example given of supporting a core member within a relationship with someone with learning difficulties outside of the core group. The strength of support between the facilitators was also evident. They spoke about the fact that they had been friends prior to this specific project, and that had helped initially, but they are a far stronger group now.

Overcoming barriers through peer support

This comment is from a core member of The Lawnmowers who had not been part of the data collection. He spoke about the strength of support which enables people to overcome barriers:

> *if we are struggling, we need that support, because what's the point in making it harder for yourself when you've got the support there, for finding ways through that? It's like a big family, sort of thing. You wanna get over this barrier, but you can't cos it's too hard, but the support to help each other to get through the same barrier (October 2009).*

The above quotation refers to peer support as being an obvious solution when struggling. It also speaks about that support enabling barriers to be overcome, referring to strength in support coming from people who are facing that same barrier.

The concept of overcoming barriers through peer support was also touched upon by the facilitators. They gave an example of a student who, at the outset of the course, was very nervous about group work. Through the supportive environment, he grew in confidence and was then able to be part of groups in other contexts within hospital life.

They also spoke about the barriers which they themselves had overcome in order to present their project at conferences: sometimes to far larger audiences than they had expected.

Dean spoke about a recent visit to a local school, and The Lawnmowers' continued core value of challenging assumptions and prejudice:

> *Dean.....we went there to work with the kids, and the kids had never seen a show of clowning like what we took out. And through the show, the kids, well they learnt that you can do shows to be laughed at. But the major thing that the kids learnt was, they learnt that people with learning problems they weren't really any different to them. And for them to be able to learn that, and know that, from a young age, means that they're gonna grow up having a good concept of people who are different to them. And that's really clear, and really good strong thing for them to take from (October 2009).*

Educating children and young people today in order that they grow up to have an inclusive concept of diversity is an extension of aspects of Mutual Support outlined previously. It relates to educating other people about the experiences of people with learning difficulties and breaking down barriers to inclusion, reclaiming dignity and respect.

<u>Making Decisions</u>

I wanted to ask The Lawnmowers about their Round Table Meeting, which had begun after I had last collected data from the group. I approached this by asking the group how they make decisions.

Grace spoke about the introduction of feedback and evaluation sheets within the context of the courses:

> *Grace: and if we don't understand something ....we circle these feedback sheets, evaluation sheets, and then we say what we think, and that helps us make decisions. We reflect on what we've done during the day and what could have been better (October 2009).*

Dean described the Round Table Meetings, and the way in which decisions are made with reference to the whole company now:

> *Dean: but before we had general decisions, about shows and things, the staff would usually generally, they would come to us and say to us "we've got this*

show". But now we're even more efficient, cos before we decide on anything, it always comes to the Round Table Meeting, and we all decide as a group, can we do that activity? Have we got time to do that? So we all make the decision (October 2009).

Dean's reference to the Round Table Meetings as enabling decisions to be made by both staff and actors is an example of the actors becoming more involved in the company. Another core member of the group affirmed the introduction of the Round Table Meetings as enabling everyone to be involved in decision-making. He specifically referred to the result of this joint decision adding to the teamwork element of working together within a supportive environment:

Core member not previously involved in Mutual Support: it's important to have discussions so we know exactly where people stand within the Lawnmowers....... And the reason for that is, in reality, when we come to do stuff, like for example the courses, that all has to be discussed as a team before we go ahead and do that. And I think it's very important that we work together discussing that (October 2009).

Finally, in order to find out about current peer support, I asked The Lawnmowers about support given and received within the courses:

Core member not previously involved in Mutual Support: you need a helping hand cos you can become isolated in all your courses, there's gonna come a time when you're isolated, and need help from other people, to get you un-isolated, and I think in reality, when you look at the word "isolation" it's a hard thing to get out of, but it's an easy thing to get into. I think that applies to the courses as well, you can become very isolated, but you can get the help that you need to get you out of isolation (October 2009).

This insight into isolation sums up the situation of many people with learning difficulties, and refers to the effect that appropriate support can have in breaking free from that isolation.

Evaluation of the research process

The meeting with The Lawnmowers ended with an evaluation of the research process from their point of view. This is relevant to the Discussion on Methodology Section (Part Three Section Three).

> *Dean: I just thought to finish off we should go round and say one thing about how we felt about Sarah coming to work with us.....*

Some people spoke about the positive nature of contact with myself:

> *.........I'd just like to say thank you for coming in, to work with us.....*

There was an element of not wanting that to come to an end:

> *Grace:....well I think it's really nice having you back today, and I think you should stay (October 2009).*

> *..........I like having Sarah around, and I want her to stay.*

Chris referred specifically to the inclusive nature of the research process that I had set out to implement:

> *Chris: ....it's been brilliant having you here, you've listened to what we had to say and not been, like if we say something, you didn't say "why did you say that?" you just let us talk, say what we want without being judgemental, and that's brilliant........(October 2009).*

Dean referred directly to the opportunity to reflect on support given and received within the group:

> *Dean: .... one of the most important things that we've all got from this is that thanks to Sarah, we've all truly opened our eyes and reflected on how we support each other, through the things that Sarah's asked us, ...so it's been a good thing to have you come and work with us, and I suppose it is a very important subject, that you've worked with us on, and it's good for us to realise how we support each other so we can continue to always support each other in the same way into the future (October 2009).*

The Company Director referred to working with a researcher, enabling different angles to be considered, specifically referring to having used my research skills in a project on peer mentoring and people with autism:

Company Director: I've really enjoyed having someone who's looking at a particular thing, how people are supporting each other, and looking at and asking questions around that. Asking good questions is good cos it makes us, me think about what I'm doing here, how I'm doing it, particularly, well all of it, having Sarah around when we were working with people with autism as well. That shaped that up into something more interesting, and usable by other people than if you hadn't been there. So I really value all of the times that we've had together.

<u>Ideas for Dissemination</u>

I asked both groups for ideas about how to "get it out there" (let people know about what has been found out) in a fun, interesting and exciting way.

Suggestions as to the format of the information included:

- making sure the front cover is colourful and eye catching so that people pick it up in the first place
- making a DVD
- acting a scene out
- putting it on a website
- a snappy poster
- making sure any pictures used are explained clearly in a glossary
- putting words that are harder to understand in different colours and explain them in plain language elsewhere
- and producing cards which groups can use to get them thinking about peer support

Both groups asked to have copies of any accessible summaries.

PART THREE SECTION TWO:
Discussion of findings

This section of the discussion continues to explore and to critique the rock of Mutual Support which has been constructed through the research process. At this stage of the thesis, the differences and commonalities between the two settings will be considered, leading to a merging of the ideas from the differing contexts. This discussion begins by evaluating the nature and scope of Mutual Support. It will explore further the themes as outlined in Part Two Section Two and built upon in the feedback and evaluation from The Lawnmowers and the facilitators/advisory group from the Understanding Research course. Figure Three on page 170 represents this discussion.

The discussion then moves on to conceptualise Mutual Support. This begins with an exploration of issues which emerge from literature outlining research into peer support within other settings, including the National Centre for Independent Living. Within this, the concept of how peers are defined, the extent to which training is important within those settings and the purpose of the peer support are explored and critiqued. The final section of this discussion on findings uses the social model of disability as a tool for evaluating the Mutual Support model of peer support and people with learning difficulties.

In order to ensure that the model of peer support being constructed is built on the foundations of Mutual Support, literature which was referred to in the literature review will be referred to again where relevant within this discussion. The discussion ends by outlining the contribution made by Mutual Support to service user involvement and the academic field of disability studies.

<u>Challenging Assumptions</u>

When embarking on this project, I had in mind to challenge dominant views that people with learning difficulties lack the capacity to support each other. I set out to look for examples of relatively basic support. I have since labelled this support "*let's all be nice to each other*" peer support*. However, the themes which have emerged from the interviews have demonstrated a far more purposeful level of support which involves relatively complex interpersonal interaction within forward-looking settings. It is the range, scope and impact of this support which is emphasised within this thesis,

ultimately addressing the question as to whether peer support by people with learning difficulties has the potential to break down barriers to inclusion.

Building on the Positive

A conscious decision has been made within Mutual Support to build on the positive accounts of experiences by participants. Appreciative Inquiry (AI) is a tool which has been used in Organisational Development. Put simply, it seeks to facilitate positive developments within an organisation by asking people involved in that organisation about practice that is valuable to them. AI then builds on those positive aspects within the organisation (Cooperrider and Whitney 2005). Reed (2007) relates this to the application of Appreciative Inquiry in a research context: "the emphasis is firmly on appreciating the activities and responses of people rather than concentrating on their problems" (p2). Reed also (2007 p26-27) also outlines the "Anticipatory Principle": the way people think about the future will shape the way they move toward the future; and the "Positive Principle": focussing on the positive results in deeper engagement with issues over a longer time.

Though the methods used in Mutual Support are not based on an Appreciative Inquiry methodology, the justification of an AI approach to research, focussing on the positive, can be applied to the way the findings within Mutual Support have focussed on accounts of times when support did happen. This issue will be discussed further in the section on times when Mutual Support is not given and received.

Differences and Commonalities between the two settings

When considering the conceptualisation of Mutual Support within the contexts of this research project, the different forms which peer support took within the settings are significant. It is necessary to address these differences prior to drawing the themes together to build the Mutual Support model of peer support and people with learning difficulties. There are several possible explanations for the difference in what Mutual Support looked like: the emphasis/profile of the context being explored within the settings, the nature of the settings, the significance of the activity being explored in the lives of participants, the nature of the research process (including the information given to participants at the recruitment stage) and the day-to-day experiences of people with learning difficulties within the two contexts.

In discussing these issues, this sub-section of the thesis justifies the drawing together of data from the two settings, whilst simultaneously highlighting the fact that a direct

comparison is neither justifiable nor desirable. The nature of the settings was so different and the diverse aspects of peer support within Mutual Support are best appreciated by looking at the diverse and varied forms of peer support. The way I have chosen to bring the two settings together has also meant that the aspects of peer support spoken about by participants are not placed within a hierarchy of support.

<u>Language used by participants</u>

It is evident from the findings section that there are differences in the themes which emerged from the two settings. The way in which the data was analysed and presented was a direct reflection of the way in which participants spoke about their experiences of giving and receiving support. Within the data from the Understanding Research course, there was an emphasis on teamwork, especially within the interviews with students. This is reflected by the frequent use of language relating to teamwork in the data. It is also reflected in some of the codes which I drew up at the data analysis stage. The Lawnmowers actors made use of a wider range of language to describe the ways in which they supported one another. Again, this is reflected in the themes as they were drawn up at the data analysis stage.

<u>The structure of the settings</u>

The differences outlined above could be explained by the nature of the structure within the settings. Within the Understanding Research course, the boundaries within which Mutual Support took place were defined: a six session course based on peer facilitated learning. The course involved teams of students supporting one another within their teams. The teamwork was supported by a group of facilitators who themselves worked as a team. The emphasis on teamwork was also a result of the nature of the learning situation: the groups of students were given specific tasks and asked to work on those tasks as teams.

Within the accounts of support from the Understanding Research course, the support given was relatively structured in relation to who was supporting whom. The men worked in teams, and their accounts demonstrate ways in which they worked together in those teams, as well as one-to-one support within those teams. Similarly, the data collected implies a distinction between the facilitators, who worked together as a team and supported the students, and the students supporting one another within a team.

Within the Lawnmowers, the instances of peer support spoken about by the actors reflect a wider range of activities within varied circumstances and among different

members of the group at different times. The amount of time spent together is also significantly greater within The Lawnmowers than the Understanding Research course.

Mutuality and reciprocity of support

The extent to which support given and received was one-way or involved more complex interaction is also significant. Within the Understanding Research course, the data analysis based on the findings from individual interviews with students suggested that the students viewed the support they received from the facilitators as one-way. In their discussion on Becoming Educators, the facilitators clearly saw their role as supporting the students, though their insight and reflection into learning being a two-way interaction demonstrates the fact that they saw themselves as facilitators within the learning process.

At the feedback meeting with the facilitators, they spoke of ways in which the students had supported them. The examples given of this included the way in which the feedback from students enabled the facilitators to develop the course as it progressed. The facilitators stated that this "two-way street" allowed them to further their skills as educators. The fact that all of the students aspire to be facilitators/tutors in the future demonstrates their understanding of the support processes within the course.

Mutual Support within The Lawnmowers reflected fluidity within supportive relationships: each of the actors spoke about giving and receiving support from different people within the group depending on the circumstances. The experiences I was asking The Lawnmowers to reflect upon were on a different scale, both in terms of the length of time over which Mutual Support had happened and the profile of the activity in the actors' lives. There was also a greater variety of situations in which Mutual Support had taken place. The boundaries of time, situation and people involved were also less definite. Those speaking about their experiences of Mutual Support within The Lawnmowers were reflecting on experiences over a much longer and more sustained period of time: one of the actors has been part of the group from its beginning over 20 years ago.

Formality/Informality

The boundaries referred to above affect the formality or structure of interpersonal interaction within the two settings. The setting for the Understanding Research course was much more structured in the first place. The way in which the Understanding Research course was set up, with the three distinct groups (facilitators and two teams),

meant that the boundaries mentioned above were already in place before the course began. The language which was used by participants reflected this.

The formality of researcher-participant relationships

The element of structure within the settings was also reinforced by the formality of my relationship within the research contexts. Again, this was influenced by the settings. Only one of the students from the Understanding Research course had freedom to come and go from the room during the interview – this allowed for a more relaxed atmosphere – evidenced by the cup of tea he made for us during both of the interviews. I did not (and did not have ethical permission to) ask the students from the course anything about Mutual Support outside of the specific context. This means that I cannot comment either on the effect which the course had on the rest of their lives or on Mutual Support within other aspects of life at the hospital.

This structure contrasts with the informality in my interaction with The Lawnmowers – the first time I visited them I went to a local cafe with Dean and Chris after the meeting. This informality was typical of my visits to their base in Gateshead. My role and the resulting influence over the research situation will be discussed further in Part Three Section Three.

The range of activities reflected upon

The range of activities upon which participants were reflecting was also influenced by the nature of the context – and this was introduced through the Mutual Support information sheets and audio CDs. The information I gave to The Lawnmowers stated that I wanted to find out about how they support one another within the range of experiences which they have as a group. In contrast, the information sheets/audio CDs which went to all those who had taken part in the course specifically stated that I wanted to ask about Mutual Support within the context of the course. This was reinforced when the Research and Development Committee required that I state the defined purpose of the interview on the consent form.

However, providing that these issues are borne in mind when drawing the evidence from the settings together, there are commonalities between the experiences of Mutual Support across the two settings: these commonalities will now be discussed within the context of conceptualising the model of Mutual Support. In exploring that model, the threads of the discussion are:

What is Mutual Support?

Who gives Mutual Support?

When is Mutual Support given?

How is Mutual Support given?

What effect does Mutual Support have?

It was these five seemingly simple questions which I used, alongside an initial draft of the findings section in building the picture of Mutual Support outlined in this discussion. They enabled a consideration of the nature and scope of the peer support that participants had spoken about in the interviews. Therefore, the discussion within this section is based on answering these questions from the data. The discussion is represented in the diagram on page 170 .

What is Mutual Support?

Mutual Support is about people with learning difficulties supporting one another within a pre-existing context which involved or involves working together on a specific project. The accounts of support were retrospective, reflecting back on support given and received within these contexts.

Within both settings, there were examples of task-orientated Mutual Support. There was a range of circumstances in which Mutual Support added to the efficiency of the completion of a task and also to the quality of the outputs of that task. Setting up for performances, and support when travelling, are examples of this within The Lawnmowers. Support with reading and writing referred to by both students and facilitators is an example of this within the Understanding Research course.

Mutual Support is also functional and practical, serving a purpose. Within the interviews from the Understanding Research course, the idea of helping one another out so that the tasks were done more quickly was expressed. Similarly, within The Lawnmowers, examples such as staying overnight and going shopping were examples of support which had a practical application. There was an example from both settings of support for peers when they were unwell, demonstrating Mutual Support as being responsive to the needs of others as and when they arise.

Mutual Support, therefore, is people with learning difficulties supporting each with practical tasks which either result in the completion of a task or enable people with learning difficulties to participate more fully in that task. It also is about people with

learning difficulties meeting one another's immediate needs for support, for example when unwell.

The nature of the activity, referred to above as "tasks" is also significant to the Mutual Support model of peer support for people with learning difficulties. For example, the Mutual Support which takes place within The Lawnmowers with an immediate purpose of getting ready for a performance has a much further reaching purpose when considered in relation to the positive effect which the shows have had in breaking down barriers to inclusion.

Similarly, Mutual Support explored the role and impact of peer support within the learning process at the stage when the Understanding Research course materials were being piloted. There are plans for the course to be rolled out throughout the NHS Trust and beyond. This will enable more people with learning difficulties to be better equipped when faced with participation in research projects. It will also enable those who have taken part as students to become facilitators themselves, something which all three students who spoke to me expressed an interest in.

Accounts from both settings demonstrate the practical support outlined above being built upon by encouragement through interpersonal interaction. Within the Understanding Research course, the references to listening to one another and respecting one another are examples of this. The Lawnmowers spoke about encouraging one another during workshops and performances, and pulling together as a team. This challenges assumptions around people with learning difficulties and interpersonal interaction. It also represents reclamation of dignity and respect within the context of a group of people who have, historically, been oppressed.

Though the interaction between Laura and Richard (when Richard entered the recording to set up the keyboard for singing Happy Birthday) was brief, it provided a glimpse into an aspect of Mutual Support which involves supporting someone with complex needs. The behaviour described (biting) would often be described as "challenging" (Heyman Swain and Gillman 1998) and Laura and Richard provide insight into peer support within this context.

Mutual Support also involves working as a team. The students from the Understanding Research course were aware of the importance of "pulling their weight" and contributing to the team. The facilitators in particular spoke about the positive effect of awareness of strengths and weaknesses within a team. The Lawnmowers' accounts of support also included acknowledgement of different people having different strengths

and weaknesses and supporting one another within that – an essential element of teamwork. The Lawnmowers also spoke about pulling together for a specific task.

Mutual Support is also about peer mentoring. Though there are obvious overlaps between support and mentoring, a mentoring relationship is more specifically focussed on teaching and learning. The Understanding Research course is perhaps most evident in terms of peer mentoring: an area in which the facilitators have supported The Lawnmowers, through sharing examples of good practice, in particular lending the files in which evidence of their work had been gathered. This idea of inter-context peer education was also evident in the DVD made by The Lawnmowers. This DVD was used at the outset of the original research project, resulting in the use of The Lawnmowers' drama skills in introducing the men who became facilitators to the complex ideas which were to become central to their thinking within the project. The students also spoke about the use of DVDs at the start of each session.

Mutual Support is also about people with learning difficulties educating others, including service providers and others whose work involves people with learning difficulties, about what is important to them. This is evident in The Lawnmowers' work with trade unions and employers. It is also evident from the ever widening groups of people who have taken part in Theatre for Change and Forum Drama Workshops.

Grace and Dean explained the significance of Forum Drama at the second feedback meeting:

> *Grace: We do Forum Theatre, which is, we have a scene, say it's a bad scene, we do that, and then we ask the audience how they would change it, then we get them to step into our shoes and see if it'll change the scene, and also it'll change people, what they view, and how they feel.*

> *Dean: and if anyone in that audience has similar problems, then they get good ideas of how they can sort themselves out. And it really helps them with their lives (October 2009).*

The facilitators from the Understanding Research course have also been involved in educating others about their experiences through presenting their work at conferences. I myself witnessed the power of the challenge to conventional assessment of "capacity to consent" that emerged from this work when Tina Cook presented the work at a local NHS Trust Mental Capacity Act Research training event.

The idea of people with learning difficulties educating others, both people with learning difficulties and staff and students, is not unique to Mutual Support. For example, Building Bridges Training is an independent group whose training includes education for professionals or future professionals about inclusive support and involving people with learning difficulties in planning services. They also run workshops for people with learning difficulties, including community safety and choosing staff (Building Bridges Training 2009). This idea builds on the growth of Disability Equality Training which, when based on a social barriers approach to communicating the experiences of people with learning difficulties, has the potential to educate professionals (Levinson and Parrit 2006). Connect in the North has also devised training programmes involving people with learning difficulties in training personal assistants (Hunt 2008).

The basis on which the above training was built was that of people with learning difficulties as experts about the services they receive and also opportunities for self advocacy within the context of training others about how people with learning difficulties were to be treated (Weeks et al 2006). Mutual Support sheds further light on the development of people with learning difficulties as educators by exploring the interpersonal interactions which took place within this context from the point of view of the people doing the educating.

Price and Barron (1999 p822), writing specifically in relation to The Lawnmowers, stated that "*peer group education played a central part in the exercise for it was recognised that there was a great shortage of learning disabled role models*". As mentioned in the findings section, the formalisation of existing peer mentoring within The Lawnmowers is taking place through the courses which began in September 2009. In time, this will extend to core group members mentoring other people outside of their core group.

Who gives Mutual Support?
Mutual Support is most often given by people with learning difficulties working together within a specific context. All of the participants gave examples of Mutual Support given and received by and from others who have a learning difficulty. Sometimes one person gives Mutual Support to another individual. Other times, more than one person is involved at either the giving or the receiving end of support, or both.

An aspect of the question of "who gives Mutual Support?" is people who have previously been supported themselves in the same or similar situations supporting

others (a significant aspect of peer mentoring). Within the Understanding Research course, the facilitators supported the students in learning about research. This support was based on the understanding of concepts which the men had developed through the extensive collaboration which had taken place in their research with Tina Cook and Pamela Inglis. The way in which the facilitators nurtured and encouraged students in teamwork adds a further dimension to that setting, taking the experiences of support beyond learning about concepts relating to Understanding Research. Similarly, the support which The Lawnmowers extend to newcomers was based on the support which they themselves had previously had in settling into a different environment.

Cowie and Wallace (2000) propose that peer mentoring within a school setting is about an older pupil mentoring a younger mentee. Within this, the relationship is fixed and is based on the assumption that the older pupil knows more than the younger one. The emerging findings within Mutual Support suggest a far more fluid model of peer mentoring, with the most common basis for peer mentoring being past experience and awareness, regardless of age or "ability".

Mutual Support works best when it involves a mixing of strengths and weaknesses within the groups of people, based on the focus of activity. Examples of this can be seen in the mixing of groups of people who could and couldn't write within the Understanding Research course, and being aware of people's physical strengths and weaknesses when The Lawnmowers were putting up the set for a show, or setting up for a Krokodile Klub.

When considering participants' accounts of support, the distinction between people with learning difficulties and people who support them within the contexts being considered is not so clear cut as the title of this project might suggest. This raises questions: by focussing on people with learning difficulties, has Mutual Support drawn a distinction that would not necessarily be recognised by people within the contexts? If so, is this in fact reinforcing barriers to inclusion as opposed to breaking them down?

In answering these questions, this discussion will first consider the value of peer-to-peer relationships, and it will then consider the role of non-disabled allies within the accounts of Mutual Support, which is based on the concept of interdependence (Goodley 1997). The discussion will propose a "layering of support" which can be seen within both contexts, leading to a discussion around inter-dependence. The sub-section also includes a response to the question asked at Skills for People in July 2009 about how non-disabled supporters can support the development of peer support.

<u>The value of Peer-to-Peer relationships</u>

This section outlines what participants said about Mutual Support specifically being between people with learning difficulties. Chris' reflection on his relationship with Pete, which was presented in the "role of non-disabled allies" section of the presentation of themes emerging from The Lawnmowers, articulated how a peer relationship, for him, did have different qualities:

> Chris: *me and Pete go back years, right, I call him worse than muck, right, but if anyone else calls him, I'll smash their face in (June 2008).*

Dan, one of the students from the Understanding Research course, had a different view on the assets of a peer-peer relationship. I asked him if he thought it was good when finding something difficult to be around other people who were also finding that thing difficult: *"Yes. Sometimes I do, sometimes I don't, it depends on me fettle[14]".* During an advisory group session, the facilitators described the strengths of a peer-to-peer learning situation, by referring to the students as not feeling threatened because the facilitators had learning difficulties as well. The facilitators also emphasised the role of Tina Cook and Pamela Inglis in supporting them to support the students. This will be returned to overleaf.

