

PEOPLE WITH LEARNING DISABILITIES AND THE INTERPERSONAL
CONSTRUCTION OF SELF-DETERMINATION

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The candidate confirms that the work submitted is his/her own and that appropriate credit has been given where reference has been made to the work of others

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ABSTRACT

People with learning disabilities experience limited self-determination and have very little opportunity to take control and make choices affecting their own lives (Stancliffe and Wehmeyer, 1998). In recognition of this, government policy emphasises the importance of empowering people with learning disabilities to take more control and make choices that influence their own lives (DoH 2001, 2009). In order to meet the values set out in policy, the interactions between people with learning disabilities and the staff who support them is of particular importance. This study focuses on the interpersonal construction of self-determination between service users with learning disabilities and front line staff.

Discourse analysis, informed by principles of discursive psychology, was used to examine naturalistic data from video recorded interactions. Secondary data was generated through the use of a recall session where staff and service users met separately with the researcher to watch the recording and comment on parts of the video they felt were important.

The analysis revealed a number of actions present within the talk that served to facilitate or limit self-determination. Staff frequently occupied a position of power in influencing the available opportunities for self-determination. Actions used within the talk included but were not limited to: recruitment of parental view, colluding to enable choice, coaching, using constructions of competence and incompetence. Repertoires of incompetence and competence, protection and independence were identified. Ideological dilemmas around protecting service users vs encouraging self-determination and autonomy were also found.

The research is discussed in relation to the wider literature concerning empowerment and self-determination. The findings suggest that the policy goals of facilitating choice, control and enhancing service user's self-

determination are complex in practice and difficult for frontline staff to achieve. A number of clinical implications are identified including the use of video material as an effective training tool for interventions aimed at developing staff confidence and competence in empowering practices.

TABLE OF CONTENTS

ABSTRACT	4
TABLE OF CONTENTS	6
LIST OF TABLES	8
LIST OF FIGURES	8
ABBREVIATIONS	9
CHAPTER 1: INTRODUCTION	10
1.1 Learning disabilities: terminology, definitions and prevalence	10
1.1.1 Terminology	11
1.1.2 Rejecting the label	12
1.1.3 Definition of learning disability	14
1.1.4 Prevalence of learning disabilities in the UK	15
1.2 Choice and self-determination in people with learning disabilities	18
1.2.1 Self-determination: a dictionary definition	18
1.2.2 The role of staff as mediators of self-determination	19
1.2.3 The importance of opportunities for choice	21
1.3 Research with people with learning disabilities	24
1.3.1 Literature search strategy	24
1.3.2 Traditional research paradigms	25
1.3.3 Emancipatory and participatory paradigms	26
1.3.4 Theoretical overview of discourse analysis	27
1.4 Discourse and the exercise of power	29
1.4.1 Discourses pertinent in interview research	29
1.4.2 Discourses pertinent in everyday interactions	32
1.5 Summary of the literature and the current research	36
1.5.1 Research Question	37
1.5.2 Research Aims	37
CHAPTER 2: METHOD	38
2.1 Theoretical rationale for the methodology	38
2.1.1 Theoretical background of discursive psychology	39
2.1.2 The use of naturalistic data	43
2.1.3 The use of video recall/ interview data	44
2.1.4 The use of video	45
2.1.5 The consultation group	46
2.2 Ethical Considerations	47
2.2.1 Capacity to consent	48
2.2.2 Confidentiality and data security	50
2.3 Sample	51
2.3.1 Sample size	51
2.3.2 Participant selection- Inclusion criteria	52
2.3.3 Participant selection- Exclusion criteria	54
2.4 Recruitment Procedure	54
2.4.1 Service user recruitment	54
2.4.2 Staff member recruitment	56
2.4.3 Secondary data collection: video recall	58
2.4.4 Obtaining consent	60
2.5 Analytical steps	61

2.5.1 Researchers position.....	63
2.5.2 Ensuring quality	65
2.5.3 Transcription Conventions	66
CHAPTER 3: ANALYSIS.....	67
3.1 Staff and Service User Demographics	68
3.2 Martha and Pam: a pen picture.....	68
3.2.1 Using constructions of competence and incompetence	70
3.2.2 Restricting and encouraging a voice	74
3.3 David and Julie: a pen picture	77
3.3.1 Asserting independence	79
3.3.2 Confirming an existing routine	81
3.4 Roy and Simon: a pen picture.....	85
3.4.1 Colluding to enable choices	86
3.4.2 Closing down uncomfortable conversations	89
3.5 Kris and Jenny: a pen picture.....	91
3.5.1 Coaching	93
3.5.2 Acquiescing or agreeing.....	96
3.6 Actions occurring across pairs.....	98
3.6.1 Recruiting the parental view	99
3.6.2 Testing, doubting and checking	102
3.7 Summary of main findings	106
CHAPTER 4: DISCUSSION	107
4.1 Current research findings in relation to wider literature	108
4.1.1 Positioning and power in relation to opportunities for self- determination.....	108
4.1.2 Managing roles and conflicting values	113
4.1.3 Reflection on video recorded interactions.....	116
4.2 Strengths and Limitations	119
4.2.1 Methodological issues	119
4.2.2 Analytical Considerations	124
4.3 Clinical implications	127
4.4 Avenues for future research.....	129
5. REFERENCES	131
Appendix 1: Literature Search Strategy	142
Appendix 2: Staff and Service User Information Sheet	143
Appendix 3: Service User and Staff Member Consent Forms.....	146
Appendix 4: Information Letter	151
Appendix 5: Ethical Approval Letters	153
Appendix 6: Research and Development Letters.....	156
Appendix 7: Flow Chart of Consent Procedures	157
Appendix 8: Transcriber Confidentiality Agreement	158
Appendix 9: Prompt Sheet	159

LIST OF TABLES

Table 1: Number of times video was paused for reflection	60
Table 2: Table depicting demographics of staff-service user pairs.....	68

LIST OF FIGURES

Figure 1: Publishing guidelines	25
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ABBREVIATIONS

BPS: British Psychological Society

DoH: Department of Health (UK)

DA: Discourse Analysis

DP: Discursive Psychology

LD: Learning Disability

SU: Service User

SM: Staff Member

CHAPTER 1: INTRODUCTION

This study aims to examine the discourses used by staff and service users in every day interaction. In particular, this study looks at how staff and service users position themselves within the talk and how opportunities for self-determination are both opened up and closed down. Given that people with learning disabilities often need support towards developing self-agency and self-determination there is a growing body of research looking at how this might best be facilitated. The current study contributes to this literature by looking specifically at every day interactions between staff and service users, identifying the discursive devices which are employed in order to achieve particular actions.

In order to contextualise and focus the aims of the current research, an outline of the wider related literature is provided. Firstly the terminology, definitions, and prevalence of learning disabilities are discussed. Within this the label of having a 'learning disability' is discussed in the context of the social exclusion and a historical view of the social inequalities and prejudices this group have faced. Following this, notions of choice and self-determination are introduced and specific definitions agreed upon. The important role that staff have in mediating self-determination and choice is then discussed. Subsequently a review of the research relating to people with learning disabilities and the exercise of power through language is discussed before illustrating the current research questions.

1.1 Learning disabilities: terminology, definitions and prevalence

This section provides a rationale for the terminology used within this study; current professional definitions and diagnostic criteria are then explored. Contextual information regarding current UK prevalence rates also given.

1.1.1 Terminology

There are number of different words used to define and categorise people with learning disabilities for example, within academia the term '*intellectual disability*' is prevalent while in the United States of America '*developmental disability*' or people with '*intellectual impairments*' are commonly used terms. Typically, '*learning difficulties*' is the term preferred by those who received the label (BILD; 2010). However, professionals working both in education and clinically have disputed the use of such a term, arguing that the term '*difficulty*' described and relates to discrete difficulties with learning at school such as dyslexia, which is markedly different from a more global learning disability. From a social constructivist perspective, professionals (and indeed the labels used to define others) maintain a powerful system of disablement (Rapley, 2004). In this sense, it can be seen as a diagnosis of difference- of deficit- defining people by what they cannot do. This leads to others intervening in terms of providing support and sometimes protection. However this can often mean placing restrictions on the lives of people with learning disabilities.

Within the UK and the NHS specifically, the term 'learning disability' is more regularly adopted. For this reason, throughout this document I have chosen to refer to 'people with learning disabilities' to describe the population of focus. This is also the term used by the services that were involved in this study; therefore, it was thought to best reflect those who took part.

The term *service-user* will also be used in reference to those individuals participating in this research. This is a term often used to refer to individuals who are currently- or have in the past- accessed services. For clarity, it is important to indicate here that within some of the transcripts presented in the analysis chapter, service users are occasionally referred to as 'customers' by their support staff. (In some services this is the adopted terminology.)

1.1.2 Rejecting the label

People with learning disabilities are a population who are labelled by others, as they do not conform to the cultural norms of typical intellectual development. It is important to examine the way in which labels are used to identify and define this group as it lends to the understanding of their historical social exclusion. Indeed, discourses of difference and disadvantage surround this particular group.

The use of a diagnostic label is simultaneously helpful and unhelpful. It is useful in that it helps determine the specific needs of an individual and what support they may require from services. In this way, it could be argued that labels are primarily for the benefit of commissioners and those providing services with little benefit for the individuals who make up this group (Hardie and Tilly; 2012). Categorisation has its roots in positivism and has become a tool that clinicians have developed to provide a framework within which to understand the spectrum of learning disabilities that exists.