As outlined in the literature review (page 34-35) the Normalisation/SRV movement was based on the principle that disabled people, specifically people with learning difficulties, should be encouraged to build relationships with non-disabled people (Race et al 2005). The implication was that relationships between people with learning difficulties were less socially valued and therefore less desirable (Flynn and Aubry 1999). Mutual Support challenges these assumptions. It demonstrates ways that support for people with learning difficulties by people with learning difficulties can lead to breaking down barriers to inclusion and (in the case of the Understanding Research course) a more meaningful learning experience.

The following extract is taken from Cook and Inglis' recent article which explored the themes relating to consent that emerged from the Understanding Research project. It relates to the significance of engagement with peers in the process of understanding:

> "*If you don't mind me saying, I'm not being rude, but we can explain it better than you. You're good at telling us something, but we are better at talking about it. We know how to talk to each other you know. We are better at getting it*

---

[14] Geordie phrase referring to overall well-being, or general inclination.

> *simple – well not simple you know – right for ourselves" (man 4) (cited in Cook and Inglis 2009 p60).*

Pamela Inglis' (2008) thesis, which drew upon interviews with all who had taken part in the Understanding Research course, explored the discourses underlying learning disability practice within a forensic setting. A staff member who had been involved in the initial Collaborative Action Research Project acknowledged the significance of the support which the men gave to each other:

> *"Luke's understanding of the material was seemingly greater than John's but he was able to....kind of coach, if you like, and assist him to develop his own answers" (Staff 4) (Inglis 2008 p126).*

The critical concept within this discussion is that of value: how much value is placed by other people on support which people with learning difficulties give and receive from one another? How much do participants value Mutual Support? The question of the value placed on peer relationships by those taking part can be answered by considering the enthusiasm and value placed on the group, who were often referred to as "a second family".

This concept of value links with the role of non-disabled people in Mutual Support: how much do they value people with learning difficulties supporting their peers? How much did participants value the support of non-disabled people within the settings being considered.

In Inglis' thesis, there was recognition from staff of the men's expertise and greater understanding of concepts. This resulted from the greater depth of engagement with concepts by the men compared with staff who did not attend all sessions (Inglis 2008). This further highlights the effectiveness of the peer mentored learning experience.

<u>The role of non-disabled allies</u>

When considering who gives Mutual Support, it is important to consider the role of non-disabled people. A conscious decision was made that formal data collection would involve only people with learning difficulties. However, the project would not have been possible without the support of non disabled people, both staff at the hospital and The Artistic Director and Project Manager from The Lawnmowers.

At the feedback meeting at Skills for People (July 2009) one of the questions (asked by the non-disabled Deputy Chief Executive) related to the role of support staff in the development of peer support and people with learning difficulties. She asked if the project had found anything out about how support staff can facilitate peer support. This

question relates directly to the issue which has arisen elsewhere in the project around the role of non-disabled allies.

The idea of layers of support, which was outlined in the section on the role of non-disabled allies in the presentation of data from The Lawnmowers, might also be applied to the role which the two non-disabled co-researchers (Tina Cook and Pamela Inglis) had in the Understanding Research Course: they supported the facilitators in supporting the students. The emphasis within the role which these two people took was on providing support which was conducive for enabling people with learning difficulties to be supporting each other in the learning process.

Goodley (1998) explores the role of support offered by advisors within self advocacy groups. He differentiates between support from (non-disabled) advisors that was empowering and that which was disempowering, linking empowerment with a social model of disability and disempowerment with an individual/medical model of disability. He emphasises the type of action/intervention as opposed to a type of supporter. The support from non-disabled allies spoken about by those taking part in Mutual Support were examples of support leading to empowerment based on a model of inter-dependence.

The concept of layering of support, which is built not only on a model of inclusion and enabling self determination, but also the concept of inter-dependence (Goodley 1997 p376). A model of inter-dependence recognises that most people do not desire independence per se, as that would lead to isolation and a denial of meaningful interpersonal interaction. A model of equality within a team which includes non-disabled supporters who value the insight of people with learning difficulties and their desire and ability to support each other is far more applicable to the accounts of support that have emerged within Mutual Support.

The consideration of the roles of non-disabled people must also include the question as to whether the settings being considered would run without them. How much influence have non-disabled people had over the instances of peer support which participants gave? Would the situations on which Mutual Support is built have occurred at all without input from (in the case of the Understanding Research course) Tina Cook and Pamela Inglis and (in the case of The Lawnmowers) the Project Manager and Artistic Director? When considering the role of non-disabled supporters in Mutual Support, it is also important to recognise the role of hospital staff. Inglis (2008 p83) refers to the staff

as the "*most important resource for the success of any forensic service*": this includes arrangements for outsiders such as myself to meet with patients.

In answer to the question raised at Skills for People, I propose that the role of non-disabled supporters in Mutual Support includes being sensitive to the potential for peer support right from the start of any project. The nature of the project would determine the form Mutual Support would take. The ideas within Mutual Support suggest that non-disabled supporters should see their role as enabling peer support, and this can involve supporting one person or group of people so that they in turn support other people or groups of people. There are instances when it is appropriate that support systems be relatively formal, though equally there is need for room for spontaneity and flexibility. Within this flexibility, Mutual Support is a gradual process which involves time and space for confidence and trust to develop.

I would suggest that non-disabled allies should not discount the value of peer support, and the unique qualities within a peer relationship. There is a need to remain open to the fact that instances occur when people with learning difficulties are better placed to support one another, or to explain complex concepts. It is also important to remain aware of the potential for people with learning difficulties to support non-disabled allies. An example of this can be found in the two-way interaction within the learning situation of the Understanding Research course:

> "*it wasn't just supporters helping out researchers with learning difficulties we all helped each other. It was a two-way thing*" (Mark- diary entry) (Inglis 2008 p30).

Support for people with learning difficulties outside of the immediate contexts of Mutual Support

When considering the "who" within Mutual Support, the support that has been extended to others outside of the core groups is significant. The Lawnmowers' work involves building confidence and extending social networks among local groups of people with learning difficulties. The Forum Drama work also supports other people with learning difficulties to make differences in their lives. Price and Barron (1999 p822) also referred to the opportunities created by The Lawnmowers "*for other learning disabled people in Gateshead to benefit from the work of The Lawnmowers' group*".

Similarly, the work which has emerged from the Understanding Research course has been disseminated, challenging assumptions that capacity to consent to research is fixed and that traditional approaches to obtaining consent are the best ways of approaching the consent process when involving people with learning difficulties in

research. The work has also been used by the CETTiI (Centre for Excellence in Teacher Training for Inclusion at Northumbria University) and the proposed programme for rolling out the course on a wider scale will mean more people with learning difficulties have the opportunity both to access the training materials and the peer-mentored learning experience:

> "*Because somebody who knows about it [research] and has got learning disabilities- [they] could explain it to somebody who has got learning disabilities. And then they could get better and they could learn more about it. And they'll go away and tell somebody [else] with learning difficulties about it*" (John, taken from Inglis 2008 p142)

When does Mutual Support happen?

There were a range of instances when Mutual Support happened. Firstly, Mutual Support happens when people within the settings have a need and other people within that setting realise that need. This includes when people are struggling or upset, times when a task needs completing (as outlined above) and when people realise that someone is experiencing something similar (either past or current experience) to them and can offer support based on a mutuality or commonality of experience.

The times when Mutual Support happens often occur when people are facing barriers. Mutual Support in these contexts includes support when people need representation. Examples of this came from The Lawnmowers' work with families and trade unions. Mutual Support also occurs when people are new to an idea (in the case of the course) or are newcomers to a group or skill (in the case of The Lawnmowers). There were instances of Mutual Support happening as a fixed part of a routine as well as instances of more spontaneous support.

Mutual Support is given to people outside of the participants in this research when they are inspired by the achievements of those groups. This is applicable to the achievements, such as the accreditation of work, and through the conferences the facilitators from the Understanding Research Course have attended. The Lawnmowers' work in improving the lives of people with learning difficulties has also extended regionally, nationally and internationally.

I am unable to comment on when and if Mutual Support extended to life outside of the Understanding Research course for those who took part. My conversations with participants did not and could not include other aspects of life at the hospital, nor any discussion of their diagnosis, treatment or index offence. Although this regulation was put in place to satisfy R and D and NHS Ethics committee regulations, and meant that I

did not get to know participants as well, it was not an entirely negative influence on the research process. Focussing on the course enabled a more in depth exploration and analysis of Mutual Support. The focussing on a positive experience without reference to past or present difficulties also emerged as a positive aspect of the project, though the facilitators also spoke about camaraderie based on common experiences prior to the initial research project.

Though not directly part of Mutual Support in terms of formal data collection, a situation in which Mutual Support extended to local groups of people with learning difficulties was as part of a four day action research project which involved The Lawnmowers and a local specialist college for young adults with autism (June 2008). I was attached to the project, observing all three days within the active phase of the research and writing up and evaluating the peer mentoring activity that took place.

The active phase of the project began with two learners from the college who, supported by staff, spent a day at The Lawnmowers' base. Three actors, supported by the Artistic Director, introduced the learners to a range of Lawnmowers' activities. This was then followed by the actors and Director spending two days at the college. The aim was that, by the end of these two days, the two learners who had visited The Lawnmowers would be delivering activities for their peers at the college. The structure of this project was similar to the Understanding Research course in terms of the structured development of peer mentoring, providing further evidence for the potential of peer mentoring and people with learning difficulties.

When does Mutual Support *not* happen?

When considering when Mutual Support is given and received, it is also important to consider when it did *not* occur. All participants were asked if there were times when they had not felt supported. Within The Lawnmowers, one actor stated that she did not feel supported when struggling to walk any distance. She described being left behind by the group. This same actor spoke about a time when she had observed another group member being separated from the rest of the group at a conference. Both she and this actor spoke about lack of teamwork in the specific situation of getting the set ready. That particular actor explained how this issue had been resolved. Within the Understanding Research course, the students spoke of several occasions when they had found it hard to concentrate.

When considered in relation to all of the data which was collected, it could be argued that these instances are few and far between – and to be expected among any group

of people working together. A counter argument to the positive nature of the majority of answers could be that the way in which the topic was introduced swayed participants to focus only on positive instances. A further counter-argument could be that participants were afraid of possible negative consequences of saying they did not feel supported. However, the evidence that two people at least felt able to speak about times when they had not felt supported suggests that they were able to express negative, as well as positive, experiences.

The question of participant "accuracy" in the accounts which they have given lies alongside this issue. This leaves me, as the person in the project who is presenting the findings and building theory based on them, with a dilemma: how do I incorporate the examples of not being supported into my theorising around Mutual Support? How can I know whether or not the experiences which the participants recounted really did happen?

Having considered the issues outlined above, I am not ignoring the accounts of times when support did not happen, neither am I questioning the accuracy of the accounts from participants whose responses were solely of times when they *had* been supported. The rock of Mutual Support which has been constructed through this research is built on examples of support given and received, enabling the construction of a model of best practice which can be built on in the future. I fully acknowledge that had there been more instances within the data of support not happening or of negative experiences, my consideration of the examples given would have required a different approach.

Using Mutual Support in other contexts

Given that a conscious decision was made to focus on positive accounts of support when constructing the model of peer support, it is important to acknowledge the barriers and challenges that may well be faced when seeking to implement the model in other contexts in the future. It is important to acknowledge that interpersonal interactions are complex and not always straightforward. The development of supportive relationships, whatever the context, will raise issues and conflicts. The barriers and challenges faced in implementing Mutual Support within any setting involving people with learning difficulties will be unique to that setting and influenced by many factors, including the nature of people's impairments and expectations within each setting. It is, therefore, hard to generalise. However, it is important to state that Mutual Support should not be viewed as the be-all-and-end-all of service provision, and

future developments of the model should take place alongside other emancipatory work that involves creating a truly inclusive society for all, not just people with learning difficulties.

It is also important that Mutual Support is not used as an excuse by non-disabled people working with people with learning difficulties to leave them alone to support one another. The role of non-disabled allies in Mutual Support is clearly central and, as outlined above, the approach taken by non-disabled people seeking to develop Mutual Support needs to be considered carefully with each new interaction within every initiative. Alongside this, a further issue that needs to be considered when developing Mutual Support in the future is the personal investment of many people on many different levels into the settings that were central to Mutual Support. The dynamics within the two pre-existing settings, which were a result of that investment, and which come across in this thesis, were striking but were not a result of input from this research project.

Having considered what Mutual Support is, who gives it and when it happens, this discussion now moves on to explore how Mutual Support happens.

How does Mutual Support happen?

Firstly, Mutual Support happens through accessible communication, which is often initiated by the person giving support. Instances of this from the Understanding Research course include the accessible format of the materials used and the tasks presented to students within the course. This then enabled further peer education. The facilitators highlighted the need for making the concepts which they were explaining accessible. They also recognised the need to continually adjust the approaches and techniques they used within the course in order to be more supportive.

A discussion on how Mutual Support is given would not be complete without the acknowledgement that, at least initially, Mutual Support happens through input from non-disabled people. Again, it is the approach to this input which is significant within the model of Mutual Support. Related to this, Mutual Support happens through establishing a context in which support by people with learning difficulties for people with learning difficulties is encouraged, including investment of time and money.

Mutual Support also happens through non-disabled people acknowledging the role of people with learning difficulties in peer education:

"[man 3]'s understanding of the material was seemingly greater than that of [man 2] but he was able to....kind of coach, if you like, and assist him to develop his own answers" (staff 6) (cited in Cook and Inglis 2009 p60).

However, at the same time as acknowledging the role of non-disabled people, the significance of people with learning difficulties in responding to one another's needs, and working together on a team, is the overriding influence on how Mutual Support happens.

The nature of interpersonal interaction within Mutual Support

When considering *how* Mutual Support happens, it is important to consider the nature of interpersonal interaction within the examples given by participants. Again, it would be possible to get bogged down in analysis based in psychology, theorising the interactions that took place. This is not compatible with the methodological stance in Mutual Support, as it would involve interpreting what people have said, and the interactions they were talking about, as opposed to valuing their accounts of their experiences.

However, the depth of insight, empathy and compassion, both within the situations that participants recounted and within their accounts of supporting one another is significant. It is useful at this point to return to the four dimensions to humanness outlined in the literature review: attributing thinking to the other; seeing individuality in the other; viewing the other as reciprocating and defining social place for the other (Bogdan and Taylor 1998 p246-247). These dimensions highlight the significance of recognition of other people which is highly evident throughout the examples of Mutual Support, especially in relation to responding to needs of others.

Within the Lawnmowers, examples of insight into others' needs include when others had been upset or distressed, and within Dean and Grace's reflections on what makes a good friend or supporter. The facilitators' insight showed understanding of the students' learning processes, in particular in the context of the adjustments made as the course progressed. Their insight into teamwork, especially the importance of responding to strengths and weaknesses within a team, was also central to the development of peer support with the course. The students all spoke about the importance of Mutual Support being built on respect for others within the team situation.

The significance of the insight, empathy and compassion showed within Mutual Support must not be underestimated. As stated in the literature review, people with

learning difficulties, historically, have been excluded from mainstream society, leading to lack of respect and dignity. This has led to assumptions that people with learning difficulties lack the capacity for even straightforward interpersonal interaction. The impact of people with learning difficulties reclaiming a past which has been characterised by lack of respect by showing respect to one another through Mutual Support is a challenge to these assumptions. This leads to the final aspect of the evaluation of Mutual Support: what effect does Mutual Support have?

What effect does Mutual Support have?

This discussion of the nature and scope of Mutual Support now turns to the effect of Mutual Support. This will be followed by a diagram representing the model of peer support which has emerged so far. The first level of the diagram outlines the what, who, when and how of Mutual Support, each of which has been discussed above. This forms the basis of the model, the second level of the diagram, with the third level of the diagram illustrating the effects of Mutual Support. It is these effects that form the basis of my argument for the potential of peer support and people with learning difficulties to break down barriers to inclusion.

Brown (2005) refers to the process of empowerment through peer support:

> *"peer counselling and building close relationships are key to personal empowerment... personal empowerment is key to political empowerment".*

The main aspects of empowerment through Mutual Support relate to education, peer mentoring, more meaningful participation, fulfilment of ambitions, affirmation and reclamation of dignity and respect. All of these lead to a breaking down of barriers to inclusion.

As stated in the literature review, the service user involvement movement is based on the significance of participation leading to individual and collective empowerment (Branfield et al 2006, Mercer 2004, Campbell et al 2007). When considering the Mutual Support model of peer support and people with learning difficulties and linking it to empowerment, the level of participation is highly significant. All of the examples given within Mutual Support have been based on contexts where people with learning difficulties have responded within group participation.

Data emerging from different aspects of the research provides evidence for the development of people with learning difficulties as educators. The facilitators, speaking specifically about "Becoming Educators", provide insight into the skills which they used
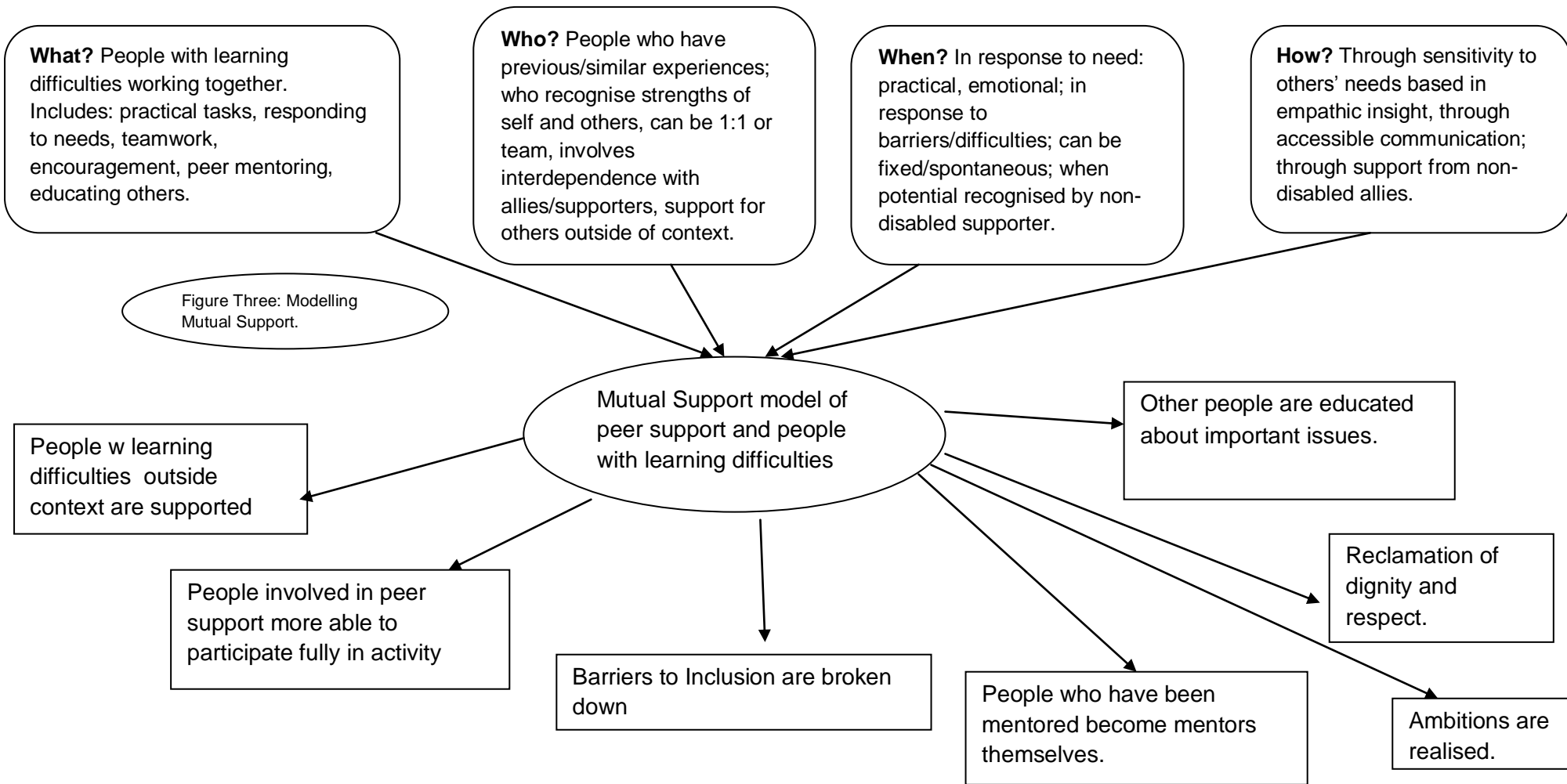
within a specific learning situation. The evidence surrounding the level at which participants were able to reflect on their role as educators illustrates the potential for developing this area of support.

It is beneficial, however, to widen the remit as to what is considered to be education. The Lawnmowers' role in the area of education is around educating people who work with people with learning difficulties from the point of view of having direct experience of the issues which people with learning difficulties face. The most obvious example of this within Mutual Support is the performance at Coach Lane Campus, Northumbria University, when there were students and lecturers in the audience whose working life is centred around supporting people with learning difficulties. The feedback forms from people who had been in the audience spoke of people being challenged to think about what people with learning difficulties can do.

A tangible measure of breaking down barriers is demonstrated in the ambitions which people have and how far they are being supported to do that. Again, the plans for the future which people spoke about were relevant to the contexts of the settings. One Lawnmower actor spoke about how his musical ambitions had been fulfilled since being part of the group, with another actor referring specifically to supporting him in this goal. This second actor also spoke about ambitions which she hopes to fulfil with support from the group.

The plans for the future about which students spoke centred on the peer education element of the course. When asked how they would like to build on what they had done, rather than speaking about developing what had been learnt on the course, all three students spoke about becoming tutors themselves. This emphasises the impact which the facilitators' role had on the process from the students' point of view.

A further, tangible effect of Mutual Support is that it enables those involved to participate more fully in the context. This is evident throughout the data from both settings. Alongside the reclamation of dignity and respect, this is an example of breaking down barriers to inclusion, which will be discussed further in the section which follows the diagram. The diagram overleaf outlines the nature and scope of Mutual Support that has emerged from the discussion so far.

What? People with learning difficulties working together. Includes: practical tasks, responding to needs, teamwork, encouragement, peer mentoring, educating others.

Who? People who have previous/similar experiences; who recognise strengths of self and others, can be 1:1 or team, involves interdependence with allies/supporters, support for others outside of context.

When? In response to need: practical, emotional; in response to barriers/difficulties; can be fixed/spontaneous; when potential recognised by non-disabled supporter.

How? Through sensitivity to others' needs based in empathic insight, through accessible communication; through support from non-disabled allies.

Figure Three: Modelling Mutual Support.

Mutual Support model of peer support and people with learning difficulties

People w learning difficulties outside context are supported

Other people are educated about important issues.

People involved in peer support more able to participate fully in activity

Reclamation of dignity and respect.

Barriers to Inclusion are broken down

People who have been mentored become mentors themselves.

Ambitions are realised.

Conceptualising Mutual Support

Having outlined the shape of the Mutual Support model, this discussion of findings now moves on to conceptualise the peer support spoken about by those who have taken part in the project. This begins by comparing Mutual Support with other literature which focuses on research into peer support in specific settings, leading to a discussion of Mutual Support within the context of the National Centre for Independent Living (NCIL) report (Bott 2008). It is followed by a discussion on Mutual Support and the social model of disability. This in turn leads to an outline of the contribution of Mutual Support to debate surrounding service user involvement and the academic field of disability studies. The contribution of Mutual Support to self advocacy, user involvement, the social model of disability and the disabled people's movement is summarised in the table on page 186.