Tied up with the notion of diagnosis is the language of difference, which is deficit driven. For people with learning disabilities, this has both implicit and explicit implications for their capacity and dependence on others. Multiple layers of disadvantage thus add to the discourse of need, care and protection surrounding the stigmatisation of this group (Sutcliffe and Simons, 1993). Diagnosis is a construct that emphasises the pathological and problem-saturated narratives of people's lives. The way in which we conceptualise disability is important; it defines how we understand individuals with disabilities, which has consequences for clinical practice and service provision (Jenkinson, 2007). The dominant medical perspective locates the problem or disability within the individual. Consequently, services have evolved with a philosophy of helping people by treating or trying to change the individual and there is little to no acknowledgment of wider societal and relational influences on the construction of the disability (Oliver, 1992).

Diagnosis and labelling are reductionist, as status is ascribed to the individual through the lense of one aspect of their lives, with other aspects of an individual's identity being ignored or supressed (McLaughlin, 2009). Gillman, Heyman and Swain (2010) note that a learning disability diagnosis is associated with powerlessness and control by other professionals who position themselves as an expert in being able to give a diagnosis. It is important therefore to consider the effects that these common and accepted practices have on the lives of people with learning disabilities. This relates directly to the current research that looks at the everyday important practices of front line staff who support people with learning disabilities.

The term people with 'learning disabilities' will be used within this research study; however, it is important to stress that people with learning disabilities do not readily identify with the label of being a learning disabled individual (Cunningham, Glenn, Fitzpatrick, 2000). There are a number of explanations for this. The most prominent psychological interpretation is that association with a devalued group can have significant consequences for an individual's self-esteem; therefore, in order to protect their self-esteem, people with learning disabilities distance themselves from the group (Goffman, 1963; Taylor and McKirnan, 1984). These accounts conceptualise the lack of identification with a label as an unconscious denial strategy which protects that individual's self-esteem. Finlay and Lyons (2005) conducted necessary research into how people with learning disabilities saw themselves. In their research they interviewed 36 people with learning disabilities and asked them questions which guided them towards identifying descriptions of themselves. In the following year, 29 of the original participants were re-interviewed. Themes from the interviews were collated and it was revealed that people with learning disabilities either implicitly or explicitly expressed uncertainty over the meaning of the label. Indeed, this is understandable given that people with learning disabilities are often not privy to the assessment procedure and therefore have limited knowledge around what does and does not constitute a learning disability. A further explanation for

why people with learning disabilities may not identify with the label is noted by Beart (2005) who worked closely with self-advocacy groups. She suggested that there is a lack of open discussion between parents and staff working with people with learning disabilities and therefore little opportunity to explore the meaning of a label in order develop an understanding of it.

The application of a label is perhaps more important than the label itself or whether an individual openly identifies with this category. The British Institute of Learning Disabilities (BILD; 2010) suggest that any label should be used respectfully. Within the current research, one of the aims is to enable people with learning disabilities to have a voice; I hope they have felt valued throughout and had a positive experience of the research process.

1.1.3 Definition of learning disability

As learning disability is a socially constructed concept. Its meaning and how it is identified and defined has varied over the years. There are a number of definitions of learning disability that are currently used. The health and social care white papers (DoH 2001, 2009) notes that a learning disability is present if they meet the following criteria:

- Significant impairment in intellectual function
- Significant impairment in social or adaptive dysfunction resulting in a difficulty to cope independently
- An impairment with early onset (prior to adulthood) and with a lasting effect on development

These criteria match the criteria given by the World Health Organisation in the International Classification of Disease (WHO, 2007) and the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013).

The causes of learning disabilities differ and many are unidentified. Often the presence of a learning disability is influenced by biological, medical, social, behavioral and educational factors. These factors can influence the level of a learning disability at different developmental stages: namely; prenatal, perinatal and postnatal (Luckasson, Coulter, Polloway, Reiss, Schalock, Snell, Spitalnik and Stark, 1992).

Due to the variety of causes, people with learning disabilities present very differently and with different levels of severity. Many individuals with learning disabilities also present with comorbid physical health conditions and may have sensory and mobility difficulties as well as other difficulties such as autism and problems in communication (Emerson, McGill and Mansell, 1994). Indeed, it is these multiple layers of disadvantage that contribute to the discourses of need for this client group.

1.1.4 Prevalence of learning disabilities in the UK

As the concept of learning disability is socially constructed (Dudley-Marling, 2004), there are implications for determining the prevalence of learning disability, as the definition of those who have a learning disability has shifted over time. Social constructionism is a framework which suggests that meaning is derived from the integration of social, cultural and historical contexts (Dudley-Marling, 2004).

It is difficult to get an accurate estimate of the prevalence of people with learning disabilities in the UK. Government information suggests that in 2011 there were approximately 1,191,000 people with a learning disability living in the UK (Emerson, Hatton, Robertson, Roberts, Baines, Evison, and Glover, 2011). From this number, there are 905, 000 adults over the age of 18 years. It is thought that from the adult population, only 21% (189,000) are known to access services.

Given this population of people accessing services, we may conclude that there is an equally vast number of staff employed to support these individuals, therefore there is both an ethical and economic requirement to examine the way in which staff support these individuals. Currently, this area remains under researched.