Comparison with other settings

This section of the discussion outlines the evidence from other contexts in which peer support has been evaluated, in order to establish the similarities and differences within these contexts, and the emerging findings on Mutual Support. My thinking in the area of comparison developed late on in the project. There were two main reasons for this. Firstly, I wanted to go into the exploration of peer support and people with learning difficulties with an open mind, and did not want this to be influenced by comparison with other settings. This was an element of maintaining the views of participants as central to the analysis of data and subsequently the findings within Mutual Support. Secondly it was hard to know whether settings in which peer support has been conceptualised or evaluated were comparable with the specific settings within Mutual Support.

When considering the nature and scope of peer support available to any group of people in the 21st Century, the vast network of support online needs to be considered (Seale 2007). However, an exploration of online peer support in relation to people with learning difficulties is not relevant to Mutual Support for two reasons: the complexities of accessibility, and the issues surrounding interpersonal interaction and online interaction. Though both of these issues are important, to explore them would detract from the focus of Mutual Support which emphasises direct experiences of interpersonal interaction involving groups of people with learning difficulties in contexts where that interaction is literal as opposed to virtual.

The literature which exists on peer support can be broadly divided into two categories: peer support within groups of people with specific medical conditions and/or their carers, and peer support within schools. Both of these groupings seemed incompatible with a social barriers approach to understanding learning difficulty: comparison with groups within health settings might reinforce a deficit model approach, and comparison with peer support groups within schools might reinforce the "eternal child" portrayal of people with learning difficulties, which has been a vehicle for reinforcing barriers to social inclusion for people with learning difficulties. However, when the outputs of a search for literature relating to peer support included inclusion and citizenship (Newton and Wilson 2003, Parsons and Blake 2004, Cremin 2007), I realised that further exploration was needed. Hartley-Brewer (2002) also links peer support with participation leading to empowerment. The following sub-sections of this discussion outline the emerging themes from a wider range of literature relating to peer support.

Defining peer support

There is evidence in the literature of peer support initiatives in a wide range of contexts. Recently published research articles include: a peer counselling programme for the elderly with depression living in the community (Ho 2007), a telephone peer-delivered intervention for diabetes motivation and support (Dale et al 2009), peer-group support intervention for AIDs orphans (Kumakech et al 2009), e-mail support as part of a college smoking-cessation website (Klatt et al 2008), peer emotional support in the emergency department (Griffin 2008), antenatal peer support workers and initiation of breast feeding (MacArthur et al 2009), and prevention of postnatal depression (Dennis et al 2009), self–help in a consumer run centre for individuals with mental illness (Schutt and Rogers 2009), other settings of peer support within mental health services (Coatsworth-Puspoky et al 2006, Sells et al 2008, Barber et al 2008, Adame and Leitner 2008, Chadwick and Liao 2009), addiction recovery (Boisvert et al 2008), and people with dementia (Collins 1999).

Rather than outlining the forms which peer support took in the research projects outlined in the above articles, I conducted a content review of the issues raised. The issues which arose from that content review include: the conceptualisation and definition of "peer", the nature and purpose of the support, the length of time over which support was given or received, and the formality of the support, including training given to those doing the supporting and the role of those who initiated the context within which peer support occurs. The following discussion explores these issues, based on the literature but specifically in relation to Mutual Support.

<u>Who are "peers"?</u>

A specific issue raised throughout Mutual Support is how the concept of "peer" is defined. The questions already outlined relating to this include the line which Mutual Support has drawn in exploring peer support in relation to people with learning difficulties. How can the promotion of inclusion be linked to a label which has historically re-inforced exclusion and in some cases segregation?

Kumakech et al (2008) define a peer group as possessing experiential knowledge and similar characteristics sharing lay assistance. The emphasis is on knowledge which is based on common experience. The groups who have been involved in Mutual Support are based around common experiences. However, any definition of the people involved as having similar characteristics would be based around a reinforcement of labelling: there is as much diversity within the characteristics of people who have taken part in Mutual Support as would be found in any group of people. Similarly, the positioning of lay assistance within a group of people who have experiential knowledge is not compatible with the ethos of Mutual Support which places people's insight into their own experiences at the centre of knowledge production.

As stated in the introduction to this thesis, whatever the context, the notion of "peer" is based on having something in common. In order to define the "peer" element of Mutual Support, an exploration of what the people taking part have in common is necessary. All of the people who took part in Mutual Support have been labelled as having a learning difficulty. The fact that they are either involved in The Lawnmowers or a resident at the hospital implies that, for whatever reason, the barriers which they have faced means that their current lifestyle is based around a setting which is specific to people with learning difficulties as opposed to mainstream education or employment. Therefore it can be assumed that those who have taken part in Mutual Support were active within the settings, meaning that, for whatever reason, they have been labelled as having a learning difficulty. However, it must be noted that the two settings contrast starkly in relation to the choice on the part of those taking part as to their current and future situations within these and other settings. The issues surrounding the experiences of people labelled as having a learning difficulty will be returned to in the discussion on the application of the social model of disability to Mutual Support.

<u>Training</u>

A specific issue which is raised by a review of articles relating to research and peer support in other contexts is that of the training which "supporters" are given (Baginsky 2004). Many of the articles listed above involved a period of training prior to a monitored period of peer support. This is significant, as Mutual Support was retrospective in that the exploration was of situations which would have happened regardless of the existence of my PhD project. Any training within Mutual Support was relatively informal. The facilitators spoke about input from Tina Cook and Pamela Inglis around the best ways of supporting their peers. This advice occurred as the course evolved in response to specific issues within the course. "Training" was far less formal within The Lawnmowers, the support which has evolved over many years was based on the ethos of the organisation as opposed to structured training. Linked to the profile of formal training within peer support initiatives is that of the formality of the arrangement within the settings.

The issue of training also relates to the formality/informality of support networks in the lives of people with learning difficulties raised in the literature review (Atkinson 1986 Gold 1994), and the extent to which barriers to social interaction faced by people with learning difficulties necessitates a formality of arrangement (Emerson and McVilly 2004). Within Mutual Support, the contexts had been set up, and both had evolved over a period of time. However, the interactions spoken about by participants also reflected spontaneity and a depth of response to others that was not demanded. The issue of training and formality adds further to the role of non-disabled allies in facilitating the setting up of contexts that provide people with learning difficulties opportunities for empowerment through participation.

The purpose of support

Another issue which is relevant to the current discussion is that of the purpose of the support. Within the literature, the purposes of support included: motivation through telephone support (Dale et al 2009), early intervention focussed on improvement of well-being (Ho 2007), provision of social support for improved coping (Kumakech et al 2008), smoking cessation (Klatt et al 2008), initiation and long term continuation of breast feeding (Mac Arthur et al 2009), prevention of post-natal depression (Dennis et al 2009), recovery from addictions (Boisvert et al 2008), empowerment through decreased isolation, and through the role of supporting others (Schutt and Rogers 2009), improvement in recovery attitudes, spirituality and engagement (Barber et al 2008) and treatment of severe mental illness (Sells et al 2008).

A more specific conceptualisation of peer support and people with learning difficulties can be found in the work done on accessing Direct Payments (referred to in the literature review: Bewley and McCulloch 2004a, 2004b). This work is relevant to the aspect of peer education within Mutual Support, as it showed the impact of information around accessing Direct Payments being more significant when the exchange of information is between individuals within groups of people with learning difficulties. They refer to the "*unique role*" that people with learning difficulties who have already accessed Direct Payments have to play in informing and inspiring those who wish to do so.

Despite a lack of recognition of the significance of this support, the study highlighted the unique role that people with learning difficulties can have in supporting one another, in this case in accessing service provision. Relevant to this current discussion is the definition of peers within the study, the purpose of the peer support, and the training/formality of the arrangement. Within Bewley and McCulloch's work, their definition of peers is based on a commonality of barriers faced: access to direct payments by a marginalised group of people (people with learning difficulties). The specific purpose of that support is overcoming those barriers. The study started off searching for formal support within organisations, but then moved on to look for examples of more individual support. The emphasis is on the passing on of information and the inspiration to overcome barriers by people who had already successfully overcome similar issues.

The difference between the majority of the settings explored in the studies outlined above and Mutual Support is that they were set up specifically with the aim of fulfilling the purposes outlined through peer support. Mutual Support is about exploring the role and impact of peer support within pre-existing settings. It is therefore more beneficial to this discussion to return to the point from which the ideas behind Mutual Support originated: Centres for Independent/Inclusive Living.

Peer Support and the National Centre for Independent Living (NCIL)

In considering peer support within the context of the independent living movement and disabled people with a range of impairments, Bott (2008 p6-14) outlines the types of peer support:

- *people with an impairment or long-term health condition supporting other people with similar experiences (Bott defines these "self help groups" as the most common established form of peer support)*
- *peer support for people who are caring for others*
- *peer support to achieve a policy goal – for example, parents with learning disabilities campaigning for better recognition of their right to be parents*
- *peer support for people in challenging social situations*
- *peer support amongst worker groups*
- *peer support to combat social exclusion*

In the conclusion to this report, Bott (2008 p34) recommends that a national strategy should be developed by the Department of Health which specifically develops the role of peer support in the transformation of social care and personalisation. But where do people with learning difficulties fit into this strategy?

> *"the term peer support is not so widely used in describing the support people with learning disabilities give to each another, yet – to at least some extent – the term self-advocacy appears to involve similar activities"* (Bott 2008 p8).

It is therefore important to explore if and where the overlap is between the Mutual Support model of peer support and people with learning difficulties and self advocacy and people with learning difficulties. I will return to this issue in the final section of this discussion on findings which relates Mutual Support to the social model of disability, self advocacy and the disability movement (see pages 181-188).

Bott (2008 p21-23) outlines the NCIL's expert panel's summary of good practice in peer support: defining peer support was significant, as was defining the boundaries within which it happens. In addition to highlighting the blurred boundaries between self advocacy, independent advocacy and peer support, the report states that the boundaries between befriending, peer counselling and peer support are not necessarily clear cut. Within the area of training raised above, the NCIL's position was that some level of training, mentoring and supervision is needed. The report (Bott 2008 p22) also raises the issue of resources, linking adequate resources to standards of service. The importance of choice within a relationship taking place in a non-threatening environment where all involved are comfortable is also emphasised.

Referring to the "*transformation in the delivery of health and social care services*" which peer support and self advocacy have brought about the NCIL's expert panel, it is stated that "*it is therefore surprising and disappointing how little attention peer support receives in the context of national development and local delivery of social care*" (Bott

2008 p24). Within any consideration of service provision, time and resources are an inevitable factor. Put crudely, if people with learning difficulties are enabled to support one another with similar effects to those outlined in the Mutual Support model, service providers would save time and money. However, the significance and impact of Mutual Support goes far deeper than that, in the sense of purpose and fulfilment expressed by those who have spoken about giving and receiving support within this study.

At the centre of the independent living movement is inclusion and participation based upon the social model of disability. It is at this point that the discussion on Mutual Support turns to the social model as a tool for understanding the emerging model of peer support. Within this context, a model is viewed as enabling insight into situations that are hard to explain (Finklestein 1996) and a way to organise the knowledge that we do have about that idea (Uhrmacher 2006).

Mutual Support: applying the social model of disability

This final section of the discussion on findings applies the outputs of Mutual Support to the social model of disability. It begins with a justification of the use of the social model within the Mutual Support project. It then discusses issues raised when seeking to apply the social model to the experiences of people with learning difficulties. This is followed by a section which specifically applies the social model to Mutual Support by exploring the ways in which it does and does not break down barriers to inclusion. The discussion then moves on to explore a significant aspect of the social model in relation to inclusion and disabled people, that of individual vs. collective voice. This then leads to a discussion on the commonalities and differences between self advocacy and Mutual Support.

<u>Why use the social model of disability in Mutual Support?</u>

There has been much debate among disability studies academics as to the continuing use of the social model as a way of understanding disabled people's experiences (Shakespeare 2006, Sheldon et al 2007). Those who defend the social model of disability do so on the basis that it is not the social model which is conceptually flawed, but the fact that there has been too much debate on the issue and not enough effort put into applying it within practical and theoretical situations (Tregaskis 2002):

> *"in the last twenty years, we have spent too much time talking about the social model and its usefulness....and devoted too little time to actually implementing or attempting to implement it in practice" (Oliver 2009 p41).*

Too much debate and not enough applied use of the social model has resulted in loss of focus on the contextual use of the social model. Finklestein (2004) in particular has emphasised the application of the tool needing to be within specific contexts. Such implementation should include research situations, and Mutual Support is one such specific context.

It was this call to "stop talking the talk and start walking the walk" (Oliver 2009 p8) which inspired me to remain true to the idea which underpins the academic discipline from which I come. As well as my personal theoretical and conceptual ties with disability studies and, therefore, the social model of disability, the origin of the idea for Mutual Support, being located within the independent living movement (as outlined in the introduction to this thesis), was also based in the social model of disability. As a result, remaining with the social model of disability as the framework against which Mutual Support is evaluated makes the project more complete in coming "full circle" to where it originated from. In addition, with the exception of the fact that one of the participants has Down's syndrome, I know nothing about the impairments of the people who have taken part in Mutual Support. This makes a discussion on the social construction of impairment outside of the scope of this thesis, though others have debated this issue in detail (Goodley 2001, Goodley and Rapley 2001, McClimens 2003).

At the outset of Mutual Support, I had sought to move beyond the social model and had planned to apply a social constructionist understanding of learning difficulties to the outputs of the project (outlined by Burr 2003 and Rapley 2004). However, as justified above, and in response to the direction the research took as the project evolved, I returned to using the social model as a framework for understanding the model of peer support and people with learning difficulties as it emerged from this project.

However, it is important at this point to emphasise that the field of constructionism remains central to the methodology, and to the epistemological stance of knowledge production within research within Mutual Support. Building on the methodological stance which emphasises the construction of understanding the world being built in interaction with other people, the Mutual Support model of peer support and people with learning difficulties has been co-constructed through the research process. This discussion on findings, and the concluding sections of the thesis, take a step back from that model, applying it to the social model of disability. Oliver (2009 p116) articulates a vision of the research context and the purpose of the research process that resonates with my own: "*the research act is not an attempt to change the world through the*

process of investigation but an attempt to change the world by producing ourselves and others in differing ways from those we have produced before, intentionally or not".

The social model can also be used as a tool to understand the collective nature of Mutual Support at the same time as acknowledging the wide range of experiences and life situations of those who have been involved in the project. One of the issues raised within Mutual Support is that of diversity within the groups of people with learning difficulties, and between the two settings, which have been central to the research: does Mutual Support imply that people with learning difficulties are a homogenous group of people? It is clearly evident that, even with the small number of people involved, the group of people who have been referred to as "*people with learning difficulties*" are a heterogeneous group. One of the strengths of the social model as a tool for understanding the experiences of disabled people, and people with learning difficulties in particular, is that it acknowledges diversity. By focussing on the barriers to inclusion which people with an impairment face, the social model acknowledges that impairment is individual but that barriers to inclusion are faced collectively by people who have an impairment.

<u>The social model of disability and people with learning difficulties</u>

In questioning the relevance of the social model of disability to people with learning difficulties, the most obvious line of inquiry is to explore the extent to which people with learning difficulties experience oppression and discrimination: what is the evidence for barriers in society faced by people with learning difficulties? It is important to consider the nature of barriers to inclusion faced by people with learning difficulties, thinking beyond the physical environment (Boxall 2002). This links with the discussion around the place of people with learning difficulties within the social model of disability (Chappell, Goodley and Lawthom 2001).

Before moving on to apply the social model of disability to the outputs of Mutual Support, it is important to consider where people with learning difficulties as a group lie within theorising about the social model of disability. There are obvious barriers in terms of access to debate around the social model which excludes people with learning difficulties and their groups from participating fully in debate which has been central to the disability movement (Boxall et al 2004, Aspis in Campbell and Oliver 1996). The question arises, therefore, as to whether it is simply access to participating in academic/theoretical debate which has excluded people with learning difficulties from

being included in the social model, or whether there are fundamental issues with the application of the model to the experiences of people with learning difficulties:

> *"disabled for us means information problems but when we're talking about the social model, if information was accessible, then we wouldn't be disabled"* (Docherty et al 2005 p 40).

<u>Applying the social model of disability to Mutual Support</u>

The barriers to inclusion broken down by Mutual Support address the material and ideological constraints that surround relationships and people with learning difficulties that Chappell (1994) cites as central to a social theory of disability (see literature review, page 28).

As cited in the literature review, a group of people with learning difficulties explored the social model in relation to their experiences (Docherty et al 2005). They outline the barriers which disable people with learning difficulties: information which isn't accessible, jargon and offensive terminology, people's negative attitudes, people not listening to us, people being patronising, people who don't want to know and just walk away, and people who want to know you but just drop you afterwards (Docherty et al 2005 p35-38). Mutual Support proposes ways in which many of the barriers which Docherty et al outline might be broken down. Docherty et al's list of the barriers faced by people with learning difficulties is not a comprehensive list, but it is based upon direct experiences of people with learning difficulties, providing a basis on which to apply the social model of disability to Mutual Support.

With regard to accessibility of information, both groups involved in Mutual Support were using innovative ways of presenting information that might traditionally been in a written document that was inaccessible. However, what is significant to Mutual Support is the role that peer support played within those presentations of information. In the case of the Understanding Research course, this involved the interactive peer-mentored learning experience which enabled people with learning difficulties to access complex concepts. Within The Lawnmowers, the support relating to educating other people about the experiences of people with learning difficulties using Forum Drama enabled fuller participation by the actors and resulted in a presentation that was accessible to them and to others with learning difficulties.

Mutual Support also breaks down the barriers of jargon and offensive language which often disable people with learning difficulties. A direct example within the contexts of Mutual Support lie in exploring the barriers to understanding within the Understanding

Research course, and an exploration of ways in which students overcame those barriers through Mutual Support. The concepts which were being understood within the Understanding Research course were, by definition, jargon. The avoidance of the use of jargon was something that the advisory group from the course emphasised to me each time we met. The overcoming of the barrier of offensive language within Mutual Support has been most effectively evidenced in the interpersonal interaction, and demonstrated in the reclamation of dignity and respect outlined earlier in this discussion on findings section. However, perhaps most significant to Mutual Support are the final four barriers outlined by Docherty et al. These barriers all relate to interpersonal relationships and people with learning difficulties being regarded and treated as less than human. Again, it is the empathy and compassion expressed by the people who have been central to Mutual Support that is central to this breaking down of barriers.

It must be acknowledged, however, that Mutual Support does not provide direct evidence of breaking down barriers to inclusive relationships between people with learning difficulties and non-disabled people in general. There are many more steps needed in order for this to happen. The strength of Mutual Support has been an in-depth exploration within specific contexts. However, the issue of wider acceptance and recognition needs to be addressed through the dissemination process of Mutual Support and any further research that emerges from this dissemination process.

<u>Collective vs. individual voice</u>

When thinking about the social model and people with learning difficulties, specifically in relation to Mutual Support, it is important to acknowledge the distinction between the individual and collective voice (Dowse 2001). The fact that the disability movement was a response to individual disabled people coming together collectively to highlight the oppression they faced (Campbell and Oliver 1996) is relevant to the outputs of Mutual Support. The majority of the formal data collection within Mutual Support involved individual interviews. However, the peer support spoken about by those individuals within the specific group settings, and the emerging model of peer support, portray collective support with the potential to break down barriers, for example through peer mentoring and support within inclusive employment opportunities.

As stated in the literature review, Goodley (1997) related individual models of disability to dependence and the social model of disability to independence and choice. It is therefore significant to this discussion on Mutual Support and the application of the

social model of disability that the emerging model is one of individual interactions coming together in a collective model of support, breaking down barriers to independence and choice. One aspect of the disability movement has been groups of disabled people uniting on the basis of common experience and supporting one another: might the evidence from Mutual Support raise the profile of people with learning difficulties to do so, and therefore result in their being more included within mainstream disability movement?

Mutual Support and the self advocacy movement

As stated in the literature review, Mutual Support builds upon the success of the self advocacy movement and people with learning difficulties. As this section of the discussion on findings is concerned with relating the Mutual Support model to models of disability, it is useful to first explore work done relating to the self advocacy movement and models of disability. However, it is also important to acknowledge that there are differences between self advocacy and Mutual Support.

Research cited in the literature review (McVilly et al 2006a, 2006b) stated both the importance of friendships to people with learning difficulties within the self advocacy movement, and that it was an area in which important work was yet to be done. Mutual Support has built on this work. In many ways, self advocacy is part of Mutual Support in relation to the effect of breaking down barriers to inclusion through individual participation, leading to collective empowerment. However, Mutual Support is also more than self advocacy in terms of the strength of interpersonal interaction and support that have emerged.

Goodley (1997) locates self advocacy within models of disability. He states that self advocacy is based on the user participation paradigm, and that the collective action and speaking up for rights challenges individual/medical models of disability. He also emphasises the key tenet of the social model: self determination which challenges notions of impairment, inadequacy and limitation. The collective self determination of people with impairments can be no more evident than in the self advocacy movement.

There are significant implications of the collective activity which have emerged from Mutual Support, implications which question the model of individuals with learning difficulties needing to be changed in order to conform to normality, and which support the argument for the social model of disability. This is specifically demonstrated within the support within the context of teaching and learning, which was central to the Understanding Research course but also significant within The Lawnmowers (and

becoming more so as peer mentoring is developed through the courses which are now underway).

A further example of the collective nature of Mutual Support is demonstrated in the aspects of education that are relevant to Mutual Support. Traditionally, education and learning is viewed as an individual activity, especially with regard to the systems used in assessment which are pivotal in any individual's progression through the system (Gergen 2009). However, every aspect of teaching and learning which the participants spoke about within Mutual Support was within the context of collaboration which drew on interpersonal dynamics. For me, this was emphasised when the facilitators corrected my conceptualisation of their role as one-way, stating that the students supported them within their roles as facilitators.

In relating the outputs of Mutual Support to models of disability, it is important to consider the ways in which methods of support "*reflect and reproduce discourses of disability*" (Goodley 1998 p440). Llewellyn (2009 p846) developed this idea further by exploring the support given to people with learning difficulties within focus group settings. She explored the support given to people with learning difficulties who had come from different contexts: a long-stay institution, a day centre and a self advocacy group, and concluded that "*the philosophy by which supporters of people with intellectual disabilities in focus groups are influenced may have important effects on the individuals within the groups and on the results of the study*". Williams et al (2009), in exploring relationships between people with learning difficulties and their personal assistants, also related the approach to supportive relationships to perceptions of learning difficulty.

Mutual Support has further developed this idea by exploring the support given by and for people with learning difficulties within group settings. The philosophy behind that support has formed the basis of how learning difficulty is perceived within Mutual Support.

Perceptions of learning difficulty

In considering perceptions of learning difficulty, the literature review referred to philosophical discussion surrounding what it means to be human (Judge 1987, Parmenter 2001). The medical deficiency model which has influenced perceptions of learning difficulty was also referred to (French 1999, Johnson and Traustadottir 2000, Hamilton and Atkinson 2009). The literature review then linked these perceptions with the lack of opportunities available leading to marginalisation and oppression (Stainton

1998, Learning Disability Coalition 2008). It is therefore important to consider the perceptions of learning difficulty which have emerged from Mutual Support. It is also important to acknowledge that perceptions of learning difficulty within supportive relationships directly influence the form those relationships take (Coles 2001).

From the outset, Mutual Support sought to challenge assumptions about what people with learning difficulties are unable to do, replacing them with notions of what can be done with appropriate support. As I have said elsewhere, the scope of support given and received went far beyond my expectations. It was based on a philosophy of treating others with learning difficulties with dignity and respect. The philosophy of both settings within Mutual Support, reflected in quotations from participants, is that of never underestimating potential: this can be related to aspects of self determination in challenging notions of impairment, inadequacy and limitation.