1.2. Historical and current service provision

Despite government initiatives promoting the rights and inclusion of people with learning disabilities (DoH 2001, 2009) they remain one of the most marginalised groups within the UK. Negative societal attitudes and discriminatory behaviour towards this group continue to perpetuate their exclusion (Scior, 2011). Indeed, as a group, they have and continue to experience stigma and disempowerment.

From medieval times into the late 19th century, the legal system classified individuals with learning disability as idiots who lacked reasoning ability (Wright, 1996). The end of the 19th century saw people with learning disabilities further segregated and oppressed with the development of large institutions, purpose built to protect society from those that had now become labelled as ‘mentally’ or ‘morally deficient’ (Jackson, 1996).

In this era, the influence of the medical profession can be seen; people with learning disabilities were understood as having an *organic disease* (Caine et al., 1998). Galton’s writings about gene heritability became influential to the eugenics movement which wanted to increase the biological quality of the human race through selective parenting (Nunokoosing, 2000). People with learning disabilities were prevented from having sexual relationships and enforced sterilisation was ‘normal’ practice (Caine et al, 1998). The separation of men and women in institutional settings meant that people with learning disabilities often had little opportunity to develop meaningful sexual relationships. The movement of people with learning disabilities out of

large institutions into smaller community settings means that many of these environmental barriers preventing the development of sexual relationship in the past, no longer exist. Nevertheless, people with learning disabilities still have social barriers to contest with and still report limited opportunities in developing sexual relationships. Research suggests that many still experience a lack of autonomy in the decision about starting to use contraception with these decisions often being made by others (McCarthy; 2010).

With the development of community services and the new philosophy of Normalisation later named Social Role Valorisation Wolfensberger, 1983), disability became understood as a disempowerment through reduced social standing. As a philosophy however, normalisation is largely directive of people with learning disabilities and sits somewhat uneasily with the values of self-determination. One of the aims relating to social role valorisation is to increase the social status of people with learning disabilities in order to help them contribute to society in a meaningful way, and as a result live more normal and valued lives. These ideas are encapsulated in the structure of service provision today and indeed are reflected in the dominant discourses promoted in public policy: social inclusion, autonomy, choice and control (DoH 2001; 2009).

More recently, the influential Mansell report (2007) suggests that services should not only be provided locally within the community to increase social inclusion and open up more opportunities for greater independence, but also on the personalisation of care to that individual. Whilst these issues are still high on national and local agendas, within services there still remain difficulties in translating values encapsulated in policy and legislation into real world practice (Finlay, Walton and Antaki, 2008). Focusing on the everyday nuances in interactions between staff and service users is one way in which to explore if and how these values might be enacted in practice. A powerful illustration of this is evidenced with the exposure of abusive practices in the public case of Winterbourne View (DoH 2012a; 2012; 2013).

Reports since Winterbourne note that even with the promotion of community living, people with learning disabilities continue to be disadvantaged in the quality of care they receive (DoH, 2012). One year since Winterbourne and guidelines continue to reemphasise the need to transform care to address issues of disempowerment and develop practice (2013). While efforts to address disempowerment at a service level continue to be explicit, a focus on the more subtle power dynamics that exist in the everyday interactions between staff, carers and service users is arguably more important in terms of addressing this issue more fully. Research relating to empowerment in everyday practice is explored in more detail within later sections.

1.2 Choice and self-determination in people with learning disabilities

Discourse of choice, empowerment and encouraging self-determination in people with learning disabilities permeates policy documentation (DoH 2001; 2009). Nevertheless, some of the difficulties in translating these values into everyday practice are now more frequently acknowledged. In order to focus the current research, working definitions of self-determination and choice are presented and an exploration of how these definitions relate to people with learning disabilities will be discussed.

1.2.1 Self-determination: a dictionary definition

In the Online Oxford English Dictionary (2013) '*self-determination*' is defined as:

-'self-determination'- noun [*mass noun*]

- the process by which a country determines its own statehood and forms its own government: '*the changes cannot be made until the country's right to self-determination is recognised*'

- the process by which a person controls their own life: '*services for the mentally ill should aim to promote individuals' capacity for self-determination*'

In the second example given, within the Oxford English dictionary, the mantra of services needing to promote the capacity for self-determination is once again reinforced. Self-determination can thus be understood in both a political and personal sense. In the political sense, self-determination is regarded as a people's right or right of a *country or government* to self-govern without excessive influence of others. Self-determination as a basic human right has influenced services for people with learning disabilities, where value is placed on an individual's right to make self-determined choices (Wehmeyer and Bolding, 2001). Historically self-determination within a learning disability setting emerged from the guiding principles of normalisation and independent living, which recognise the western values of autonomy and independence (Nota, Ferari, Soresi and Wehmeyer, 2007). In the latter dictionary definition, self-determination relates to the personal self-determining *process* in which individuals exert some control over their own lives by acting as causal agents (Wehmeyer and Palmer, 2003). This definition of self-determination will be the focus throughout the current research. It is particularly relevant for people with learning disabilities who continue to experience limited opportunities for self-determined action or control in their lives (Stancliffe, Abery and Smith, 2000).