Mutual Support: contributions to discussion/debate

Before bringing this discussion of findings section to a close, two of the aims of the project will be discussed: the contribution to current debate on service user involvement and the contribution to the academic field of disability studies.

Mutual Support: contribution to service user involvement debate

The literature review cited Holman (2008 p13) speaking about relationships and people with learning difficulties in relation to service provision. He stated that friendship should be considered within preventative services. It would be possible to think of Mutual Support as "*one option to at least get people out of the house and meet others*" (Holman 2008 p13). However, Mutual Support goes far beyond that in terms of participation leading to empowerment. Within the service user involvement debate, it is also important to note that people with learning difficulties outside of the specific contexts were supported through Mutual Support.

Mutual Support contributes an in depth exploration of the interpersonal interactions which took place within a model of peer support which leads to empowerment through participation. It is significant that this model is based in groups of people with learning difficulties who have not always been central to mainstream user involvement initiatives. As stated in the literature review, it can be possible for organisations to claim involvement of those who use their services without truly involving service users and their views (Mercer 2004, Beresford 2003). The model of peer support which has emerged from Mutual Support is one of people with learning difficulties being extremely

involved in supporting one another. This justifies the contribution of Mutual Support to a movement which prioritises full, meaningful participation.

Mutual Support: Contribution to current disability studies debate

Mutual Support's contribution to the academic field of disability studies is rooted in the fact that people with learning difficulties have not always been included in theorising about disability (Chappell 1998), leading to Docherty et al (2005 p42) locating themselves as people with learning difficulties "*right at the bottom, so we're like the doormat of disability".*

Like all disabled people, people with learning difficulties face barriers to inclusion. These barriers may differ, but the prejudice faced by many disabled people can be more acute for people with learning difficulties. Mutual Support has challenged assumptions that people with learning difficulties lack the ability to join together and challenge those barriers collectively. Mutual Support has also shed light on interpersonal interactions within that collective challenge.

Therefore, Mutual Support presents a challenge to the field of disability studies to explore the barriers which have left people with learning difficulties feeling excluded from mainstream disability studies. Mutual Support also proposes that the social model of disability remains a useful tool for understanding the experiences of disabled people within contexts which promote empowerment through participation.

The table (overleaf) summarises the similarities and contribution of Mutual Support to self advocacy, service user involvement, the social model of disability and the Disabled People's Movement. It also outlines the implications of Mutual Support within these key existing   models   of   support   and   service   provision.

	Similarities with Mutual Support	Contribution of Mutual Support to.........	Implications............
Self Advocacy	People with learning difficulties challenging discrimination and speaking out about rights; origins in oral history research; people with similar experiences supporting one another; strength of supporting one another within above.	Builds on self advocacy with evidence of the depth and meaning of interpersonal support. Provides evidence for insight into support for people with learning difficulties by people with learning difficulties and its strength and purpose	Mutual Support could be developed further within self advocacy settings; where people with learning difficulties are supporting one another, that support could be built on to challenge discrimination, speaking out for rights
Service User Involvement	Based on a model of "bottom-up" service provision; based in the views of people who are considered experts based on their direct experience. Emphasis on empowerment through participation.	Highlights meaningful participation by people with learning difficulties (who are not always acknowledged within movement); evidence for peer support being applicable and effective within many aspects of service provision	Mutual Support is a potential aspect of service development that involves meaningful participation by people with learning difficulties which leads to self determination and empowerment. Also provides evidence for meaningful involvement and people with learning difficulties
Social Model of Disability	Focuses the issue on barriers in society, not what is 'wrong' with an individual; in particular through challenging ideas that people with learning difficulties lack capacity to support one another and break down barriers to learning	Mutual Support is a tool for breaking down some of the barriers to inclusion faced by people with learning difficulties; for example barriers in learning processes through peer mentoring	Mutual Support is a creative example of ways in which people with learning difficulties are breaking down barriers in society. The challenge is to ensure that this is recognised by wider society
Disabled People's Movement	Collective movement of disabled people speaking out against discrimination; the strength of support that comes from uniting with others who have had similar experiences	Parallels with DPM suggest that contributions from people with learning difficulties should be more widely acknowledged within DPM	DPM should be challenged to think about barriers that have marginalised people with learning difficulties

Discussion on findings: conclusion

This discussion on findings began by justifying the bringing together of the experiences of peer support within the two differing settings. Having acknowledged and explained the differences in the language used by participants, the structure of the settings, and the formality/informality within each setting, the findings were brought together by exploring the nature of the support, including who was involved. This led to a discussion on the role of non-disabled allies, during which a "layering" of support based on a model of inter-dependence promoting autonomy and self determination was proposed.

The exploration of the nature and scope of peer support included the conditions under which Mutual Support happened, highlighting the significance of the interpersonal interaction spoken about by participants. This led to a consideration of the effects of Mutual Support. These effects are represented in the third level of the diagram on page 170. They form the basis of my proposal of Mutual Support being a model of inclusion for people with learning difficulties.

The second section of this discussion on findings explored the issues which arise from looking at peer support within other contexts: defining "peers", training given to peer supporters, and the purpose of the support. It was the report from the Centre for Independent Living which most closely mirrored the emerging model of Mutual Support. This then led to a consideration of Mutual Support in relation to the social model of disability.

Due to recent debate, it was necessary to justify the use of the social model within this context. This justification led to a consideration of the nature of the barriers to social inclusion faced by people with learning difficulties. The ways in which Mutual Support directly addresses many of the issues posed by those barriers were outlined. This includes accessible learning situations and the prejudice which assumes people with learning difficulties to be incapable of interaction with others.

Having considered the evidence from accounts of peer support, and related this to models of disability, I conclude that Mutual Support is a collective model of support which challenges assumptions about the role and impact of people with learning difficulties supporting one another. Mutual Support has the potential to break down barriers to inclusion and demonstrates the value that people with learning difficulties place on giving and receiving support.

PART THREE SECTION THREE:
Discussion on Methodology and Methods Used

This section discusses the methodology which was used within the project. It reflects the need for continual reflexivity on the part of researchers seeking to implement an inclusive approach to research, in order to "*expose the real dilemmas that we face in meeting the challenge of inclusive research*" (Porter et al 2006 p11). This detailed exploration of the pros and cons, practicalities and pitfalls has been kept separate from the outline of the methodology in Part Two in order for clarity within the former section to be maintained. Within this discussion, it is important to distinguish between methodology (the theory of the approach to research) and the methods used (which are determined by the methodology).

Throughout this section of the thesis, the limitations of the methodology and methods used will be acknowledged, as will ideas for changes in research design which would be made if embarking on the project again, or when involved in similar projects in the future. This reflects the fact that, unlike many people coming to the PhD process, this is the first significant research project in which I have been involved. If I were to be carrying out similar research in the future, the learning process within Mutual Support would be a foundation upon which to build. I have no qualms in stating that there are factors within the process which would be different were I to be starting the project again with the knowledge and experience I have now. As such, my position as a researcher has been that of a learner (Clough and Barton 1995).

This discussion on methodology/methods is divided into three sections. The first section explores the research process in relation to the ideal of inclusive research. It takes each of the aspects of Walmsley and Johnson's (2003) definition and asks how far each of the ideals were met within Mutual Support. The second section of the discussion is a more in depth consideration of the complex ethical issues which have surrounded the research process, including the ethical approval process.

The third section of the discussion outlines the limitations of the research processes used within Mutual Support, including a consideration of other approaches which might have been used. The overall summary of this section will address the central question: how firm were the methods used to build Mutual Support?

Inclusive Research?

As stated in the methodology section of this thesis, the ideology underpinning the approach to research within Mutual Support has been an inclusive one. Within this approach, there has been an emphasis on the co-construction of knowledge in the interaction between myself and the people with learning difficulties who have taken part. This section of the discussion on methodology and methods used is based upon the definition of inclusive research and people with learning difficulties outlined by Walmsley and Johnson. It answers the questions which are raised by the five points in their definition (2003 p64), evaluating the extent to which Mutual Support has been an inclusive research project.

The issues surrounding how inclusive the research process has been are directly relevant to the evaluation of the co-construction of knowledge within the building of Mutual Support: if the participants were not included within the research processes, there would be little basis for the conceptualisation of the Mutual Support model of peer support and people with learning difficulties as a co-construction.

The discussion below takes each of the five aspects of Walmsley and Johnson's definition of inclusive research in turn, evaluating the extent to which the ideals of inclusive research were or were not attained within Mutual Support. This includes recognition of the complexities of involving others with a PhD research project. It must also be recognised that discussion around the efficacy of a research project must acknowledge that it is impossible to know the effects of a project (in this case, in the lives of people with learning difficulties) before considerable time has elapsed since the project (Jones 2008).

1. Was the research question owned by disabled people?

The notion of ownership implies possession, and the extent to which something belongs to the person or people who own it. One of the foundations of emancipatory research, characterised by its development alongside the disabled people's movement, has been the ownership of the research (Ward and Simons 1998, McClimens 2004).

Ultimately, a research question based on an emancipatory approach to research would be owned by disabled people and their organisations and would lead to emancipation (freedom from oppression) for disabled people (Barnes 2004b). Similarly, a pure participatory approach to research and disabled people would involve a group of disabled people identifying an issue or situation which they want to research and

approaching a researcher for support, or a researcher approaching a group of disabled people and asking them what they would like to research, leading to a research question which would be "owned" by that group of people (French and Swain 1997). I cannot claim that either of these ideals were attained within Mutual Support.

However, within Mutual Support there were ways in which the forming of the ideas behind the project were directly influenced by the views of disabled people. Walmsley and Johnson specifically refer to the research *question* in this element of their definition of inclusive research. The research question within Mutual Support has changed and developed based on the way in which the project evolved. This is evidence of the ownership of the research question *becoming* more owned by those who were taking part, also based on literature.

If I were asked to make a statement about the ownership of the research question at the stage of writing up this thesis, I would propose that it is joint between myself and the participants. Other groups of people with learning difficulties have influenced the development of the research question. This has included the informal contact I have had with groups locally and literature which prioritises the views of people with learning difficulties, including grey literature such as websites and other promotional material as well as academic literature. This formed part of my contribution to the mutual construction of knowledge within the project.

This mutual construction began with my engaging with current literature which prioritises the views of disabled people who are part of the independent living movement. As stated in the introduction to this thesis, the idea evolved from the concept of peer support/peer counselling being one of the seven aims of Independent Living, within a large scale research project which emphasises the need for meaningful dialogue between researchers and research participants (Barnes and Mercer 2006; Barnes, Morgan and Mercer 2001).

When considering the ownership of research, it is important to conceptualise research within the wider context of disabled people's struggle for change, which is greater than any one single project:

> *"Emancipatory disability research is not a unitary project or group of projects, but rather an ongoing process determined by disabled people and their organisations"* (Barnes and Mercer 2006 p68).

As a project, Mutual Support builds upon work already done which is based on the views of disabled people, therefore contributing to this ongoing process.

The informal contact I have had with people with learning difficulties who have not directly participated in the project has also influenced my thinking, adding to the sense in which the ongoing development of the research process has belonged to people with learning difficulties. Within these groups, people's responses have been characterised by an enthusiasm for what I have been doing. The following quotation from one of The Lawnmowers actors is an example of the views expressed by many people with learning difficulties and their supporters with whom I have had contact over the last three years:

> Sarah: Is there anything you want to ask me, either about what I'm doing, or about how Monday went, or?
>
> Dean: Not that I can think of.
>
> Sarah: Is there anything that...?
>
> Dean: Only that you're doing a brilliant job, and that you're doing a great project and that you should keep up with it, and hope it all goes well (November 08).

However, the dialogue which follows this quotation would suggest that Dean was viewing the research process as helping me move forward with my studies:

> Sarah: Is there anything else that we should've talked about today, that we.....?
>
> Dean: Not that I can think of. I think you've covered every aspect and every angle and obviously you'll be asking everyone these questions, and I'm sure you'll get lots of, you'll probably different feedback from different people, and obviously it'll all be good and help you move forward with your studies, and that's the main thing, that it helps you (November 08).

This quotation calls into question the idea that the research was owned by those taking part, as it suggests that Dean saw the purpose of the research as being the completion of my studies. It is therefore important to consider what I see as the purpose of my studies. This question is addressed in the sections which follow.

2a. Did the research further the interests of disabled people?

At the end of the day, the ultimate aim of the project was about my getting the input which I needed in order to present a thesis at PhD level. However, the opportunities which this process has afforded for self development and growth has meant that, for me, the last three years have been about far more than gaining a qualification. Part of

this has been a deeper understanding of the experiences of people with learning difficulties, which I hope is evident in this thesis, and which, as a result, makes this thesis a furtherance of the interests of disabled people.

In addition to this, neither of the settings in which peer support was explored were contrived. The project sought to look at work which was already taking place by exploring an aspect which had not been considered in detail before. By building on existing work in this way, the project started by looking at things which were already important (i.e. were within the interests of people with learning difficulties) and exploring the factor of peer support within this.

Similarly, the report from the National Centre of Independent Living (Bott 2008) clearly states that peer support is important to disabled people who are part of the independent living movement, both on a personal/social level and also at a policy level. Bott (2008) also refers to the lack of qualitative work done in this area, especially in relation to people with learning difficulties. In this way, the exploration of peer support and people with learning difficulties furthers the interests of disabled people who are represented by the independent living movement, specifically the UK Centre for Independent Living.

2b. As a non-disabled researcher, was I on the side of people with learning difficulties?

My answer to that question is "I hope so. I wanted to be. I tried to be on the side of people with learning difficulties". It is important, however, to consider the role of non-disabled researchers in the research process (Williams and Simons 2005).

A tangible example of the welcome which people with learning difficulties gave to me in the context of Mutual Support took place the first time I was invited to attend the Skills for People Programme Committee. They had looked at the information sheet I had left with them the week before. At the beginning of my slot on their agenda, they welcomed me with a round of applause, stating that they were clapping because I had gone along to find out their point of view – something which they do not always experience.

The ethos behind the methodology within the project was based on making the process accessible at the same time as not being condescending in the way I approached people with learning difficulties. The valuing of people's stories as authentic and worthy of being listened to has also been essential. This is discussed further in the sub-section of this chapter which explores narrative research. Part of the *"being on the side of disabled people"* which I have sought to do has been in answer to the most common

reaction which people make when told about the project: 'they must have very mild learning difficulties then,' or 'why would that be important?' It has been important throughout this project to acknowledge that a learning difficulty is not a learning-can't. It has also been important to think about the varied and diverse ways in which people communicate and interact with one another.

A measure of whether or not the approach taken to the project was on the side of disabled people is the extent to which the project has done anything positive for the groups of people who took part. One way in which I sought to give back to The Lawnmowers was by writing reports, one on the Action Research Project mentioned on page 164, which involved The Lawnmowers actors as peer mentors, and another on an aspect of Inclusive Practice, which involved a conceptualisation of people with learning difficulties as educators based on the November 2008 performance at Coach Lane Campus, Northumbria University. This enabled The Lawnmowers' voice to be heard in the forum of Centres for Excellence in Teacher Training and LSIS (Learning and Skills Improvement Service).

However, as Barnes (1996) points out, the concept of an "*independent researcher*" is a "myth". There were factors which influenced my independence to align myself wholly with disabled people. These factors included the R and D committee's response to my initial proposal. Other factors were the research climate, University ethos, funding, time and training available.

3. Was the research collaborative – were people with learning difficulties involved in the process of doing the research?

The notion of collaboration implies working together on a defined task. It also refers to teamwork and partnership, implying that those working together on the defined task had equal responsibility and influence. This point, then, refers to people with learning difficulties working together in equal partnership with a researcher in the process of doing the research. This is arguably the weakest area of Mutual Support in terms of the extent to which the approach was inclusive. As Chappell (1999 p110) states

> "simply encouraging people with learning difficulties to speak out about their experiences via research does not, in itself, guarantee people with learning difficulties any control over the research process".

I did pursue the idea from the first meeting with the Skills for People Programme Committee of their doing some of the interviewing at the hospital. I was inspired by the idea, and my supervisors endorsed it. However, it seemed as if the process of getting

access to meet with people myself was sufficiently complicated that introducing the practicalities involved with others doing some of the interviewing seemed insurmountable within the resources and time available. For example, I was required to obtain an NHS honorary contract, including Occupational Health assessment. There were also complications surrounding funding for this idea, and arranging transport.

This is an aspect of the project which I would like to build on in future research. However, throughout the project I was keen to "*break down traditional hierarchical relationships between researchers and research participants*" (French and Swain 1997 p26). This is an important aspect of collaborative research, and is reflected in Chris' evaluation of my approach to the research at the feedback meeting in October 2009 (see Part Three Section One, page 147).

<u>4. To what extent were people with learning difficulties able to exert control over the process and outcomes?</u>

One of the aims of setting up the two advisory/reference groups was specifically in order for the process to be influenced by these groups. However, I would say that the concept of "influence" over the research process as opposed to "control" better reflects their role. This was partly due to the straight jacket which the ethical approval process became to me. This significant factor is discussed further in the discussion on complex ethical issues section of this discussion on the methodology (see pages 98-204).

Some of the decisions made (e.g. not having the CDs done by advisory groups) were made from the perspective of practical/time issues. There was a need to be realistic about the resources available. Maybe I would have had more time for this had I not spent so much time and effort in getting through R and D. Issues also arose relating to the practicalities of organising the advisory group meetings and their timing within the project.

Rather than seeing the question of whether disabled people have had control over the research process as an either having control or not having control dichotomy, Barnes and Mercer (2006 p57) identify a continuum of "weak" to "strong" direction over the process. The situation of Mutual Support along this continuum differs between the two settings.

Within The Lawnmowers, I sought advice from those taking part; in particular one actor advised me about how the project was being received and assured me that I would be

informed if there were any aspects of the project which anyone was unhappy or anxious about:

> *Sarah: First of all, it probably seems like quite a long time ago, cos you've all been very busy, but how have the Lawnmowers felt about the previous couple of visits that – How've they been?*
>
> *Chris: As far as I know everyone was OK, everyone felt happy,*
>
> *Sarah: And people have been able to say if they were anxious or...*
>
> *Chris: Yep. But no-one's said anything, so everything must have been OK.*
>
> <div align="right">*(June 2008).*</div>

Similarly, when I met with the group in order to introduce information sheets, I took along a list of issues which I wanted to cover in the meeting, including asking them about their involvement and what the project might be able to do for The Lawnmowers. We also listened together to the audio CD at this meeting. As soon as I came away from the meeting, I went through the notes, evaluating the extent to which the points had been covered.

From my point of view, people with learning difficulties had influence over the research process and outcomes in the following ways:

- The methods used drew on the outputs of Cook and Inglis (2007) and the men involved in the Understanding Research course, in particular the information sheets. The way in which the advisory group critiqued the information sheets was central to this.
- The input from Skills for People applied ideals which are at the centre of self advocacy groups to the specific context of the research (in the format which I was proposing at that time).
- My own thinking was influenced by the informal contact which I had with local groups of people with learning difficulties – especially the considerable time spent hanging out with The Lawnmowers.

The Lawnmowers spoke about aspects of the research process and their experiences within it during the feedback and evaluation session. Direct quotations from this discussion can be found in the Part Three Section One (pages 147-148).

5. How accessible was the research question, process and reports to people with learning difficulties?

When considering the accessibility of a research process, it is easy to focus solely on the information sheets and the reports. These aspects, though important, emphasise accessibility at either end of a project without considering the process in between. Here, Walmsley and Johnson (2003) also highlight the importance of accessibility of the research question and process. These aspects have been important within Mutual Support. When considering the accessibility of the research question and process, it is necessary within the context of a PhD project to separate the presentation within a thesis from the way in which the process is accessed by people with learning difficulties.

Walmsley and Johnson themselves state that there is a place for debate within academic circles, as long as it takes place alongside an inclusive approach to research. There are, however, complex issues surrounding journal articles that discuss emancipatory research but remain inaccessible to the majority of people with learning difficulties (Garbutt 2009). Therefore, perhaps the relevant question at the stage of writing up this thesis with regard to accessibility is: how accessible were the relevant aspects of the research question and process to people with learning difficulties? A measure of the accessibility of the research question, emphasised in the way it is presented to participants, is the extent to which people engaged with the topic. The advisory group from the Understanding Research course shed light on the importance of questions within the research process: "*good questions get good answers".*

The accessibility of the process needs to be unique for each individual, particularly in relation to the individual interviews: it was important to be sensitive to the level of assurance needed by each individual. What was being assured for one participant would have been condescending to another. This also related to the iterative process of consent which will be returned to in the ethics section of this discussion on methodology.

Within the context of a PhD project, it is very hard to produce a thesis which is accessible to people with learning difficulties at the same time as satisfying the University requirements. However, it is also important that the views expressed by those who took part in the project and the model of peer support on which these have been built are not left to gather dust on a shelf of the British Library, or an electronic database of theses full of long words which I don't understand either.

The feedback meetings which are summarised in Part Three Section One of this thesis, and the accessible summaries which evolved during these meetings, are the beginnings of dissemination. I also need to address the challenge of how to disseminate the findings of this project among practitioners and wider groups of disabled people.

Summary of evaluation of aspects of inclusive research.

The following section summarises the above discussion which evaluated the methods used in Mutual Support in the light of Walmsley and Johnson's (2003) definition of inclusive research and people with learning disabilities. The research question was decided on by myself, though it was inspired by inclusive literature, and developed throughout the process in response to participants' views. Within the remit of a PhD project, it belonged to myself in conjunction with those taking part and other groups of people with learning difficulties, including in response to relevant literature. By taking pre-existing projects involving people with learning difficulties, by looking at peer support as an aspect of their work, and in basing the work on literature which indicated that more research should be done in this area, the research did further the interests of people with learning difficulties.

I sought to be on the side of people with learning difficulties throughout the research process. There were instances of personal recognition from those taking part. In every aspect of the project, it was my aim to be true to the views expressed by participants and within relevant literature. There was little work done by people with learning difficulties on the actual process of the research, meaning that it is not realistic to claim collaboration in the research process. The valuing of participants' views and the way in which theory was based on this meant that the outputs of the research were collaborative.

Linking back to the outputs of the Understanding Research course enabled a more inclusive approach across all five aspects of the research which have been critiqued using the definition of inclusive research above. The use of advisory groups meant that people with learning difficulties did exert some influence over the research process. This process was adapted in response to participants' advice. An inclusive approach to research echoes the advice I was given in the initial meeting with the Skills for People Programme Committee.

Dissemination of findings is an ongoing process. Accessible summaries have been developed with people with learning difficulties in mind. Some dissemination will take place within more academic settings, but the views expressed by those taking part in Mutual Support will be prioritised within any report, remaining true to the views expressed by participants.

<u>Mutual Support: contribution to debate on inclusive research and people with learning difficulties</u>

Mutual Support has provided insight into the application of an inclusive approach to research with people with learning difficulties by a researcher who was passionate about making the research process inclusive but who did not have direct experience of wide scale inclusive research. The fact that Mutual Support is a research project enables insight into the tensions of bridging the gap between people with learning difficulties and academic research. The process of getting approval for part of the project through an NHS ethics committee is also significant to the contribution. Perhaps the most important aspect within the inclusive approach has been that of continual reflection, and a realistic evaluation of what has and has not been attainable within the ideal standards of inclusive research. This section of the thesis in particular has set out to evaluate the process realistically.

Complex ethical issues....

This sub-section of the thesis discusses in more detail the ethical principles underlying the project and how these were applied within the research situation. It includes some of the complex issues that arose within the research process. This section discusses the complexities of applying these ideals by outlining examples of situations which arose and how they were resolved. Again, this has been kept separate from the ethics section of Part Two Section One as discussing them at an earlier point would have made that section more complicated than ideal in order for the reader to understand the presentation of findings.

Each element of the research process will be considered in turn. This begins with a critique of the ethical approval process, and the ways this process have influenced the research process and outputs. This is followed by consideration of ethical issues relating to the consent process, data collection, and data analysis/interpretation. A significant aspect for consideration within ethical research, particularly research and

people with learning difficulties is that of power. This issue will be returned to in relation to specific aspects of the research process.