1.2.2 The role of staff as mediators of self-determination

In an attempt to understand the abstract concept of self-determination, Wehmeyer (1999) developed and validated a functional framework. This framework identifies four essential characteristics of self-determined action: autonomy, self-regulation, psychological empowerment and self-realisation.

An outline of these components as illustrated by Wehmeyer and Schwartz (1998) is presented below.

- **Autonomy:** where the individual acts on their own preferences/interests/ability independently and without excessive outside influence.
- **Self-regulation:** where decisions are made around what skills to draw on in a given situation. Self-regulation occurs based on the internal formulation and evaluation of an action plan.
- **Psychological empowerment:** occurs when people act based on the notion that they have capacity to behave in a way to influence a particular outcome within the environment.
- **Self-realisation:** occurs when people draw on existing knowledge about themselves, their strengths and limitations and act in a way that capitalises on this knowledge.

All four characteristics are important in the enactment of self-determination; these characteristics can be developed through an individual's learning experiences which promote the acquisition of skills that facilitate self-determined action. Importantly for people with learning disabilities, staff act as mediators of the development of self-determination. In most instances, people with learning disabilities are reliant on others to provide them with opportunities and adequate support, so they might experience their own influence on the world, resulting in the development of self-agency. Furthermore, as many people with learning disabilities experience little control over their lives they may develop a learned helplessness, which could further reduce the likelihood that they will act on opportunities to exercise choice (Jenkinson, 1999). With this in mind, it is essential to consider the role of support staff in encouraging people with learning disabilities to make self-determined choices, which enable a sense of control (Brown and Brown, 2009). Given the importance of staff in mediating the development of self-determination, the interpersonal relationship between staff and service users will form the basis of the current research.

1.2.3 The importance of opportunities for choice

Opportunities and experience of choice-making are important if self-determination in people with learning disabilities is to be encouraged (Wehmeyer and Bolding, 2001). Wehmeyer and Garner (2003) found that choice availability is a primary predictor of self-determined action. Indeed, choice or choice-making is described as one of a number of single-component skills of self-determined behaviour (Wehmeyer and Palmer, 2003). Consequently, an understanding of self-determination can be explored through a focus on the available opportunities for choice interactions.

The term '*choice*' is used abundantly within the learning disability literature, however there is a little consensus regarding its definition (Harris, 2003). It is a term often used synonymously with others like 'control' or 'decision-making' (Brown and Brown, 2009). In order to establish how the current study will use and define choice, a definition is provided. The term decision-making is often applied to choices which have more importance or are likely to have a bigger impact on a person's life; this term is not one that will be used here (Harris, 2003). The term choice or choice-making is preferred within the current study. Whilst this term is limited to smaller decisions, it is reflective of the data collected within the current study that focuses on the everyday choices.

In the Online Oxford English Dictionary (2013) '*choice*' is defined as:

- '**choice**' - noun [*mass noun*]

- an act of choosing between two or more possibilities: *the choice between good and evil*
- the right or ability to choose: '*I had to do it, I had no choice*'
- a range of possibilities from which one or more may be chosen: '*you can have a sofa made in a choice of forty fabrics*'

- a thing or person which is chosen: *'this disk drive is the perfect choice for your computer'*

-'choice'- adjective

1 (especially of food) of very good quality: *'he picked some choice early plums'*

2 (of words or language) rude and abusive: *'he had a few choice words at his command.'*

From the definition above it is evident that choice can be used in multiple ways, it is a noun, an adjective and a verb. Harris (2003) notes that the promotion of choice for people with learning disabilities is often hindered due to confusion around its conceptualisation. Within the learning disability literature, it is commonly used as a noun but also used to suggest the action related to the verb i.e. 'to choose' or 'to make a choice' (Brown and Brown, 2009). This sense is adopted within the current study. Choice or having choice is considered important to an individual's quality of life; it is an expression of a person's wishes and therefore is facilitative of control and self-determined behaviour (Smyth, 2006; Wehmeyer and Bolding, 2001). In this sense, choice is closely related to the concept of self-determination (Harris, 2003). Self-determination not just about making a choice, it is a process of learning about choice-making and developing a sense of autonomy or influence. For example, we learn how to make a choice by experiencing the outcome of this choice. In this way a sense of self-agency and an understanding of our ability to influence the external world is reinforced. Simply offering a choice will not always encourage the enactment of self-determination; it is more complicated than this. For example, if a person is offered a forced choice of two things and neither are particularly favourable for that individual, whatever choice is made has little reinforcement and therefore the process of learning is hindered. It could be argued then that self-determination in this instance may not evolve. In this sense self-determination is more of a process and the ability to make a choice acts as the outcome of this process.

Within the above definition, choice is also conceptualised as a '*right*,' suggesting something that is entitled. This definition is largely agreed upon within the learning disability literature; choice is promoted as a civil right and people are entitled to the right to choose or to make choices that will affect their lives (Department of Health, 2001; 2009). This particular definition raises a number of ethical dilemmas. If choice (as a civil right) is prioritised then it could be proposed that a person is entitled to make any kind of choices, even those which are deemed risky or bad for them. While it is true that all of us can make 'bad' choices it must be acknowledged that to some extent choice, for everyone, is restricted due to societal structures and social convention (Harris, 2003). Nevertheless a real ethical dilemma exists for staff when a person with a learning disability makes a choice which is perceived as 'unwise' or a choice which is not considered to be in their best interest (Brown and Brown, 2003). Indeed, one of the principles enshrined within the Mental Capacity Act (MCA) (DoH; 2005) states that '*a person should not be treated as unable to make a decision merely because they make an unwise decision*'. Conflicting agendas can lead staff to encounter ethical dilemmas, such as the need to balance matters of choice against risk and the protection of adults assessed as lacking capacity (Fyson and Kitson, 2007; Finlay, Walton and Antaki, 2008; Dunn, Clare and Holland, 2010).

The MCA is a legal framework designed to empower and protect vulnerable people that lack capacity to make their own decisions. It allows others to intervene if someone is assessed to lack capacity to make decisions themselves. Indeed the act draws attention to the value of individual autonomy (Williams, 2014). According to the principles of the act, a person is assumed to have capacity unless it is established that they lack it. If a person is assessed to lack capacity then any decisions made on their behalf must be made within their best interest. The act is limited around big decisions that are situation and time specific and less so for small choices. Some of the dilemmas faced by care staff will be explored in more detail in later sections

focusing on discursive research that examines staff and service user interactions. Additionally, the dominant discourses that maintain the disempowerment of people with learning disabilities are also explored. Indeed, the language used within the MCA (DoH, 2005) legislation is likely to influence how people talk about increasing autonomy.

1.3 Research with people with learning disabilities

This section provides an overview of the literature search strategy used in order to identify literature relevant to the current research. An illustration of how traditional research paradigms have perpetuated the disempowerment of people with learning disabilities is also given. Alternative paradigms relating to participatory and emancipatory research are explored. Finally an overview of Discourse Analysis (DA) is presented in order to clarify the assumptions and theoretical principles that underpin the current research. Further details of the analytical principles influencing the current research are discussed in the method chapter.

1.3.1 Literature search strategy

In order to provide some insight into the process I undertook when identifying relevant literature, an outline of the search strategy employed is provided. Electronic literature searches were conducted using PsycINFO (OVID), Medline (OVID) and EMBASE (OVID). Search terms included multiple combinations of words and synonyms of the same word for example 'learning disabilities' and or 'intellectual disabilities'. Abbreviated substitutes of particular words were also used for example 'learning disability (ies)'. Filters were built into the literature search sequentially with other combinations of words such as; 'learning disability AND self-determination,'. For a full list of combinations and search terms see Appendix 1.

Research papers were read in order to establish direct relevance to the current research. The guidelines produced by Elliot, Fischer, Rennie and

Stiles (1999) relating to the publication and production of research in psychology were used to critically evaluate each paper. These guidelines were chosen as Elliot et al. (1999) comment on both qualitative and quantitative criteria in which to assess the quality of research. Articles were included where they met the majority of the criteria, set out within Elliot et al. (1999) paper. An overview of these criteria is provided in figure 1 below.

Figure 1: Publishing guidelines

- | |
|--|
| <ol style="list-style-type: none">1. Explicit scientific context and purpose2. Appropriate methods3. Respect for participants4. Specification of methodology5. Appropriate discussion6. Clarity in presentation7. Contribution to knowledge base <p style="text-align: right;">(Elliot et al, 1999).</p> |
|--|

Furthermore, consideration was given to whether qualitative research papers included credibility checks. This is considered particularly important for qualitative research in order to establish the papers trustworthiness. Given that research in this area is largely qualitative, the qualitative guidelines for authors and reviewers developed by Malterud (2001) were also considered in relation to qualitative papers included in this research.

1.3.2 Traditional research paradigms

Traditionally, research is conducted in a top-down manner; research *on* rather than research *with* participants (Kiernan, 1999). Here the initial area of interest and research questions are decided and asked by the researcher, who then recruits participants in order to generate data and draw conclusions. Research conducted in this way has been criticised for neglecting the participant's individual perspective. Consequently, questions that are most important and relevant to their lives can be lost.

Disempowerment has permeated these traditional research protocols for centuries. Whilst there is a large body of research pertaining to people with learning disabilities, typically many studies fail to capture the *voice* of the service user. With an increasing focus on inclusion and the empowerment of people with learning disabilities, it follows that the perspectives of people with learning disabilities ought to be considered. As a result people with learning disabilities have been encouraged to have a more active role in the research process (Flood, Bennett and Mesome and Northway, 2012; Bigby, Frawley and Ramcharan, 2013).