The ethical approval process

> *"ethical actions cannot be judged entirely on the principles by which research is planned and conducted"* (Swain, Heyman and Gillman 1998 p22).

As stated above, there is a distinction between gaining the approval of ethics committees and doing ethical research. However, it is essential that all research is governed and monitored in order to ensure its quality, and the safety of participants and researcher (Ellem et al 2008). Research governance is particularly important within research which involves people with learning difficulties, often described as '"vulnerable people".

Within Mutual Support the different settings required different protocols. The study on peer supported learning which focussed on the Understanding Research course required approval within the NHS at both R and D level and LREC. It was the R and D approval stage that dragged on for over a year. Looking back, it is hard to ascertain the exact reasons for this, and therefore any discussion within this thesis would be merely speculative. I do acknowledge the lack of clarity in my initial proposal which led in part to complications within the approval process in the first place. This discussion of the ethical approval process will focus on the influence which the protocol within the proposal which was finally approved by LREC had on the research process, and the ethical issues which this raised.

Within this research situation, the main source of power imbalance stems from past exploitation within a research context where researchers have enforced power over participants. Stalker (1998) posits that the tendency which some people with learning difficulties have towards acquiescence has been constructed by the way in which so many aspects of their lives are controlled by other people. The main way in which I sought to redress this power imbalance was through the implementation of an inclusive approach which put the views of participants at the centre. However, this ideal is hard to maintain within current ethical approval systems.

Understandably, it is necessary to outline the methods which will be used in the research context and have these approved by experienced researchers and others who will be aware of potential ethical issues. The sticking point in this cycle comes at the point where a researcher does not have permission to ask participants about the process prior to gaining ethical approval. Within the NHS, the Research Ethics

Committee (REC) was formed to oversee traditional medical research such as drugs trials. Such research is easier to define before it takes place (Rodgers 1999).

Throughout the active research, I often felt restricted by the nagging thought of "is what I am doing in this situation specifically outlined on the ethics document?" I found this disempowering. I am not saying that a researcher should have free rein to do anything. However, a system in which the nagging thought is "is what I am doing within a high standard of ethical research?" would have been more conducive to a transparent project which adhered at all times to a highly ethical approach to research.

For example, in the case of all three students from the Understanding Research course, staff specifically stated that they would be happy for me to meet with the men without staff presence. However, as my ethics document had stated I would always have a "chaperone" I was unable to do so. The fact that staff were present at all times must have influenced the interaction between myself and participants.

Similarly, the way in which the ethical approval process is based on a one-off document written at the beginning of the research process does not allow for the researcher to respond to situations as they arise. The fact that the original document has to be adhered to could potentially result in the researcher being unable to adjust their approach to make it more ethical. In an article on the application of social research methods within the NHS system, Richardson and McMullan articulate these issues:

> "*Once approval has been given, no changes can be made, either to the protocol or to any of the accompanying materials (participant information sheet, questionnaires, interview schedules, consent forms etc.) without going back to the REC and the Trusts to gain permission for the change. There are obvious practical problems with the system; for example with conducting iterative qualitative research, which dictates that much of what is required to be known by the REC before the start of the research cannot possibly be known until the research has begun and some data have been analysed*" (2007 p1119).

Baxter et al (2001 p90) refer to the "protection principle" by which ethics committees are guided having the potential to conflict with the empowerment of participants in the research process. However, from a personal point of view, now that I have direct experience of a research project in which an inclusive process was the target, I have a firmer foundation on which to build research proposals in the future.

As outlined in Part Two Section One, the research process took different forms within the two different settings. Issues which were raised by these differences include:

- the role(s) of gatekeepers in the process,
- the way information intended to help potential participants to decide whether or not they take part is handed over to them,
- the forum in which they look at/listen to this information,
- the format which this information takes,
- and the formality of the consent process, including the use of consent forms and the setting in which data collection took place.

The discussion now moves on to consider those specific elements of the research process and ethical issues which arose within them.

The consent process: complex ethical issues

Gate-keeping

The consent process is influenced by a number of factors, including the way in which a researcher is introduced to potential participants. Factors within this include who introduces the idea of taking part to people. Wiles et al (2005) identify two specific problems relating to gate-keeping: over-protectiveness and failure to provide opportunities for participants to choose whether or not to take part.

In the case of The Lawnmowers, the first contact which I had was with the Project Manager and Artistic Director. However, I introduced myself and the project in person, being present when the actors first listened to the audio CD. In contrast, it was staff at the hospital where the Understanding Research course had taken place who specifically introduced the possibility of taking part in my research to those who had taken part in the course. However, Tina Cook had mentioned my project to them previously, and it was evident throughout my contact with participants that they associated our meetings with the positive experience of having done the course:

Sarah: Is there anything you want to ask me?

Dan: No. Apart from how's Tina?

Sarah: How's Tina? Tina's fine......

Dan: Tell her I was asking after her.

Sarah: I will do, yes, and I mentioned to her what you said about the second part of the course that you'd done with her as well, and she's working on it. She knows that you're all really keen to get on with more (First interview).

<u>"Researcher misconduct" or too rigid a system?</u>

A concrete example of the potential for confusion within a rigid approach to recruiting participants occurred during the consent stage of the research process at the hospital. As per the outline which had been approved by LREC (see appendix B page 242) the forensic services manager worked from a list of those who had taken part in the course. Having been given staff contacts for the potential participants, I left information sheets and audio CDs for staff to look at with the men. I then arranged to meet with those who were still interested.

On the second occasion, I was introduced to a gentleman who was happy to chat, but said he knew nothing about the course. Driven by my trust that the system for recruitment was infallible, I told him I would bring along some of the materials from the course to the interviews, and that I was sure he would remember them. He then signed the consent form, both pages, and I and the member of staff who was there witnessed – six signatures in all.

The next day I was chatting with Tina Cook, partly about this gentleman as I was trying to think of ways of supporting him to "remember the course". She said she did not know that name, and certainly did not recognise my description of him. We went back to the list which the forensic services manager had worked from, and Tina confirmed that, though he was on that list, he had, in fact, not taken part in the course at all. No wonder he couldn't remember it! I went along to the meeting which I had arranged with him, in order to apologise for the mix up: "I told you I didn't know anything about it" he said - I apologised, we laughed - and I thanked him for having been willing to take part.

I came away from this incident challenged on a personal front by the way in which I had taken authority from the staff as opposed to the person themselves. But I also wondered how frequent the occurrence of power wrongly enforced through false knowledge influences the lives of patients within this setting. This situation was partly precipitated by the system which had been put in place. The way in which I approached potential participants through staff who I had approached through the services manager was supposed to make the whole process more ethical, but in the end did not seem a very ethical process, at least for one participant: what if a similar mistake had been made within a drugs trial or a more invasive research study and it had not been realised soon enough?

My answer to the question raised in the sub-heading to this sub-section is that I did make a mistake, and that is something I learnt from and am glad it was put right when it

was. However, I can also see ways in which my meeting potential participants might have been more relaxed and therefore more ethical.

Consent forms and information sheets: the ethical issues

A more general issue, relating to consent forms and information sheets, surrounds the formality which they introduce to the researcher-participant relationship. This was especially evident within the consent forms within the NHS setting, as the participant, member of staff and myself had to sign both pages: this made the consent process, and potentially the whole research encounter, more formal. Similarly, does the complexity of covering all eventualities actually lead to creating issues which did not exist? Wiles et al (2005 p8) highlight the potential that "labouring the point" has to put people off taking part in research.

However, the issues which were outlined on the consent form were all issues which needed to be dealt with, and having them outlined in a systematic way did ensure that they were covered. However, was there justification for the formality of the consent form at the hospital? How did this influence the process?

Iteration within the consent process

> *"in order to ensure genuine consent, it is imperative that consent procedures are not viewed simply as a series of tick boxes........ but are kept under constant review throughout the research process"* (Scott et al 2006 p284).

As stated elsewhere in this thesis, in addition to the consent process being viewed as more than signing a form it is essential that consent to taking part is re-visited and that participants are given the opportunity to ask questions at any point in the process. In particular, the iterative nature of the consent process was emphasised within Cook and Inglis' (2007) work on Understanding Research. I specifically made sure that at the beginning and end of each interview I gave participants the chance to ask any questions they had. I also agreed with each participant who they would speak to within the setting if they had any concerns, or any general questions about the project.

However, as Wiles et al state: "*participants may get fed up of being repeatedly asked if they want to continue to participate*" (2005 p11). I found there was a need to be especially sensitive to individuals at this point: the reassurance and multiple opportunities to ask questions that some participants found reassuring seemed condescending to other participants.

Confidentiality and anonymity

High standards have been adhered to in relation to confidentiality and anonymity. Within the hospital setting, it was made clear to all involved what action I would take in the instance of disclosure which gave rise to concern for the safety of the participant or others. In actuality, no eventuality arose that caused me to even contemplate whether or not this was necessary.

Issues surrounding anonymity when writing up this thesis have been more complex than simply using pseudonyms when directly quoting participants. In particular, it has been important to consider the thesis as a whole and be aware of instances where the sum of information throughout the whole thesis might identify someone. It has been hard to do this, as both the settings involved a small number of people. It has also been my aim to portray the dynamics within the settings, as this has been part of the research process. Again, this has had to be done with care so as not to expose individuals from within the settings. Within this thesis, a conscious decision has been made to name The Lawnmowers but not the hospital in which the Understanding Research course was located. This reflects the desire expressed by The Lawnmowers to be named within an academic project that involved their work. Naming the hospital would be more complex given the nature of the overall setting and the fact that it is the course that was the focus, as opposed to other aspects of life within the hospital, justifies this decision.

In addition to this, participants from The Lawnmowers expressed a wish to be identified. This issue has been identified in relation to oral history research:

> "*There are two aspects of the issue of anonymity: one is the importance of enabling people with learning difficulties who want to, to speak out about their own history and be acknowledged, in order to break the silence of centuries (Atkinson 1997); the other is the right of individuals to make their own decisions about what parts of their lives they want to be made public, and to have control over their own privacy or anonymity" (Rolph 1998 p136).*

The request to readers at the beginning of the Findings section with regard to this issue relies on the integrity of readers, coupled with readers catching the vision of valuing and respecting people which is central to the whole project.

Data Collection: complex ethical issues

The discussion on ethical issues now moves on to the data collection phase of the research. In this context, it is important to consider the effect of my approach to all interactions with potential and actual participants. The advisory group from the Understanding Research course provided useful input into this aspect of the project.

The men emphasised the need for body language to convey acceptance of the participants and a relaxed atmosphere. The way in which questions are asked, and the influence on the content of the questions over the answers which people give, were also mentioned during the meeting with the advisory group in March '09: *good questions get good answers.*

An ethical issue which arises during active research is the definition of "data". Within the proposal for Mutual Support the definition of data became significant, as this in turn stipulated the situations in which conversations could be recorded, used in the data analysis and therefore quoted directly in this thesis. This resulted in accounts of interactions such as the advisory group meetings being in the form of my notes. Though this avoided issues around confidentiality and identification of participants, it is questionable as to how ethical it is to refer to what participants have said by paraphrasing or summarising their words. This also influences the impact which they have on the project. Views expressed by the advisory groups formed part of the theory building, and are referred to within this thesis as justification for the research design. However, they were considered in a format which included my interpretation at an earlier point than if the meetings had been recorded and transcribed.

During the final feedback session with the Understanding Research advisory group, I resolved this issue, at least in part. I had previously asked the men's permission to record the conversation. I emphasised that I was recording the session so that I did not have to take notes, and that I would not be using direct quotations from the recording in the final thesis.

Data Collection: Narrative research

> *"..........narrative inquiry is a field in the making. Researchers new to this field will find a rich but diffuse tradition, multiple methodologies in various stages of development, and plenty of opportunity for exploring new ideas, methods and questions." (*Chase 2005 p651).

This discussion now moves on to discuss the use of a narrative approach to exploring peer support and people with learning difficulties. In particular it focuses on the ethical issues surrounding this approach to understanding people's experiences. It also discusses ethical issues surrounding the "truth" of people's accounts. This evaluation of the process and methods used in gathering the views of participants is significant to the co-construction of knowledge within Mutual Support as it is integral to how participants' accounts of peer support were constructed. The discussion also considers some of the

issues which arise when applying this approach to research and people with learning difficulties, drawing upon evidence from Mutual Support as well as relevant literature.

Narratives are "storied ways of knowing" (Reissman 2006 p189-190). As stated in the literature review, the approach to data collection, analysis and interpretation within Mutual Support has been based on experience-based narrative research. Within this approach, Squire (2008b p28) outlines the ways in which the general guidelines for qualitative research apply: most interviewing is semi-structured; narratives are gathered from a number of participants who have experience within the same or a similar context; and it enables an exploration into narrative themes based on an exploration of experiential commonalities.

Squire's statement that "*unlike many qualitative frameworks, narrative research offers no automatic starting or finishing points" (2008b p4)* justifies the use of the adoption of a narrative approach which has been adapted as the research process and has evolved within Mutual Support. This is also reflected in the rarity of rigid frameworks for analysing data which contrasts with approaches such as grounded theory (Squire 2008b p4). Both of these factors have meant that there was more flexibility for the research to be shaped by participants' views as the process evolved:

> "*Open-ended interviewing, at least in comparison to an interview conducted through a set of questions pre-determined by the interviewer, ostensibly allows for the data collection to be constructed between the interviewer and the interviewee"* (Swain et al 1998 p26).

However, the way in which the data collection process evolved within Mutual Support did not reflect an approach to narrative research which begins with a very open question and then allows the person who is telling their story to speak at length about their experiences. This shift away from an "open question" narrative approach was partly a reflection of the issues surrounding accessibility of this approach to people with learning difficulties. The way in which the project within the NHS setting became focussed on the Understanding Research course also influenced this. The questions were more specific and focussed. This was also a reflection of the level of insight into their experiences which participants showed, as the conversation naturally developed from thinking about concrete events to more abstract issues such as (within The Lawnmowers) what they wanted other people to know about how they support one another and other people with learning difficulties.

The flexibility in the approach, away from a single open-ended question, allowed for adjustment within the research process to be made based on the views which

participants expressed, resulting in a more inclusive approach to the whole process. The approach to narrative research which was adopted also allows for interaction between researcher and participants (Squire 2008b p7) – another key element of an inclusive approach to research - and the conceptualisation of the knowledge within Mutual Support being co-constructed between the researcher and participants:

> "*if you are convinced of the importance of narratives' co-construction, you will engage throughout in active narrative interviewing, an interaction that even may be understood as conversation or co-research*" (Squire 2008b p30).

Much of the data collected within Mutual Support was participants' accounts of their own experiences, often of specific events, from their point of view. However, these narratives of experience could not be aligned in any way to Labov's definition of an "event narrative", in which the syntax of an account of an event is examined (Labov and Waletsky 1967).

Narrative research and inclusion

> "*we adopt a biographical/narrative research model since it permits us to analyse social exclusion from the point of view of the main actors and also because of the emancipatory qualities we find in the said methodological approach*" (Susinos 2007 p 118).

Within the field of disability studies, a narrative approach has been used in research in a number of different contexts. It is interesting to explore this further. A superficial consideration of the application of individual stories to an understanding of disability that focuses on barriers in society faced by disabled people might question the utility of applying individual narratives to social phenomenon. Smith and Sparkes (2008) address this issue, stating that personal stories are also social and cultural. This has certainly been the case within the contexts of Mutual Support as the contexts being explored are very much social situations. The consideration of cultural factors is also highly relevant to The Lawnmowers use of theatre and music with a goal of facilitating social change.

This discussion on narrative research now focuses on the role of narratives in research and people with learning difficulties. Booth and Booth (1996a) refer to four "interview problems" when carrying out research with people with learning difficulties: inarticulateness, unresponsiveness, a concrete frame of reference and difficulties with the concept of time. Roets, Goodley and VanHove (2007), referring to the self advocacy movement as "*testimony to a determination to oppose how they have been defined and treated in society*," explore the construction of alternative narratives in the

self-advocacy movement (p323). They continue to explore the use of the narratives of such self-advocates as challenging the grand narrative of intellectual disability as deviance, defining self advocates as *"active social agents"* (p324). This is applicable to the methodology within Mutual Support, as the individual narratives of participants have become a vehicle for challenging assumptions that

> *"[other] people might think they [people with learning difficulties] might not have the whereforeall to do that" (Chris, June 2008).*

The research design within Mutual Support has specifically focussed solely on the accounts of people with learning difficulties. This is reflected in the fact that no data from non-disabled supporters, including family and carers, has been collected. This was a conscious methodological stance, but raises issues around the distinction which Mutual Support draws, as discussed in the Part Three Section Two when considering the definition of peers.

Another methodological and ethical issue arises when co-constructing knowledge using narratives: how can I be sure that the accounts of support which people are giving really did happen? However, despite a common misconception to the contrary, this issue is not peculiar to research with people with learning difficulties: how can anyone ever be sure that other people's accounts of events are "true"? At the centre of a narrative, and inclusive, approach to research is a valuing of people's accounts of events and the development of an understanding of what these accounts represent.

When issues like this arise, it would be possible to spend considerable time going back and forth between everyone who had been at the event which participants are recounting, checking out what "really" happened. This, however, would not be productive within an inclusive approach to narrative research. Rather, the processes of validation throughout Mutual Support have been used to construct a firm basis. It is important to emphasise that it is the recognition of both researcher and respondent subjectivity that are central to qualitative research (Chappell 1999).

Is it also possible that it could be argued that all of the data on which I am building this "rock" is, in fact, based on events which did not happen? I would argue against this cynical view by saying that the very fact that people with learning difficulties who have taken part in Mutual Support clearly perceive themselves and others as giving and receiving support is worthy of the exploration which has taken place within this thesis.

Data Analysis/interpretation: ethical issues

Throughout the Mutual Support project, the ethical principle of respect for autonomy has been sought both through consultation with advisory groups and asking for feedback from participants. Within the data analysis stage of an inclusive approach to research, it is important that participants are given opportunities to be involved in the interpretation of data. This section focuses on the data analysis element of the project, discussing further the methods which were used and critiquing their effectiveness and relating them to ethical issues. It also discusses the use of Nvivo8 and mindmapping as tools for storing, retrieving data and presenting emerging themes.

Walmsley and Johnson (2003) raise the complex issue of accessibility of the data analysis stage of research within an inclusive approach to research. They highlight the fact that, whilst inclusive researchers have justified complexity within methodologies of inclusive research, this has not been applied to the data analysis stage "*because of the perceived need to work in ways that enable people with learning difficulties to come alongside" (p169).* Within Mutual Support, a PhD project, it has been necessary for detailed data analysis to take place within the conceptual framework of the co-construction of knowledge. Thus, the approach to data analysis adopted has been such that the views of participants have driven it. However, it has been outside of the resources of this project to make the processes and tools used accessible to participants, though I would add that it must not be assumed that this would be impossible; Cook and Inglis' work (2007, 2009), for example, has challenged similar assumptions that had been made around people with learning difficulties accessing complex ideas within research processes.

Coding data: ethical issues

As stated in the methodology section, the storage, retrieval and coding tools within NVivo8 were used as part of the process of collating and analysing data. Critics of the use of CAQDAS have stated that using it means researchers are less likely to immerse themselves in their data, engaging with ideas in a flexible way, thus going against the ethos of qualitative research (Kelle 2004). I ensured this did not happen by only using aspects of NVivo8 which ensured that all data was accounted for, and not being regimented in my use of the software.

There are other tools within NVivo8 that I did not use. Some of these tools relate to demographic information about participants, which I neither gathered nor used. Other tools relate to doing searches within certain aspects of the project for keywords or concepts (the "query" tool). I did not use this facility because I felt that this computer

generated search would not account for the unique words and phrases used by participants, and that the importance of context might be overlooked in using the "query" facility.

When used sensitively and openly, the use of CAQDAS is a practical tool which enables researchers to apply the theoretical principles behind qualitative research (Lewins and Silver 2007). The practicalities of how to do qualitative research have sometimes become lost in theoretical and conceptual debate (Kelle 2004). The concept of coding within NVivo8 is rooted in grounded theory, though it is also used in other approaches to building theory based in qualitative data. Within Mutual Support, the coding has been based on developing themes based in the data and linking them with other themes in order to, ultimately, build the model of peer support which is the focus of this thesis.

The section on data analysis within the methodology stated that coding within the project was inductive: it was about building a picture of peer support and people with learning difficulties from a "bottom-up" approach. This requires the researcher to come to the coding of data with an open mind, and not base the process of building theory on existing theory or literature. However, it is impossible to come to a research process with no pre-conceived ideas. Within the co-construction of knowledge within Mutual Support, my perspectives have been part of the research process. This perspective was also part of the coding process. However, I sought to base the development of themes on what participants were saying; the inclusive approach to the research process was integral at the data analysis stage of the project.

An inductive approach can be contrasted with a deductive approach, where the analysis begins with a theory or series of theories and analyses the data according to where it does and does not fit in with these theories. In reality, inductive vs. deductive coding is not a dichotomy; most approaches to coding will involve a combination of starting from the views expressed in the data and starting from theory. I had come to the research process with an overall aim of looking at peer support and people with learning difficulties. Some social researchers would argue that an inductive, top-down analysis is more socially oriented as it is looking for patterns based on outside phenomena rather than from the individual's viewpoint.

Within an inclusive approach to research and people with learning difficulties which was based on valuing their accounts of their experiences, it was important not to adopt an approach to data analysis which was psychoanalytic, implying that it is possible to

access people's inner thoughts and feelings by analysing what they say. It was also important that, as far as was feasible, I checked back with participants what they thought about my ideas as the themes within the research developed.

Feedback from participants is a way of checking the interpretation made by the researcher (Andrews 2004). This was a significant aspect of the data analysis and interpretation, though it was not done by giving participants transcripts or similar information. Other accessible and more interactive means were used in this important aspect of the construction of knowledge within Mutual Support.

A specific point in my interaction with every participant was to ask them what they would want other people to know about how the relevant group supports one another. This provided opportunity for them to clearly state what they want others to know. This abstract thinking came more naturally to The Lawnmowers, whose responses have been coded in the findings section under "what other people should know". Thinking about this did not come as naturally to the students from the Understanding Research course.

<u>My relationship with the organisations</u>

Within the ethics of Mutual Support, a highly significant factor of difference between the two research situations is the formality of my relationship with the groups. An interview at The Lawnmowers invariably ended up with my staying on to chat to the others, be at a rehearsal or, in one instance, go with them to their performance that afternoon:

> *Dean: One last thing I would say is obviously when you finish your project, always remember that once you're a friend of The Lawnmowers, you're a friend for life, so you'll always be welcome here any time of the week........ do feel free just to ring that bell for a coffee (November 2008).*

This incident contrasts with a time when the fire alarm went off in the Villa where I had just arrived to do an interview at the hospital. We all vacated the building and stood outside for ten minutes. During this time, I very much felt like an outsider, not wanting to chat with staff as I did not want to align myself with them, but equally unsure about speaking to patients who I did not have permission to speak with.

Dan, one of the students from the Understanding Research course, did seek to extend my role within his life by asking me to attend his care plan meeting. I had to show interest in and respect for his suggestion, whilst knowing that this would not be possible:

Sarah: Is there anything else you wanted to ask me?

Dan: Oh, there is one...are you doing anything on the 19th of this month?

Sarah: Why?

Dan: Cos I've got a CPA meeting and I'd like you to attend it.

Sarah: You've got a CP...what's that?

Dan: It's a care planning approach type of thing. The likes of [named nurse] will be there, and one or two other staff and they find out what we're doing on a daily basis and that.

Sarah: Um, I'm not sure if that totally would be my role...

Dan: No, it was just if you were doing research, you could pick up that way.

Sarah: I'm not sure about that one. I think probably not, Dan, just in that's not what my role is within the research (first interview).