1.3.3 Emancipatory and participatory paradigms

Emancipatory and participatory research paradigms have a strong history in disability studies and challenge the traditional ways of conducting research. Supporters of the new paradigm suggests that disability research should focus on reducing social and disabling barriers; this can only be done if research is controlled by those who experience the disadvantage themselves (Oliver, 1992). There are a number of criticisms concerned with the application of both paradigms to people within learning disabilities.

The aims of both research paradigms promote the importance of control within the research process for people who are disabled (Oliver, 1992). Assuming research depends on a level of academic intellect, it becomes less accessible to individuals with learning disabilities than others in disadvantaged groups who do not experience an intellectual impairment (Chappell, 2001; Gilbert, 2004). Reasonable adjustments can be made to accommodate this difficulty, for example carers or non-disabled allies are often relied on in order to provide support to the person with a learning disability in conducting the research. Nevertheless, this raises the question about whether *'good science'* can be produced by good inclusive research (Grant and Ramcharan; 2007). Indeed as it is important to acknowledge the potential influence of the researcher, particularly in qualitative research, it is

equally relevant to acknowledge the agenda and the power that the *allied supporter* would have on the research outcome.

While the current research does not meet emancipatory or participatory criteria, it felt important to acknowledge the potential disempowerment created by doing research *on* people with learning disabilities. For the current research a basic starting point was to ensure that the research area was one which people with learning disabilities consider important enough to explore (Nind and Vinha, 2013). In order to facilitate this, a consultation group was set up to establish initial ideas about what was important to people with learning disabilities. This group consisted of a number of diverse people with learning disabilities and two non-learning disabled facilitators. Ideas about what mattered to people within the group were explored and from this, the topic of choice was identified as important. Indeed this area also linked with some of my own experiences relating to the work I had done as a support worker and assistant psychologist prior to the doctorate. My own reflections on these roles and the influence of my own interest in this area are acknowledged and detailed in the method section.

1.3.4 Theoretical overview of discourse analysis

In situating the current research, it is important to clarify key assumptions behind the method of analysis in order to do this, a brief overview of Discourse Analysis (DA) and its theoretical background is presented. Historically DA developed from a critique of cognitivist thinking, which posits that language is used to represent individuals' thoughts and feelings. Therefore an individual's words can be taken as a true representation of their '*inner mental state*' (Willig, 2008). However, for discourse analysts, conversation is purposeful and has meaning that is influenced by a social context. Talk is situated in a social domain and can be interpreted or read in multiple ways (Willig, 2008). A principle tenet of DA is that it recognises the '*constructive*' qualities of language and therefore looks to examine how people negotiate and achieve interpersonal and social functions, by drawing

on available discursive resources (Potter, 2003; Willig, 2008). Given that language is seen as constructing rather than representing social reality, it follows that discourse analysts do not seek to establish any objective truth, rather the process of analysis involves looking in detail at what the talk achieves, what social goals are being met and with what consequences.

There are two predominant forms of DA – Foucauldian discourse analysis (FDA), and discursive psychology (DP) (Willig, 2008), although Wetherell (2001) acknowledges up to as many as six. Both forms share the common assumption that language constructs and scaffolds social reality which shapes our understanding of the world (Burr, 1995). However each form has evolved from differing intellectual beginnings and can be utilised to address different types of research questions.

FDA developed from a post-structural tradition and is most notably influenced by the writings of Michel Foucault. FDA views language as rooted within a social historical context that either facilitates or limits the production of specific discourses. Willig (2008) suggests that dominant discourses make available particularly ways of '*seeing*' or '*being*' in the world. This analytical approach therefore assumes that language is inextricably linked to the exercise of power, as the dominant discourses continue to reinforce the existing social structures and practices that form our reality (Potter, 2003). FDA facilitates a wider approach to analysis, allowing researchers to analyse the discursive realities which make up society as a whole. DP sees language as action-orientated; it examines how language is used to construct version of reality or achieve particular goals. It is the principles of DP which underpin the analytical processes in the current research. In the following section an exploration of current research focusing on specific discourses relevant to people with learning disabilities are explored. Furthermore, research which looks at empowerment within everyday practice is critically reviewed and specific gaps in the literature

highlighted. This is provided in order to ground the current research questions.

1.4 Discourse and the exercise of power

The power inherent in language permeates everyday interactions; it is therefore important to focus on some of the research which explores the wider discourses surrounding people with learning disabilities as well as the more subtle ways in which language and power is exercised in practice.

1.4.1 Discourses pertinent in interview research

As previously noted, people with learning disabilities are marginalised through their position in society and through the way in which powerful discourses operate around them. Research that looks to elicit service users' views using interviews is particularly important in highlighting how some of the dominant negative discourses associated with people with learning disabilities can become internalised and disempowering.

As part of a wider study looking at empowerment, choice and control for people with people with learning disabilities, Jingree and Finlay (2011) interviewed 7 women and 4 men—all of whom accessed either care home or day-centre provisions. The interviews were structured around general questions relating to choice and control and discourse analysis was applied to each transcript. While this paper does not detail the analytical stages that were implemented, its conclusions are substantiated with detail extracts from transcripts. The research found that people with learning disabilities drew on repertoires of incompetence in order to express dissatisfaction over the level of support they received. Participants also constructed themselves as competent in order to validate their own point of view.