This section of the discussion on the methodology and methods used within Mutual Support has addressed the complex ethical issues which arose throughout the research process. Each aspect of the process has been addressed and relevant issues discussed.

Evaluation of methodology

This final section on methodology relates the preceding discussion to the overall aim of Mutual Support: to co-construct a model of peer support and people with learning difficulties and then to evaluate the model. By discussing the methodology used, the strength of the model is evaluated in terms of the way it has been constructed. The evaluation begins with an outline of the limitations of the research process. It also addresses issues raised by the different approaches used within the different settings.

<u>Limitations of the research process</u>

It would be possible, within an exploration of how things might have been done differently, to embark on a tangential discussion considering possible different approaches which might have been taken to explore peer support and people with learning difficulties. However, given that qualitative research is focussed and context-specific, the list of possible different approaches and contexts could fill another thesis,

and would not be relevant to the focussed evaluation of the research process and Mutual Support. This section seeks to explore possible improvements in the research process within Mutual Support. It also discusses the limitations of the said process, within an inclusive approach to co-constructing a model of peer support in the interaction between myself as a PhD researcher and the groups of people with learning difficulties who were involved.

Within an inclusive approach to research, the collaborative nature of Mutual Support was the weakest element. It would have been ideal for people with learning difficulties to be more involved in doing the research. Within the methods used for data collection, this would have involved people with learning difficulties in interviewing one another. Though this would have added an interesting dimension to the research, there would also have been issues relating to the validation of data which was collected by different people, as well as the complexities of obtaining ethical approval for this.

Related to the issue of collaboration, I came away from the final group sessions wishing that I had done more group work throughout the project. My reasons for not having done this related to my own anxieties when putting the original proposal together, fuelled by the complications within the R and D process. However, when embarking on similar projects in the future, I will certainly build on the ending of this project and prioritise group work far more. This idea could be related to the issue of collaboration in research, as meeting in groups earlier in the project would have enabled a more specific involvement of participants in engaging with themes as a group, as opposed to through the methods I used within the individual interviews. A further issue relating to collaboration, which was restricted by constraints of time and resources, would be asking people with learning difficulties to be involved in making audio, or perhaps audio visual, presentations of information sheets.

Within the limitations of the research process, there were barriers, some of which were overcome. Others remain and contribute to the limitations of the research process. These barriers include the time and effort which had to be invested in getting through the R and D approval process at the hospital.

The different methods used in the two settings

When evaluating the methods used in Mutual Support, it is important to acknowledge the obvious differences in the methods used in the two settings, and to consider the effect of this on the research process.

The most pragmatic answer to this issue was that the methods used were appropriate to the settings. The setting within the forensic services of the hospital meant that the formality of methods used was inevitable: the project would not have happened at all had the protocol not been as structured and specific. Therefore, the only way to have made the approach used in the two contexts the same would have been to use the same methods at The Lawnmowers: this would have been highly inappropriate within this setting. In fact, I think it would have been equally likely that the research would not have progressed within The Lawnmowers had I sought to implement the methods used at the hospital, as this would not have been showing respect for The Lawnmowers' ethos.

Therefore, I argue that what took place was a response to the settings, and therefore the emerging model of peer support is rooted within the contexts, resulting in a stronger base on which the findings were built. I have not sought at any point in this thesis to claim the two settings as comparable except in the involvement of groups of people with learning difficulties working together on a pre-existing venture which involved peer support.

Discussion and evaluation of methodology: Conclusion

This summary of the discussion on methodology answers the question: how firm were the methods used in building the rock of Mutual Support?

The research process has involved a complex approval process and working with a range of people in complex settings. The factor of myself as a new researcher has also been part of that process. I have sought, through the earlier section (Part Two Section One) and this discussion, to be realistic about the research process, acknowledging that it does not fit neatly into a textbook approach to research. However, it has been responsive to the views and experiences of participants within the contexts of the research. It is important that the methods used were based within the growing literature on research and people with learning difficulties which values their views and breaks down the "researcher" and "researched" dichotomy which has dominated experimental research.

This discussion is integral to the overall aim of Mutual Support, as it has evaluated the methods used in the co-construction of the Mutual Support model of peer support and people with learning difficulties. The next part of the thesis brings all of the discussions

to a conclusion, returning to the aims and objectives of the project and evaluating how far they were met. The final section of the conclusion presents the vision of inclusion which has emerged from Mutual Support.

CONCLUSION

In pulling together the threads of discussion within this thesis, the conclusion begins by evaluating how far the aims and objectives of Mutual Support, as outlined in Part One Section Two of this thesis, have been realised through the research process. This includes relevant direct quotations from participants, and an outline of the implications of the realisation of each of the aims and objectives. The second section of the conclusion returns to the concept of an "ethically sustainable vision of disability" (see Part Two Section One page 52-53), outlining the vision of learning difficulty which has emerged through the process of Mutual Support.

How far have the aims and objectives been realised?

   1. The creation of knowledge

Mutual Support adopted a constructivist approach to the creation of knowledge within a research situation, and in the development of theory which has been built on this knowledge. The emphasis was on the research process being a co-construction of knowledge with the views of people with learning difficulties at its heart. Advice from groups of people with learning difficulties was an integral part of the research process, as was their encouragement about the importance of the project. This included insight from past negative experiences and how to approach the interviews which took place with students from the Understanding Research course. The project literature referring to both the Understanding Research project and the ideas emerging from the research has been an important part of the construction of knowledge.

Reflexivity on my part has also been essential, and Part Three of the thesis evaluated the model which had been built by being realistic about what might have been done differently as well as what went well. The contribution which this resulting knowledge has made is summarised below. Validation of the findings took place within the research process by providing multiple opportunities for those taking part to engage with issues, and through my reflection, which included basing subsequent questions on previous views expressed.

At the close of this project, the implications emerging from the application of this approach to knowledge creation relate to the inclusion of people with learning difficulties in a PhD research project that has prioritised their views. The research process has demonstrated how people's accounts of their direct experiences can be prioritised within the detailed and in depth process of knowledge creation that is

necessary within a PhD project. Within this, it is significant that it was possible to use people's direct accounts as part of the creation of knowledge without interpreting them or viewing accuracy as anything other than their accounts of experiences.

2. <u>An opportunity for people with learning difficulties to think about their relationships with one another, from their point of view</u>

Building on the previous aim, this co-construction of knowledge provided an opportunity for reflection by people with learning difficulties on their peer relationships. As the research process evolved in response to views expressed by participants, and I spent more time with them, opportunities arose for people with learning difficulties to speak about how they give and receive support. Overall, participants were positive about the approach used to interviewing, allowing them time to think without pressure and an atmosphere in which they felt comfortable to express their views without feeling there was a right or wrong answer.

The final group sessions, with The Lawnmowers and the facilitators, were particularly meaningful in providing opportunities for interaction and evaluation of the way I was presenting those views from the perspective of people with learning difficulties.

The Lawnmowers expressed what they felt about being part of the group. Appendix G (pages 278-279) is a visual image of this expression.

I feel like we're supportive as a team, as one team, um, cos we are always there for each other. That's how I feel.

There's a close bond with other people, and help when I need it.

We each individually have supportive skills and therefore we are each vital key elements in a really productive group....

We all support each other in a small way.

These are me friends, I love them a lot.

The use of different group activities in this context is an aspect of the project I would build on in future research.

The themes which emerged went far beyond my expectations when I set out on the project. People spoke about supporting one another within a wide range of situations and they were keen that other people know about the support they give and receive:

Dean: in a general day of doing The Lawnmowers and doing the show, you always support each other and support everyone, always being friendly and just

showing what a good group we are, and obviously showing by that, the way that we support each other comes across to people, and we think "oh, they are a very strong group together," cos they're so supportive to each other, and obviously others (June 2008).

Reflections also included depth of insight into interpersonal relationships and what it means to have a learning difficulty. The evidence of people with learning difficulties as educators, both peer mentors and educating other people about their experience, is significant. There was an insightful recognition of the importance of peer support within that learning situation:

Lawnmowers core member: when you look at the word "isolation" it's a hard thing to get out of, but it's an easy thing to get into. I think that applies to the courses as well, you can become very isolated, but you can get the help that you need to get you out of isolation (October 2009).

This central aspect of Mutual Support built on the growing body of research that prioritises the views of people with learning difficulties. The significance of inclusion within academic research also relates to breaking down barriers faced by people with learning difficulties.

3. <u>Contribution to debate surrounding service user involvement</u>

The idea of peer support and its potential use as a tool in moving towards inclusion emerged directly from the seven aims of the independent living movement. Through an in depth exploration of peer support within two focussed settings, Mutual Support has highlighted peer support as both viable in terms of people with learning difficulties being more involved in focussed projects, and also a means of breaking down barriers to inclusion. There are potential positive benefits for efficiency of services, the extent to which people who are supporting other service users are involved and the sense of meaning and purpose in their lives. This includes inspiring other people with learning difficulties:

Grace: Well, that's what we want, to inspire people, for them to have a bit of confidence, and to be able to go out there and do what they want, cos that's what we're there for – to inspire people – it would be nice if they were inspired by us. It would show that they can do their own things as well (June 2008).

Specifically, the evidence for people with learning difficulties as peer educators as well as their role in educating other people about their experiences and what is important to them:

> *Facilitator: You're always learning. Especially if you're teaching other lads. The more you teach, the more you learn. And everybody comes up with different ideas. Everybody has different opinions. And if you could just put it in a room, you wouldn't have one big enough, if you kept going (from Becoming Educators discussion).*

> *Dean: Overall, I think [Lawnmowers' workshop at Coach Lane Campus, Northumbria University] went really well, everyone who was there seemed to really enjoy it, we got quite a good response, we got some great comments back, from all the students, and the teachers and the people who were there. And they all had a lot of good questions to ask, to us, about what we had done, about what we do, so it was just a good afternoon all round. And it was well worth doing, and definitely something we should do again (November 2008).*

The positive aspects of being supported in learning by someone else who has a learning difficulty could also be developed further with potential for people with learning difficulties to become more involved in services, both statutory and independent.

The implications of Mutual Support for service user involvement include the evidence for people with learning difficulties to fully participate in work such as Disability Equality Training and educating service providers about issues of importance. At the outset of Mutual Support, the idea of peer support was based on one of the aims of Centres for Independent Living. However, the depth of evidence from those taking part suggests that Mutual Support potentially spans all of the seven aims, and is a useful tool within every aspect of independent living.

4. Contribution to discussion on inclusive research

Inclusive research and people with learning difficulties builds upon research within the field of disability studies and is built on the principle of research *with* people as opposed to researching *on* people. The research process sought to involve people with learning difficulties, and to be accessible and fun. Overall, participants were positive about the research process, and the opportunities they had to express their views:

Chris: you've listened to what we had to say and not been like, if we say something, you didn't say "why did you say that?" you just let us talk, say what we want without being judgemental, and that's brilliant (October 2009).

The ways in which the ideals of inclusive research were realised have been evaluated in detail within this thesis, with an acknowledgement of the ways those ideals were not realised. Collaboration is an aspect within research that I would build on in the future, especially as the barriers to collaboration within Mutual Support largely stemmed from my inexperience in terms of running the groups and getting further ethical approval. The experiences within Mutual Support of ethical approval processes highlight the skills that are needed in writing proposals for inclusive research projects.

An inclusive approach to research, in addition to ensuring that participants are respected and their views prioritised, strengthens all of the aims within Mutual Support, and future work which might build on this project. A significant contribution to the discussion on inclusive research made by Mutual Support is the implementation of the approach within a PhD research project, at the same time as breaking down barriers to full participation in research so often faced by people with learning difficulties.

5. <u>Contribution to debate within disability studies</u>

As the Mutual Support model of peer support emerged, the social model of disability became the obvious tool by which the model was evaluated. This has the potential to add fresh evidence to the debate surrounding the use of the social model, both in relation to people with learning difficulties and in the field as a whole.

When applying the social model of disability to Mutual Support, it can be seen that the collective model of peer support which emerged challenges barriers to inclusion:

- assumptions that people with learning difficulties cannot engage in meaningful inter personal activity
- barriers to inclusion in education for people with learning difficulties
- reclamation of dignity and respect
- barriers to employment

The emphasis on attitudes needing to change reflects the nature of the barriers faced by people with learning difficulties:

Grace: I think their views need to change a lot, cos.... was saying how people with learning difficulties and how it's hard working with people with learning

difficulties, but I wanted to say "it's no different to working with your students"' I know we have a difficulty, but we're no different to anyone else – we're all equal in the world, and that's how we wanna be tret. As equals....

Cos I think it's wrong if people have a narrow minded view of people with learning difficulties, and think they can't do things, when they can, we can actually do a lot of things, and they need to find out that we can – it might not be the same thing that they do, it might be different to what they do, but we still work together, and it would be nice if people's views changed, cos I've always wanted that, since I was young...... (November 2008).

It must be noted that the settings which were central to Mutual Support were already breaking down barriers: by focussing on the peer support which was taking place within this work, Mutual Support has highlighted activity which was already taking place, providing evidence for the effectiveness of peer support within these settings. The barriers are perhaps different to those faced by people with physical or sensory impairments but nevertheless can be understood using the social model of disability.

A significant contribution of Mutual Support within disability studies has been the in depth views of people with learning difficulties on how they support one another. Collective support is a central tenet of the disabled people's movement, but an area that people with physical impairments have not always included people with learning difficulties in. This evidence provides a potential bridge for that gap:

Chirs: they might think "oh, people with learning difficulties can't support each other, or might not know how to support each other", but then once they see us supporting each other, they might change their attitude....(June 2008).

Mutual Support: An ethically sustainable vision of learning difficulty?

When outlining the ethical principles behind Mutual Support in Part Two Section One, the significance of promoting an ethically sustainable vision of disability (Lawthom and Goodley 2006) was cited. This section of the conclusion returns to the vision of learning difficulty that has emerged from Mutual Support, questioning how ethically sustainable it is. The issue of inclusion is central to this question. Inclusion is about valuing differences within an equal society. The main way in which Mutual Support breaks down barriers to inclusion is through participation leading to empowerment.

There were significant instances when barriers to inclusion faced by individual people with learning difficulties were broken down through peer support within the immediate

contexts. The accounts of people with learning difficulties emphasised how much they valued such instances. There were also instances of barriers to inclusion in a wider sense being broken down by Mutual Support. The way in which Mutual Support is a reclamation of the dignity and respect which people with learning difficulties are often denied is also highly significant.

When considering the issues surrounding inclusion and people with learning difficulties, access is a significant. Nind and Seale (2009) explore concepts of access and people with learning difficulties. Within their research, they asked the question "*what is worth accessing?*" In their list, which was based on the outputs of a series of seminars attended by people with learning difficulties, professionals, support workers and researchers, they included: *relationships with others, friendship, acceptance, inclusion, appreciation, and intimacy* (Nind and Seale 2009 p279). Mutual Support has embraced these aspects of access issues by demonstrating the role which friendship, acceptance and appreciation through peer support can have in breaking down barriers to inclusion.

Mutual Support is also an example of research which aimed to be inclusive. However, it is important to take the inclusion debate further, and ask what the purposes of inclusion are, and who benefits from it. Swain and French (2000 p578) state that "*the inclusion of disabled people into the mainstream of society would involve the construction of a better society, with better workplaces, better physical environments, and better values including the celebration of differences*".

Coming to the end of this project, I firmly believe that the insight which the participants have shared with me, and which I have shared within this thesis is evidence that the inclusion of people with learning difficulties in society is not just about improving life for them, though that is important. I believe that society as a whole would be a far better place if difference was celebrated and the skills and insight shown by people who have taken part in this project were added to a value system in which people are valued over and above anything else. This project has demonstrated the meaning and purpose that people who have been assumed to lack insight into interpersonal interaction get from working together, and values of respect and working together which I have learnt from, and I hope others will too.

Campbell and Oliver (*Disability Politics. Understanding our past. Changing our future* 1996 p180) refer to the campaign which has highlighted the need for breaking down the barriers to inclusion faced by disabled people as a "*contribution to the history of mankind*". It is my hope that Mutual Support has, in some small way, kept the inclusion

debate alive, and contributed in its own way to a society in which diversity is celebrated and valued. In order to sustain the vision of learning difficulty that has emerged from Mutual Support, dissemination of findings and the development of ideas outlined in this thesis remain important and will be prioritised.

APPENDIX A: Accessible Summary

Mutual Support: people with learning difficulties supporting each other
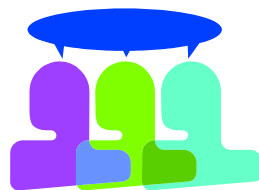

Project Summary

Sarah Keyes   November 2009

I have been doing some research. Research is about finding out about things.
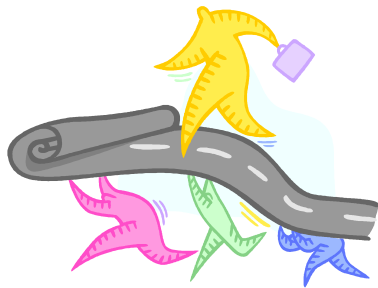
I have been finding out about how people with learning difficulties support (help) each other.

All of the people who helped me with the finding out had been working with other people with learning difficulties in groups before I met them.

I asked them to tell me about times when they had supported someone else, or someone else had supported them.

I have called this "Mutual Support".

"Mutual" means that something that is important to more than one person.

Mutual Support means that lots of people with learning difficulties have been supporting each other.

This booklet tells you about what I have found out.

WHAT I DID

I wanted to make sure that I found out about things that are important to people with learning difficulties. I also wanted to make sure that everything I did was easy for people to understand.

I asked other people with learning difficulties the best ways of doing this.

Then I asked lots of people with learning difficulties about how they support each other.

To begin with, I met with seven people with learning difficulties on their own. I asked them about times when they had supported someone else or someone else had supported them.

After this, I met with some groups to ask them what they thought about the things that had been found out.

WHAT PEOPLE TOLD ME

People told me that they respect each other, and listen to each other.

This is important because people with learning difficulties are not always listened to and respected by other people.

They told me about times when they had helped each other with things that need doing. This happens every day in lots of different ways.

They support each other when they are upset, or finding things hard.

They also encourage each other

Supporting each other also involved socialising with others.

They often worked together as teams.

They told me about times when other people with learning difficulties could understand or explain things better because they know what it feels like to have a learning difficulty.

We talked about times when people with learning difficulties had supported each other to learn.

There were times when people with learning difficulties thought of different ways of supporting each other to learn.
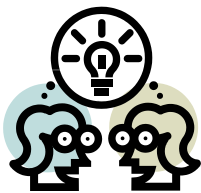
There were times when someone who does not have a learning difficulty supported someone with a learning difficulty so that they could support other people with learning difficulties.
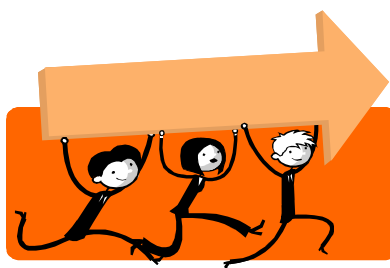
The support which people give to each other has improved life for them, and for other people with learning difficulties. For example, support for people with learning difficulties who want to do voluntary work.

Mutual support also helped people who make important decisions to know what is important to people with learning difficulties.
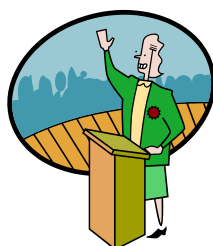
Finally.............

When people with learning difficulties support each other on a task or project, the end result is much better.......

........each person brings different strengths to the group.......

......and it means a lot more to those who have been part of it.

People with learning difficulties can break down barriers to inclusion and build a better world when they support each other.

Appendix B. Information sheets, letters and consent forms.

This appendix contains all of the information sheets and letters used in the project, and the consent form that was used within the hospital. It begins with the letter I sent to Skills for People in November 2008, asking if I would be able to go to their drop in sessions. This led to me being invited to attend their programme committee at which I was advised about what makes good and bad research etc.

This is followed (page 237) by the original information sheet for participants within the Understanding Research course. It was this information sheet that the advisory /reference group scrutinised at our first meeting in September 2009.

The following letters to staff, information sheet and consent form (pages 243-252) are the actual materials used during research with students from the Understanding Research course.

The final information sheet (pgs 253-255) is the one used within the process of sampling within The Lawnmowers.

Apart from the first information sheet sent to Skills for People, all information sheets were accompanied by audio CDs of me reading the sheets word for word.

Skills for People
ORIGINAL LETTER AND INFORMATION SHEET

School of Health, Community and Education Studies

Contact:.................

October 2007.

Dear Co-workers at Skills for People,

My name is Sarah Keyes, I am a student at Northumbria University and I am writing to ask for your help with some research which I plan to do at [Hospital]. I would like to ask you, at Skills for People, to advise me in the early stages of my project.

My project has been approved by Northumbria University's Ethics Committee and I have full Criminal Records Bureau clearance. At the moment, I am applying for approval from [Hospital].

I would like to find out what you think about my project and whether you think it will work or not. I would also like to ask your advice about how I do my research at [Hospital]. In particular, I would like to ask you how I can explain what I am doing in a way which will mean something to the people there.

I would like to show you an information sheet which I have written and ask how I can change it to make it clearer and easier to understand. I would also like to ask you if you have any ideas as to how I can make my project open to all people with learning disabilities.

As well as this, I would like to find out about how you at Skills for People help and support each other. The kind of things I would like to ask you are:

Do you think that it is important for people with learning disabilities to support each other?

Do you support other people with learning disabilities? If yes, how?

Are there other people with learning disabilities who support you? If yes, how?

What help can other people give you? when you are happy? when things are difficult?

Has anyone ever tried to help you in a way which you didn't like or was not helpful?

I have sent a sheet with this letter which tells you about research and what it means to me.

I hope that you will feel able to help me.

I know that you have 'drop in' sessions which anyone can come along to, and I am planning to come along to Key House next Wednesday (6th November) so that I can find out what you think about this letter and whether you want to help me or not. If you say yes, then I will come to your 'drop in' sessions a few times so that I can meet lots of people.

If this is not OK with you, or if you want to ask me anything about what I am doing, then please contact me or my supervisor, Professor John Swain, on the above numbers.

In the meantime, I look forward to meeting with you,

Yours sincerely,

INITIAL INFORMATION SHEET FOR SKILLS FOR PEOPLE

northumbria
UNIVERSITY
School of Health, Community and Education Studies

My name is Sarah Keyes. I am a student at Northumbria University.

I am hoping to do some research with people with learning disabilities at [Hospital].

Research is a bit like being a detective. You look for answers to questions.

I want to find out how people with learning disabilities support and help each other, and whether they would like to support each other more.

Sometimes, researchers decide what questions to ask without asking the people who the research is about what is important to them.
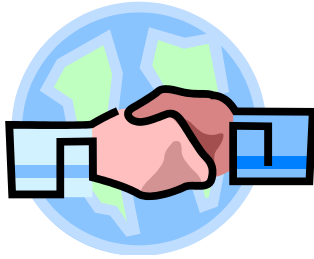
I don't want to do that. I want to ask you at Skills for People what you think about my ideas. I also want to ask you about how to make my research better and easier for people with learning disabilities to understand.

WOULD IT BE OK WITH YOU IF I CAME ALONG TO SOME OF YOUR DROP IN SESSIONS?
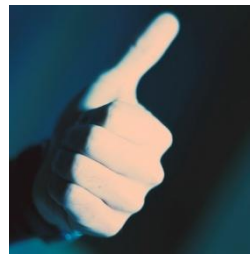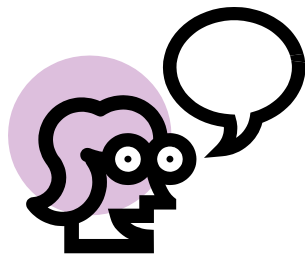
What happens if we say yes?

If you say yes, then I will come along to Key House to some of your drop in sessions. While I am there, I will meet some of you and tell you a bit about what I am doing and see what you think about it.

I would also like to show you an example of an information sheet a bit like this one. An information sheet tells people about the research and what will happen. I would like to find out from you how you think I could make my information sheet better so that people will understand what I am doing.

I would also like to find out about how people at Skills for People support and help each other.
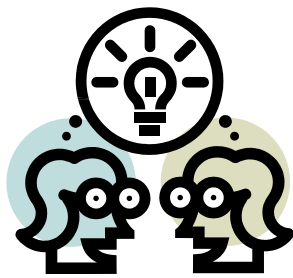
If you say yes, I would like to come back to Skills for People when I have done the research at [Hospital] (that will be in eighteen month's time) so that I can ask you what you think about what I have found out. I would also ask you about how and if you think what I have found may be useful for people with learning disabilities.
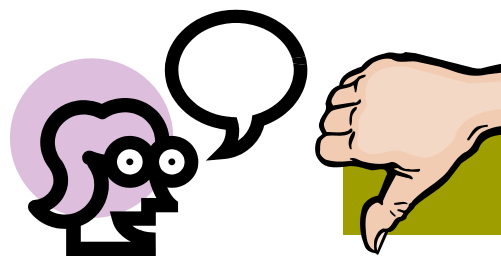
What happens if we say no?

If you say no, then I will not contact you again. It is fine to say no. You will not be treated any differently if you say no.

Thank you for looking at this.

The Understanding Research Course

Original information sheet which the advisory group scrutinised at our meeting in September 2009

My name is Sarah Keyes. I am a student at Northumbria University. I am interested in finding out about how the lives of people with learning disabilities can be improved.

I want to find out about how people with learning disabilities support and help each other.

I want to ask you about the best way of finding this out.
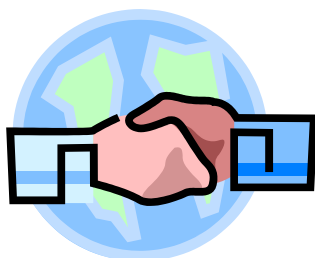
I am asking your advice about how to make the research better and easier to take part. I hope you will also tell me how to make it fun and interesting.

I am giving you a copy of the information sheet for the research I am hoping to do. Please could you tell me next time we meet what you think about it and how I should change it?

It comes with a CD for you to listen to.

Information sheet

My name is Sarah Keyes. I am a student at Northumbria University. I am doing some research.

Research is a bit like being a detective. You look for answers to questions and find out about things.

I want to find out how people with learning disabilities support and help each other.

You have been asked to take part because you were a student in the six week course about Understanding Research. I would like to find out about how you and the others supported each other.

These are the kind of things I would like to ask you:

What did other people in the group do to help you? What did they say? What did they do?

What did you do to help other people in the group? What did you say? What did you do?

Would you like to take part?

What happens if I say yes?

If you would like to take part, then please tell the person who gave this to you and they will let me know.

Then I will come and meet with you so that you can ask me anything you want to know about what will happen. I will explain that you will be given all the help that you need to take part.

When we meet, I will explain that I will not tell anybody any of what you say.
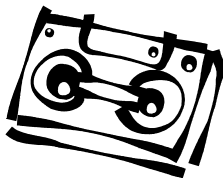
I will ask your permission to record what we talk about, so that I can remember what you say. I may use what you say when I am writing up my research, or reporting what I have found out to other people, but no-one will be able to tell that it was you that said it.

The recordings will be kept safely so that I am the only person that can get at them.

If you still say yes at this meeting, you and I will record that you have said yes. This is known as consenting.

After that, I will come and meet with you two times, so that I can ask you more.

Each meeting will last up to an hour.

After everyone has met with me two times, we will all meet together in a group so we can talk together about the things that have been found out.

When we meet, there will always be someone from the hospital staff there.
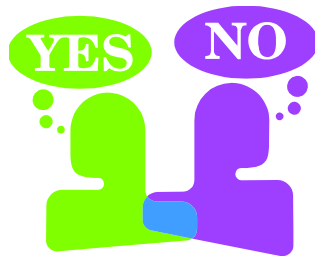
If you say yes then change your mind that is fine. Just tell me or a member of staff. You can change your mind at any time.

What happens if I say no?

If you do not want to talk to me, then tell me or somebody else. It is fine to say no, and you will not be treated any differently if you say no.

The things which are found out in this research will be used to tell people what might make things better for people with learning disabilities.

If you are not sure about anything, then please ask me next time I am at [Hospital]. I will let you know when am coming.

Thank you for looking at this.

This information sheet is a draft for the advisory group to look at and tell me what they think about it. It will not be used before the project has been approved.

Outline of how participants were identified and approached at the hospital
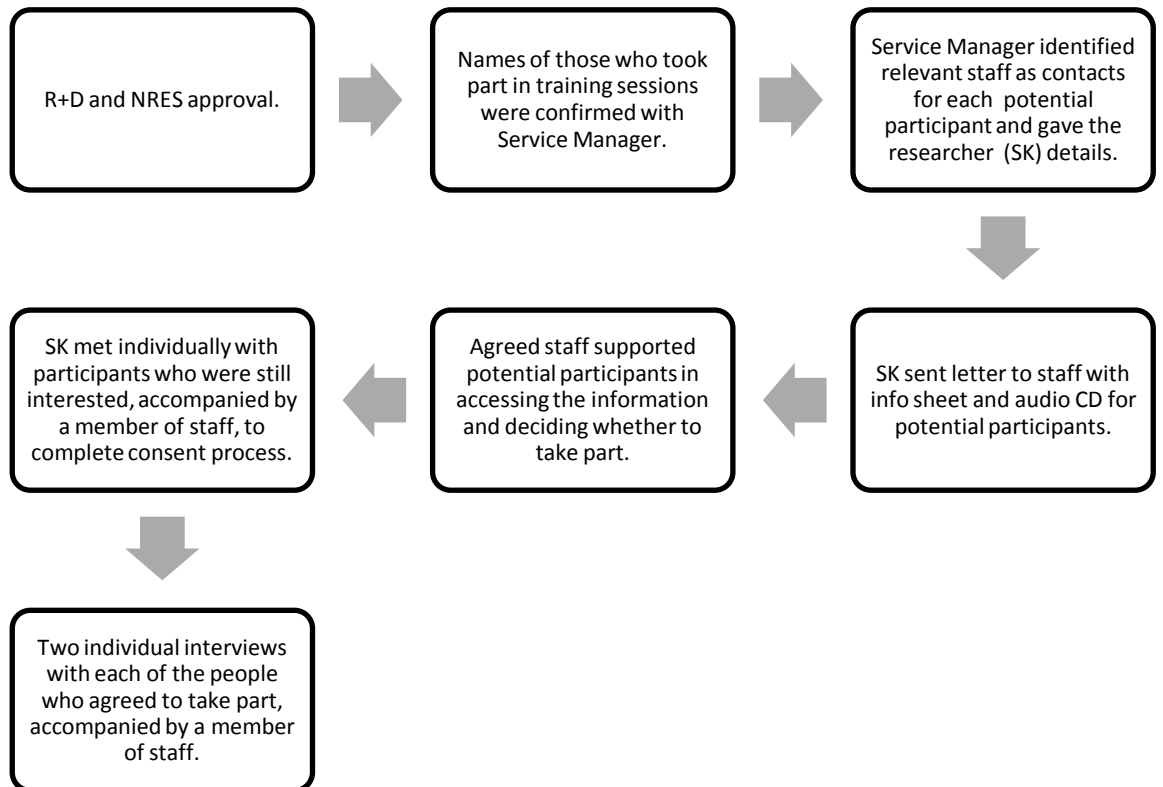
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┌─────────────────────┐      ┌─────────────────────┐      ┌─────────────────────┐
│                     │      │ Names of those who  │      │ Service Manager     │
│                     │      │ took part in        │      │ identified relevant │
│ R+D and NRES        │  ►   │ training sessions   │  ►   │ staff as contacts   │
│ approval.           │      │ were confirmed with │      │ for each potential  │
│                     │      │ Service Manager.    │      │ participant and gave│
│                     │      │                     │      │ the researcher (SK) │
│                     │      │                     │      │ details.            │
└─────────────────────┘      └─────────────────────┘      └─────────────────────┘
                                                                      │
                                                                      ▼
┌─────────────────────┐      ┌─────────────────────┐      ┌─────────────────────┐
│ SK met individually │      │ Agreed staff        │      │                     │
│ with participants   │      │ supported potential │      │ SK sent letter to   │
│ who were still      │  ◄   │ participants in     │  ◄   │ staff with info     │
│ interested,         │      │ accessing the       │      │ sheet and audio CD  │
│ accompanied by a    │      │ information and     │      │ for potential       │
│ member of staff, to │      │ deciding whether to │      │ participants.       │
│ complete consent    │      │ take part.          │      │                     │
│ process.            │      │                     │      │                     │
└─────────────────────┘      └─────────────────────┘      └─────────────────────┘
          │
          ▼
┌─────────────────────┐
│ Two individual      │
│ interviews with     │
│ each of the people  │
│ who agreed to take  │
│ part, accompanied   │
│ by a member of      │
│ staff.              │
└─────────────────────┘
```

northumbria
U N I V E R S I T Y
School of Health, Community and Education Studies

Sarah E. Keyes,
Northumbria University,
School of Health, Community and Education Studies,
Postgraduate and Research Support Unit,
Room H007,
Coach Lane Campus East,
Newcastle upon Tyne,
NE7 7XA.
sarah.keyes@unn.ac.uk

Dear

Re: a qualitative exploration of the role and impact of peer support for people with learning disabilities, using an inclusive approach to the research process.

I am a PhD student at Northumbria University. I would like to conduct a study with a small group of patients within the Forensic Services at [Hospital]. I want to explore how patients perceive the peer support which was given and received when taking part in a recent six session training course on "Understanding Research." This course was facilitated by Dr Tina Cook, and Pamela Inglis and carried out with 7 men from Forensic Services, supported by [Hospital] Staff. Dr Cook is part of my University supervision team.

 I enclose an information sheet for participants which will also tell you more about what I am doing. Potential participants will also be given an audio CD of the information to take away and listen to.

The Services Manager, Forensic Services, has been involved in the design of this project, and is overseeing the staffing resource aspect, which is vital for the project to happen.

Staff have been identified as contacts for each of the 6 potential participant. I am asking the staff contact to look at and listen to the

information sheet with them, and decide whether they would like to meet with me to find out more.

At this meeting, supported by staff, the formal consent process would take place. The member of staff who is at this meeting will be asked to play an active role in ensuring that the participant has all the information and support they need to make an informed choice.

Following this, I will arrange to meet with each participant twice in order to interview (informally) them about their views on the support, both given and received, during the training course. Again, staff will be present, for security reasons and to be available if patients become distressed or need staff support. However, staff will not be asked to play such an active role, and it is expected that they would only take part in the interview (which will be digitally recorded) if necessary.

Staff will be asked to respect the ethos and purpose of the study and not discuss with anyone else what has been said, unless necessary from the point of view of patient or researcher well being.

Thank you in advance for your time and effort in enabling this project to happen. If you have any questions or queries, please do not hesitate to contact me, details above, or your Service Manager.

Yours sincerely,

Sarah E. Keyes.

<u>Letter for staff who will be asked to look at information sheet with potential participants (will be attached to staff letter and participant information sheet)</u>

northumbria
UNIVERSITY

Sarah E. Keyes,
Northumbria University,
School of Health, Community and Education Studies,
Postgraduate and Research Support Unit,
Room H007,
Coach Lane Campus East,
Newcastle upon Tyne,
NE7 7XA.
sarah.keyes@unn.ac.uk

Dear   ,

Re: a qualitative exploration of the role and impact of peer support for people with learning disabilities, using an inclusive approach to the research process.

Further to the enclosed letter and information sheet, I have been given your name as a contact for........ who took part in the six session training course on Understanding Research. Please could you look at the information sheet with.....and support them in deciding whether they would like to meet with me and a member of staff to find out more.

Thank you for your time and effort,

Yours sincerely,

Sarah E. Keyes.

Final information sheet and consent form

Peer support for people with learning disabilities

MUTUAL SUPPORT: Information sheet for participants

My name is Sarah Keyes. I am a student at Northumbria University. I am doing some research.

Research is a bit like being a detective. You look for answers to questions and find out about things.

This sheet is to tell you a bit about my research. It will help you think about whether to say yes or no to taking part in the project.

Saying yes or no to taking part in research is not the same as saying yes or no to things which happen in Hospital, like taking medication. You can say yes <u>or</u> no to taking part in my research, and no-one will treat you any differently. Whatever you say, your treatment at the Hospital will not be any different.

ABOUT THIS RESEARCH

I want to find out how people with learning disabilities support and help each other.

I want to find out about how you and the others helped each other to learn when you did the six week training course on "Understanding Research" with Tina Cook, Pamela Inglis and other men from [Hospital]. You took part in this as a student, learning about research.

These are the kind of things I would like to ask you:

What did other people in the group do to help you? What did they say? What did they do?

What did you do to help other people in the group? What did you say? What did you do?

Would you like to part?

SAYING YES.....

If you would like to take part, then please tell the person who gave this to you and they will let me know.

Then I will come and meet with you so that you can ask me anything you want to know about what will happen. I will explain that you will be given all the help that you need to take part.

When we meet, I will explain that I will not tell anybody any of what you say. We will also agree who I would speak to if I am concerned about you or anybody else. I would never speak to someone else about you without telling you first that I was going to do this.

I will ask your permission to record what we talk about, so that I can remember what you say. Whenever I use what you say, no-one will be able to tell that it was you that said it.

The recordings will be kept safely so that I am the only person that can get at them. These recordings will be kept safely for three years after the meetings have taken place, then they will be destroyed.

If you still say yes at this meeting, we will record that you have said yes.

After that, I will come and meet with you two times, so that I can ask you more (interview you).

Each meeting will last about an hour, and no more than two hours.

When we meet, there will always be someone from the hospital staff there. They are there to help you. They are not there to check up on you or what you say. They will be asked not to tell anyone else what we have talked about.

SAYING NO......

If you do not want to talk to me, then tell me or somebody else. It is fine to say no. No-one will treat you any differently if you say no.
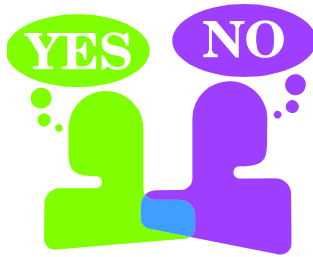
If you say yes then change your mind that is fine. Just tell me or a member of staff. You can change your mind about taking part in research at any time.

The things which are found out in this research will be used to tell people about how people with learning disabilities support each other.

If you are not sure about anything, then please ask me next time I am at [Hospital]. I will let you know when am coming.

Thank you for looking at this.

Contact Details.

CONSENT FORM FOR INDIVIDUAL INTERVIEWS. Version 3. Feb '09

Researcher: Sarah Keyes. Postgraduate Researcher, School of Health, Community and Education Studies, Northumbria University

With support from Sarah and a member of staff, please answer yes or no to these questions. SK and staff member will make a note of questions asked and any other issues which need dealing with.

I have listened to the information sheet about Sarah's research   YES/NO

I have asked all the questions I want to about what will happen   YES/NO

I know that I can ask more questions at any time   YES/NO

I have decided that I would like to join in.   YES/NO

If yes:

I know that I will meet two times with Sarah, and a member of staff will be there.   YES/NO

I know that Sarah wants to find out about how we helped each other when we were doing the six session "Understanding Research" course YES/NO

I know that Sarah has been told about any help I need to enable me to take part in the project.   YES/NO

It is OK with me if the conversation is recorded   YES/NO

I know that Sarah will keep the recordings safe, and that when she uses what I have said no-one will be able to tell it was me that said it YES/NO

I know that Sarah will destroy the recordings after three years YES/NO

Signed: Print name: Witnessed by: Also witnessed by:

-- Page 1 of 2

I know that the staff being there when I meet with Sarah is to help me. I know that they will not be checking up on what I say and will not be telling the others what I say.						YES/NO

I know that I can change my mind about taking part in the research at any time						YES/NO

I understand that taking part in this research is not part of my treatment						YES/NO

I know that saying yes or no to taking part in research is not the same as saying yes or no to treatment						YES/NO

Sarah has explained that if she is concerned about my safety or someone else's safety, she will tell a senior member of staff who knows me well and can help me. Sarah will tell me first if she is going to do this		YES/NO

We have agreed who I will talk to if I am unhappy about anything that has happened in the project – I know that this person has details of who to contact if they want to speak to Sarah, or to her supervisors (contact details below)						YES/NO

I understand that the interviews are about what happened during the 'Understanding Research' course, and not about other things to do with [Hospital] and my treatment. I know that Sarah will help me to keep thinking and talking just about the course.			YES/NO

Signed:

Print name:

Witnessed by:

Also witnessed by:

The Lawnmowers

Information sheet (which was accompanied by audio CD)

My name is Sarah Keyes. I am a researcher at Northumbria University.

Research is a bit like being a detective. You look for answers to questions and find out about things.

In my research, I want to find out how The Lawnmowers support and help each other.

I also want to find out if you supporting each other adds to your success as a group.

The kind of things I would like to ask you are:

Can you think of a time when someone else at The Lawnmowers supported you? Perhaps when things were hard? Or when you were happy?

Can you tell me about a time when you supported someone else in the group? How did that make you feel?

Do you think that The Lawnmowers supporting each other helps with the work that you do?

Has anyone ever tried to help you when you did not want them to?

If you would like to take part, then please tell ..... or ....., and they will help you sort out when you are free at a time I will be coming in. I will leave a list of times and dates.
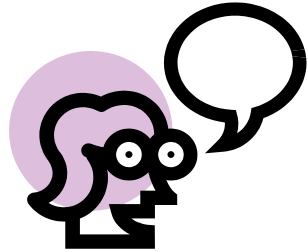
What happens if I say yes?

If you say yes, then I will come and meet with you. When we meet, I will explain that I will not tell anybody any of what you say. This means that nobody else in The Lawnmowers, or your family, or other people who take part in the project will know any of what you say.
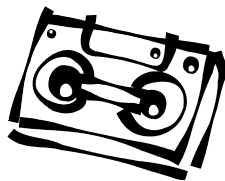
I will ask your permission to record our conversation so that I can remember what you say. I may use what you say when I am writing up my research, or reporting what I have found out to other people, but no-one will be able to tell that it was you that said it.

The recordings will be kept in a locked cupboard so that I am the only person that can get at them.
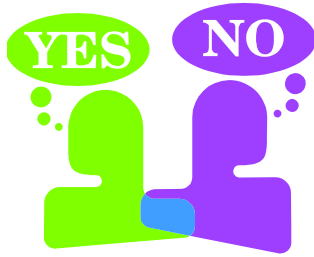
If you say yes then change your mind that is fine. Just tell me or a member of staff. You can change your mind at any time. If you decide not to take part after I have recorded you, the recording will be destroyed and what you said will not be used in my project.

What happens if I say no?

If you do not want to talk to me, then tell me or somebody else. It is fine to say no, and you will not be treated any differently if you say no.
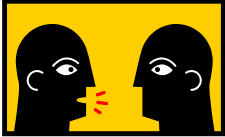
If you are not sure about anything, then please ask me next time I come along. I will let you know when I am coming. You can also phone me on ....

Thank you for looking at this.

APPENDIX C: Materials used in data collection

<u>The Understanding Research Course</u>

I used this outline with students in order to prompt discussion about support given and received within the course. It had previously been used at the end of each session of the course.

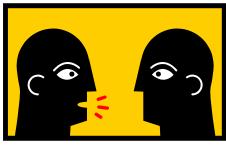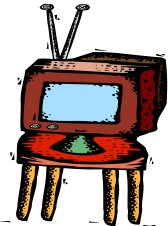| *Asking questions*	*Giving answers*
  Discussing *Checking information*	 *Giving Information* *Confirming information*
Thinking *Having ideas*	*Listening* *Concentrating*

Understanding

Paying attention

Writing

Enjoyed the activity

Happily joined in the group

Drawing

Enjoyed working together

What helped you learn the most?

Discussing **Talking**	**Listening**
Writing or drawing	**Thinking** **Concentrating**
Watching the DVD	**Enjoying the activity** **Enjoyed working together**

The Understanding Research Course.

This is an example of a summary of the first interview with a student that I used in the second interview to follow up ideas and prompt discussion.

Being part of the group

You talked quite a bit about respecting other people in the group, listening and taking turns. Was this important for you?

Can you tell me about a time when this happened?

Can you tell me about a time when it didn't happen?

Team work
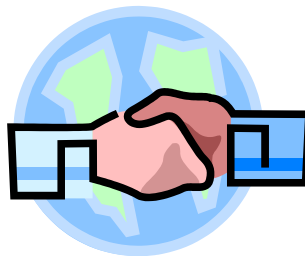
You said that it is important who is in a team. What makes a good team member?

Helping each other

You told me about helping each other:

With reading and writing.

And when someone was unwell. What else did you do to help each other?

<u>The facilitators</u> were there to help you learn.

You said that they answered your questions......

and helped you when you were stuck with activities.

What else did the facilitators do to support (help) you?

Was there any help you needed that you did not have?
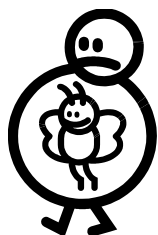
You were nervous before the first session – what might have helped you feel less nervous?
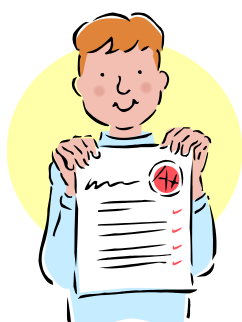
You said that getting your certificate was an achievement: what else did you achieve?
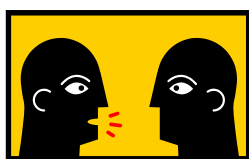
I will be telling people what I found out in my research. What do you want other people to know about how you helped each other to learn?

APPENDIX D: Other organisations involved in Mutual Support

Insight into The Twisting Ducks Theatre Group

Having been part of Interactive Development, the group were launching as their own Company in July 2009.

In time, the actors will be employed by the Company.

The two secretaries of the group are people with learning difficulties from within the group.

Links with other people with learning difficulties

I made contact with the group in response to them having been present at The Lawnmowers' performance at Coach Lane in November 2008. The group said they had got ideas from seeing the Lawnmowers, and hoped that The Lawnmowers and other groups would also gain from seeing their work.

They spoke about the importance of networking with other similar groups.

As a group, The Twisting Ducks are keen to encourage other people with learning difficulties in setting up their own drama groups.

Travelling has been an increasing part of the group's networking.

Support given and received

Examples of support within the day to day activities of the group:

- When the non-disabled supporters have to leave the room, the group continues with their rehearsals, supporting each other.
- The group watch out for each other, especially with regard to physical safety during rehearsals and performances.
- There were examples of support both given and received when learning scripts.
- People are friends outside of the group as well.
- It is important that people are given time to think and speak.

Ways of learning

The group also spoke about the best ways of learning:

- The best ways of learning scripts was from audio CDs
- Some people liked to learn through music.

What makes the group gel/bond

Several people spoke about the bond that there is within the group, and what makes The Twisting Ducks a strong group:

- Everybody is good friends.

- The common interest and passion for drama helps the group gel.
- Personalities help the group to blend well, and getting to know each other over time.
- Support was two way – both given and received.

Friends Action North East (FANE)

Friends Action North East is committed to providing opportunities for people with learning difficulties to make, keep and develop autonomous friendships. Their aims are:

1. *To take action that will directly inform and effect people's lives in terms of supporting and providing autonomous social and learning environments and opportunities to make and keep friends.*

2. *To develop networks and best practice in order to support 'friendship' development.*

3. *To champion friendship.*   *(FANE Annual report 2008).*

During the course of the Mutual Support project, I met twice with the non-disabled Project Co-ordinators. They told me about their vision for people with learning difficulties to have equal access to friendships which are equally valued by others, and the projects which were enabling them to establish this.

One of these projects is the 'Pub Night' which I went along to once. The group met in a pub, and gradually the support from non-disabled friendship builders was being withdrawn. When I was there, a group of ten people with learning difficulties were sat in the pub just like any group of friends would be, with the supporter in a nearby building with a mobile phone in case of any emergency.

The work of FANE has not been central to Mutual Support, but it has challenged my ideas as to what is possible in terms of equality and friendships for people with learning difficulties.

APPENDIX E: The Lawnmowers at Coach Lane

northumbria
U N I V E R S I T Y

**CENTRES
FOR EXCELLENCE
IN TEACHER TRAINING**

CETT *for* Inclusive Learning

As part of the CETT *for* Inclusive Learning seminar series, we are proud to be welcoming The Lawnmowers Independent Theatre Company to Coach Lane Campus.

The Lawnmowers is a company of people with learning difficulties

based in Gateshead. They research, devise, perform and run workshops that reflect their own concerns.

Monday 24th November 2008

3pm - 5pm

Room 013 (Clinical Skills Centre)

Refreshments will be provided

The actors will perform their latest show
HEROIC FEETS: *A show about planning your life.This will be followed by a short interactive session, and an opportunity for staff and students to ask questions.*

The Lawnmowers Independent Theatre Company

People with Learning Difficulties as Educators: report on an aspect of Inclusive Practice

BACKGROUND

The Lawnmowers Independent Theatre Company is a company run by and for people with learning difficulties. It is a registered charity and has been running for 23 years. The Lawnmowers consider issues which are important to people with learning difficulties, using Theatre for Change. Their productions are aimed at empowering people with learning difficulties to take control of issues which are important to them. The Lawnmowers workshops and presentations are also aimed at provoking discussion which will lead to positive changes in policy and services available to people with learning difficulties.

Theatre for Change involves a dramatic production of an issue which is important to oppressed groups, in this case people with learning difficulties. This is then followed by the use of Forum Drama, this involves acting out a scene which portrays a negative situation or experience. The audience is then given the opportunity to discuss how they might improve the situation, before being given a chance to act out their ideas in order to achieve a positive outcome.

The Lawnmowers have had links with Northumbria University over several years. Most recently, these links have been strengthened through partnership with the CETT *for* Inclusive Learning (CETTIL) based at Northumbria University. This report covers an aspect of The Lawnmowers' work over the last year which involved a performance of one of their shows, *"Heroic Feets"* at Northumbria University. The audience included lecturers and students from the School of Health, Community and Education Studies. The performance was followed by an opportunity for the audience to take part in some Forum Drama and a question and answer session. People from other groups of people with learning difficulties were also there for the afternoon which took place in November 2008.

"Heroic Feets" tackles the complex issues surrounding people with learning difficulties accessing Individual Budgets. The show, which lasts around fifty minutes, follows four actors as they seek to make changes to their lives. The show is entertaining as well as thought provoking and ends with the presentation of the first steps towards autonomous choice. It highlights barriers which people with learning difficulties have come across in accessing Individual Budgets, and also presents a realistic framework for taking steps towards controlling aspects of their own lives which most people take for granted, an issue which is of particular relevance to people with learning difficulties and those seeking to support them.

Over the years, the Lawnmowers' shows have become tools for educating people about the issues which people with learning difficulties face. This approach acknowledges people with learning difficulties as having insight into their own experiences, as well as the idea of them educating others about these experiences. The significance of this particular performance was that it involved a reversal of the traditional delivery model of education where those who are considered to be more educated impart knowledge to their students who are considered to be the learners. Many of the people in the audience were lecturers and students from courses within the University including Learning Disability Nursing, Teaching and Social Work. Around ninety people attended the workshop.

The overall aim of this report is an evaluation of the following issues within the context of this workshop: What insight did The Lawnmowers show into their own experiences? How did they communicate this to the audience? What did the audience learn from the actors? What evidence does this provide for the need for students and lecturers to listen to and learn directly from people with learning difficulties?

METHOD

The outline for the afternoon was based on the format which The Lawnmowers have found to be effective, but was adapted in order for this audience to get the most out of the experience. It began with a brief introduction from the Director of The Lawnmowers to The Lawnmowers and their work, followed by the performance of *"Heroic Feets"*. There was then an opportunity for the audience to ask the actors questions, followed by some Forum Drama.

Forum Drama involves enacting real life situations which are negative and disempowering, engaging the audience in thinking about how to change these situations. The Lawnmowers acted out a scenario, and then mingled with the audience as they thought about ways in which they might change the scene for the better. The audience were then encouraged to take on roles within the scene, testing out their ideas as to how to make the outcome positive.

The results section of this Inclusive Practice report draws on evidence from the feedback forms which the audience were invited to complete, and on quotations from recorded conversations with the actors which took place two days after the performance.

The audience were asked the following questions: what aspect did you really enjoy and why? What aspect didn't match your expectations and why? As a result of you attending this performance what would you take away and consider transferring into your own practice / future practice? Any other comments you would like to make? The quotations from The Lawnmowers, which are taken from interviews for a different project focussing on peer support, highlight the views which the actors had about their role as educators during the afternoon.

RESULTS

This results section draws on the aspects of feedback from the audience and actors which specifically highlight the role of people with learning difficulties (the actors) as educators. The quotations represent responses from the audience which demonstrate the way in which the afternoon challenged people's preconceptions about what is possible. The opinions expressed also demonstrate the potential for future partnership between The Lawnmowers and The University, specifically through the CETTil.

Feedback from the audience

The show was fantastic, uses humour to give a unique user perspective. Makes you question your own practice

The acting – a good way to get the message across and raise awareness

People with real life issues putting their slant and how things are for them. Showing what problems they are up against and the promises that are misleading

The actors demonstrated a good level of comprehension about the topic being considered – i.e. budget issues

The story was imaginative and wasn't straightforward. Wasn't too didactic. Enjoyed the forum too

Students liked: The costumes; It was funny; You could take part if you wanted & it was trying to tell us things

Was not sure what to expect but was reminded not to underestimate what can be achieved – Actors sustained easily 2 hours and challenging tasks in front of a big audience!

I have an appreciation of what can be achieved!

I found the play to be an excellent method of showing how people with learning difficulties have dreams which are possible to achieve and that more should be done in society to do so

Well done to Lawnmower group – helps with stigma and promotes understanding. Really enjoyed the performance. Nice to see skills the actors developed. Very impressed by range of activities

This was a very informative session which related to real life issues with real individuals

The Lawnmowers should be here every week!

Should be integrated into pre-reg Education so that every student can take these messages into their practice.

I'll use this as an illustration in my teaching within PGCE / Dip HE
Think about our own practice. Consider how users view our practice, Ensure I don't underestimate users ability to change

Feedback from the actors
Researcher: *What do you think the best thing about Monday was?*

Actor: *Listening to the audience laugh, when we, like when, not much when E and L came on in their costumes, but like when I came on you could hear them laughing, so that's just brilliant. So hearing the laughter, and people listening to what we were saying, and people participating, when we were saying like "I want an individual budget" Them joining in, everybody joined in, when it was their turn. But, yeah, it was just brilliant.*

Actor: *I mean it's different performing in front of a group like that, cos there were different groups there, and it was nice, though, cos it was nice to see what their views were, and when we did the workshop it was nice to see the students getting up and doing things, I mean, it makes you feel kind of proud, a sense of pride, watching them get up and take on your role...*

Researcher: *cos, it's almost like you become the teacher then, you're showing them?*

Actor: *Yeah, and I think that's a good thing, to take away from doing things like that, workshops and putting on a show, I think it's a good thing to take away their views, of what they thought the show was about, and their views on how they think it works. Cos it's a learning curve as well, you learn from them, and they learn from us.*

Researcher: *Is there anything you think could've been different, or better?*

Actor: *I think people's views. I think their views need to change a lot, cos (name) I think it was, was saying how people with learning difficulties and how it's hard working with people with learning difficulties, but I wanted to say 'it's no different to working with your students,' I know we have a difficulty, but we're no different to anyone else – we're all equal in the world, and that's how we wanna be tret. As equals. Cos I think it's wrong if people have a narrow minded view of people with learning difficulties, and think they can't do things, when they can, we can actually do a lot of things, and they need to find out that we can – it might not be the same thing that they do, it might be different to what they do, but we still work together, and it would be nice if people's views changed, cos I've always wanted, since I was young.*

Actor: *I do think it is a big thing, though, getting teachers to change their views, cos if they've never worked with people with learning difficulties, it's a hard thing, I think, to change their views of people with learning difficulties, but I think that would be a big step forward for them if they could learn that. Cos they are gonna come across people with learning difficulties, no matter what, and it's a very thing for me, for people to change their views, cos people have tret me differently all my life, and I don't like being tret like I'm an outcast, cos I got tret like I was an outcast at college, and I just want people to treat me with the same respect as anyone else.*

CONCLUSION

This small scale venture has challenged traditional models of teaching people whose career involves working with people with learning difficulties. It highlights the effectiveness of the use of drama by people with learning difficulties to communicate their views. The performance of *"Heroic Feets"* demonstrated the insight which this group of people with learning difficulties have into the complex issues involved in planning their own lives. This was communicated to the audience with effective use of humour as well as thought provoking drama.

The use of Forum Drama meant that the students and lecturers in the audience had an opportunity to consider real life situations and suggest practical ways of improving them. This provided an opportunity for the audience to put into practice the values which The Lawnmowers had communicated through "*Heroic Feets."* The actors said they would have liked more audience participation at this point: this is something to be built on in the future.

It was important that the audience came to the workshop with an open mind, and the quotations suggest that they were challenged to think about what people with learning difficulties can do, as well as the issues which "*Heroic Feets"* tackles and raises. The quotations from the actors, in particular the final two quotations, highlight the need for those who work with people with learning difficulties to provide inclusive support which listens to people's views about what they need.

This venture also challenges the dominant view of a teacher-learner dichotomy. It challenges the idea of 'learner,' highlighting the need for everyone to be open to learning new ideas and how these ideas might be applied within an inclusive approach to supporting people with learning difficulties. The audience came away from the workshop having learnt through the presentation from the actors. This challenges the concept of learning difficulty by highlighting the fact that all people have things which they find difficult to learn about, and that an Inclusive approach to supporting people with learning difficulties is best conceptualised within a context of continuous learning by people who are supporting people with learning difficulties.

Both The Lawnmowers and those who attended the workshop have said they would like to build on the links which were made through the workshop by holding similar events in the future.

For further information, please contact Sarah Keyes, Postgraduate Researcher at Northumbria University: sarah.keyes@northumbria.ac.uk c/o *School of Health, Community and Education Studies, Research and Enterprise Office Room H007 Coach Lane Campus East Newcastle upon Tyne NE7 7XA. 0191 215 6703.*

APPENDIX F: Feedback and Evaluation Sessions

<u>Outline of presentation at Skills for People. July 2009</u>

Notes which I took along to accompany PowerPoint presentation.

Slide one:

- Reintroduce self and project.
- Come back to what they advised me at the beginning: 'finding out about' is a better phrase to use than 'research'.
- Reminder of what the project is about: peer support and people with learning difficulties.

Slide two: How that finding out is done is important.

- Inclusivity/accessibility have been important parts of the project.
- Skills for People Programme Committee have helped me with that.

Three purposes of this presentation

1) To tell you a bit about how that finding out has gone.
2) Ask you what you think about how things have gone
3) Ask your advice about where to go from here.

Slide three: How have things gone?

- It's been a roller coaster with lots of ups and downs. Meeting with Skills for People Programme Committee has been one of those 'ups', and has kept me going.

Outline of the journey.

I first met with Skills for People Programme Committee in November 2007.

At that time I was expecting the research to take place at [Hospital]. But because the ethical process got so complex, I wasn't able to use all of the ideas from Skills for People. That is something I would like to do differently another time.

Slide four: using audio CDs.

An idea which I did use was that of audio CDs. This meant that people didn't have to read and they had heard my voice before deciding whether to meet me.

Slide Five: More people got involved in the project.

Brief outline of the Understanding Research Course.

The Lawnmowers also got involved.

Slide six: What has the project achieved.

- People can and are supporting each other. This confirmed what Skills for People said in November 2007.

- The support which people told me about was far more than 'lets' all be nice and friendly'. The support which people told me about has had a real purpose. For example, choices in living, fulfilling ambitions and accessing financial support.
- The project has also bridged the gap between academia and community groups. Breaking down the barriers.

Slide seven: Where next?

- The support which I have found out about will become more and more important as the work that organisations such as Skills for People have done means that there are more choices out there.
- Another important idea which has come out of the project has been people with learning difficulties as educators themselves.

What have I learnt personally:

- Never underestimate what people with learning difficulties can do. I have been continually challenged about this
- The issues with access at [Hospital] have given me a glimpse into the discrimination which many people with learning difficulties face.
- But it was the enthusiasm of people with learning difficulties which kept me going.

Slide eight: feedback groups.

- Part of my pulling together of the things I have found out will be some group meetings (then planned for September 2009).

Slide nine: Conclusion.

- What do you think about what I've found out?
- Are there any ways that Skills for People might use what's been found out?
- Do you have any questions?

THANK YOU for your help with this project.

Questions asked following the presentation:

Did I find that people at [Hospital] were supporting each other?

Had I involved an advisory group in the project (question from member of staff who had not been at any of the other meetings)?

Had I found anything out about how support staff might support the development of peer support and people with learning difficulties?

Had I done any work with people with brain injuries and learning difficulties and peer support?

One lady commented that she had been at a boarding school in the 50s and 60s and they had supported each other then. I asked her for an example, she spoke about support with practical things, especially as there were so few staff.

Feedback and evaluation sessions. October 2009

Meeting one at The Lawnmowers. 07.10.2009

The session involved the Company Director, one support worker, three of the actors who had taken part in individual interviews and four other core members of the company.
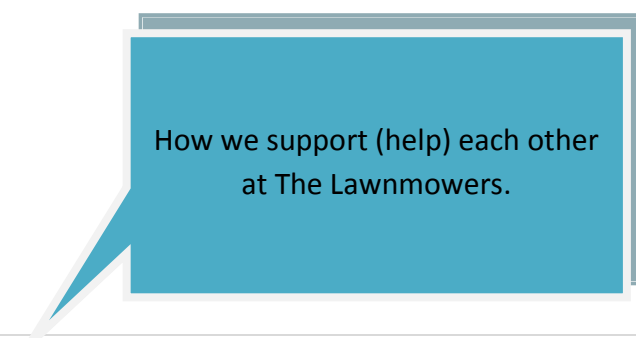
1. The session began with a classic Lawnmowers' game ice/breaker.

This was followed by the use of a 'keys' exercise. I had seen the group use this technique for discussion in other contexts, and adapted it in order to spark thinking and discussion about support.

2. A bunch of keys was place in the middle of the room. I asked the group to think about how much The Lawnmowers support each other: if they thought the group supports each other as much as it possibly could then they should stand with the keys in the centre of the room; if they thought the group does not support each other at all, they should stand as far away as possible. If their evaluation of support is in between the two extremes, then they should stand at an appropriate distance from the keys.

The Project Manager counted down 5-4-3-2-1 action, all but two of those there went and stood in a huddle/hug right at the centre of the room, two others stood a little further away. I then went round asking each person why they had stood where they had, recording what they had said.

3. I then asked the group to form a still image which represented how The Lawnmowers support each other. One by one they added to the still.

4. We then moved on to more structured discussion. I asked the group to work in pairs, presenting them with statements or questions linked to pictures. These statements and questions were linked to the themes which had emerged from previous data analysis: (time did not allow for all the areas I had taken along to be discussed). They then fed back to the group as a whole.

    I placed this speech bubble in the centre of the table:

How we support (help) each other
at The Lawnmowers.

We encourage each other.
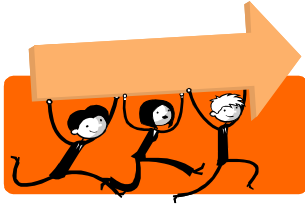
We help each other to make life better when we are not at The Lawnmowers.
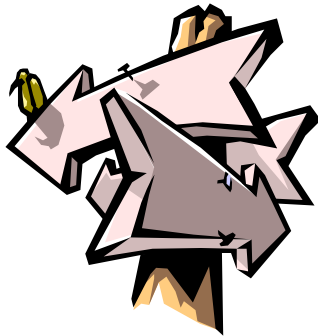
How do you make decisions?

We support each other when someone is finding things hard or is upset.

Session two at The Lawnmowers: 28.10.2009

The discussion picked up from the previous group meeting. Again, in small groups, the following points were discussed and then fed back to the group as a whole.

People within The Lawnmowers support others outside of The Lawnmowers.

I then asked how the group have been supporting each other during the first few sessions of the courses.

I asked them for ideas about dissemination.

At their suggestion, they finished off by going round the group one by one saying what being part of Mutual Support had meant to them.

As with the above sessions at The Lawnmowers, I had translated some of the themes which emerged from data analysis into pictures and statements. There were three facilitators at the group, so we discussed them all as one group. The way in which the discussion flowed meant that many of the issues were covered prior to me presenting the relevant picture and statement.

As with the presentation of data within the findings section of this thesis, I had divided the discussion into three areas: teamwork, teaching and learning and achievement/enjoyment.

Teamwork

The students worked in teams for lots of activities within the course .
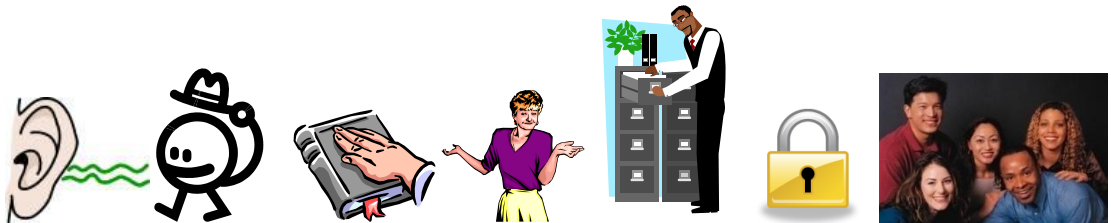
Ground Rules were important within the teams.
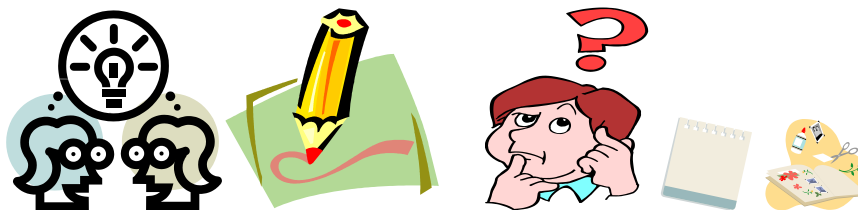
The students supported each other with the activities.

It was important that we (the facilitators) worked together as a team.

Teaching and learning

We (the facilitators) supported the students with learning.

We (the facilitators) used lots of different ways of supporting the students to learn.

Achievement

Completing the course was an achievement.

Getting our certificates was great.

Would you (the facilitators) have completed the course without support from each other?

We also spoke about the role which Tina and Pamela had in the original research and the pilot course.

We finished off with some tips from them about putting together an accessible summary.

APPENDIX G: The Lawnmowers' Images of Support

The Lawnmowers: Images of support

We each individually have supportive skills and therefore we are each vital key elements in a really productive group.

These are The Lawnmowers. They are also my friends

We all support each other in a small way.

These are me friends, I love them a lot.

I'm standing here because there's a close bond with other people, and help when I need it.

I feel like we're a supportive team, cos we are always there for each other. That's how I feel.

APPENDIX H: Lists of Nvivo8 codes used in data analysis

Table one: free nodes formed during stage one of data analysis (descriptive content analysis). "Sources" indicates the number of interview transcripts in which that free node occurred. "References" are the number of times that free node occurs within all transcripts.

		Sources	References
Free Node	All, The research process.	7	8
Free Node	Lawnmowers. Attitudes of non-disabled people.	1	3
Free Node	Lawnmowers. Fulfilling ambitions.	2	2
Free Node	Lawnmowers. Individual support given or received.	7	12
Free Node	Lawnmowers. Nov '08 performance.	3	5
Free Node	Lawnmowers. Peer relationship - uniqueness.	1	1
Free Node	Lawnmowers. People with learning difficulties as educators.	2	4
Free Node	Lawnmowers. Support for newcomers.	2	2
Free Node	Lawnmowers. Support for others with learning difficulties.	7	11
Free Node	Lawnmowers. Support from non-disabled 'allie'	5	12
Free Node	Lawnmowers. Support in independence.	2	4
Free Node	Lawnmowers. Support prior to being with Lawnmowers.	4	5
Free Node	Lawnmowers. Support when doing performances	4	5
Free Node	Lawnmowers. Times when not supported.	3	4
Free Node	Lawnmowers. What makes a good supporter.	3	3
Free Node	Lawnmowers. What want others to know.	3	4
Free Node	Lawnmowers. working as a team	2	2
Free Node	Understanding Research. Support from facilitators in learning	7	13
Free Node	Understanding Research - DVD	4	8
Free Node	Understanding Research Individual support given or received.	6	8
Free Node	Understanding Research What makes good research.	2	2
Free Node	Understanding Research Future plans	5	10
Free Node	Understanding Research Personal feelings during course.	4	8
Free Node	Understanding Research Reasons for getting involved in course	1	2
Free Node	Understanding Research Support from peers	2	5
Free Node	Understanding Research Teamwork and interpersonal interaction.	7	36
Free Node	Understanding Research Things that didn't help.	6	9
Free Node	Understanding Research Things that helped with learning.	3	5
Free Node	Understanding Research What want others to know.	4	4
Free Node	Understanding Research. Achievement	5	10
Free Node	Understanding Research. Best ways of learning.	4	13
Free Node	Understanding Research. Having fun together.	2	2
Free Node	Understanding Research. Teaching skills	3	7
Free Node	Understanding Research What research is.	2	4
Free Node	Understanding Research What we did on the course.	4	12
Free Node	Understanding Research What makes a bad team?	1	2
Free Node	Understanding Research. Tina and Pamela's role	4	4

Table two: Presentation of tree node structure formed during stages three and four, leading to final thematic framework.

Table 2a: tree nodes relating to data collected at The Lawnmowers.

		Sources	References
Mutual Support @ The Lawnmowers.		0	0

		Sources	References
	Lawnmowers Improving life opportunities.	2	4
	Lawnmowers. Emotional Support or Encouragement.	4	9
	Lawnmowers. People with learning diffs as educators.	3	7
	Lawnmowers. Practical support.	8	12
	Lawnmowers. Role of non-disabled allies.	5	13
	Lawnmowers. support for others with learning diffs	7	13
	Lawnmowers. times when not supported	3	4
	Lawnmowers. What makes good supporter.	3	7
	Lawnmowers. What other people should know.	4	6
	Support prior to being with Lawnmowers.	4	5

			Sources	References
Tree Node	UR What want others to know.			
	Tree Node	What want others to know.	4	4
Tree Node	UR. Achievement.			
	Tree Node	UR Overcoming fears and anxieties	4	7
	Tree Node	UR Plans for the future.	5	6
	Tree Node	UR Working as a team.	5	11
	Tree Node	UR. Seeing the final result.	3	5
Tree Node	UR. Teaching and Learning.			
	Tree Node	Tina and Pamela's role.	4	4
	Tree Node	UR Facilitators' reflections.	1	6
	Tree Node	UR. Ways of learning. Students' reflections.	6	33
Tree Node	UR. Teamwork and interpersonal interaction.			
	Tree Node	Teamwork in other contexts.	3	3
	Tree Node	URTW One to one support as part of the teams.	6	12
	Tree Node	URTW Things that we did as teams.	6	31
	Tree Node	URTW What makes a good team.	4	7
	Tree Node	URTW. Facilitator's Insights.	1	3

Table 2b: tree nodes relating to data collected from students from the Understanding Research Course, and the "Becoming Educators" discussion (facilitators).

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