Similarly Scior (2003) conducted interviews with 5 women with learning disabilities' that were recruited through 2 community teams and 1 advocacy

agency. Importantly the interview was combined with photographs and drawings in order to facilitate service user understanding. Scior (2003) also gave considerable thought to her own position and the influence this had on the interpretation of the data set. Within the transcripts, Scior (2003) identified 'guardianship discourses' which were used to construct people with learning disabilities as vulnerable and in need of support and protection. These discourses were particularly evident in choice talk about the possibility of having children. The research highlights how these constructions allow carers to maintain a level of control over people with learning disabilities and restrict certain choices under the guise of protective discourses. Indeed the discourse of protection permeates service policy which constructs people with learning disabilities as vulnerable adults.

Research that focuses on staff who work with people with learning disabilities, highlight the difficulties of their role in facilitating empowerment, choice and control. Indeed, it is important to acknowledge staffs' own context and the often powerless positions they occupy when attempting to implement policy. In a recent study examining the discourses used by care staff in the promotion of choice and control, Jingree and Finlay (2008) illustrate some of the dilemmas faced by staff. They conducted interviews with 12 female and 3 male staff who worked in a service that provided residential care and day services for people with epilepsy and learning disabilities. In this paper, they detail the analytical steps and provide extracts to illustrate observed discourses. The theme of 'increasing autonomy' was noted within the talk as staff drew on discourses about people's rights to make choices and have control in their lives. Indeed, these discourses are made available to staff as they dominate public policy -it is not surprising that staff draw on these constructions in order to advocate on behalf of service users. What is perhaps most interesting about these findings is that 'increasing autonomy' talk was often contrasted with 'practicalities talk' which focused on why choices could not be endorse or facilitated. As well as attributing difficulties to biological and stable traits within the person with

learning disabilities, staff also identified the constraints of environmental factors when attempting to facilitate choice; for example not having enough staff to support a client's requests.

An earlier study by Wilcox, Finlay and Edmonds (2006) identified similar discourses of 'individual pathology' and 'contextual' or environmental constraints in examining the construction of behaviour that challenged services. In their study, 10 support staff from multiple services were interviewed. Again the research method was clearly demonstrated with analytical steps outlined and transcripts presented to illustrate the conclusion drawn. 'Individual pathology' discourses came from dominant medical notions of deficit and located the problem within the service users. This construction allowed service users to be positioned as 'different' from others. On the other hand the 'context discourse' constructed challenging behaviour as an understandable and 'normal' reaction to environmental circumstances. Importantly the authors reflected on the use of these discourses in order to manage blame. Staff have a duty of care and are therefore responsible for the safety of service users as well as having an obligation to facilitate more adaptive behaviours. Displays of behaviour that challenges services casts doubt on staffs effectiveness within both roles that they occupy. Therefore; it is not surprising that staff draw on discourses in order to manage blame; this is a protective strategy. Nevertheless, that management of blame can deter staff from identifying useful avenues to better their practice (Wilcox et al; 2006).

These studies have been limited to the use of interview data and despite producing interesting results, some fail to provide detail of participants or the method of analysis, making them difficult to validate. Similarly, it is important within interview research that the influence of the researcher is acknowledged. For example, their orientation to certain questions and their presence may have promoted the production of more socially desirable answers. Without considering this, the validity of the conclusions drawn

could be called into question. Indeed this is present within Scior's (2003) research but less explicit in others reviewed above. Finally some of the research above is now a decade old. The following section reviews more recent research focusing explicitly on everyday live interactions of staff and service users.

1.4.2 Discourses pertinent in everyday interactions

Interaction is central to issues of empowerment and disempowerment; it is therefore important to review the literature that examines interactions between staff and service users. Empowerment is important in the promotion of public policy around increasing self-determination, choice and control for people with learning disabilities (Finlay, Walton and Antaki, 2008). Issues of choice and control are manifested by the way in which people interact and talk to each other. The talk between people with learning disabilities and the staff who support them is often strikingly asymmetrical. This was evidenced in a study conducted by Antaki, Young and Finlay (2002) where staff members conducted a service audit within a supported living scheme. The service audit was framed as a chance for people with learning disabilities to express their view on the service they received. 5 staff and 5 service users took part in the study. Service users were asked questions, based on a standardised questionnaire, in order to elicit feedback on the quality of care that service users received. There was little detail of the method used within this research although it was clear that the data was gathered via audio-recordings. Nevertheless the analysis was substantiated with extended transcripts from the interactions observed. Antaki et al. (2002) found that instead of sticking to the neutral and objective question format, care staff made various adaptations that were found to influence the answers that service users gave. These adaptations consisted of non-neutral questions or leading questions, giving advice or evaluative feedback. For example offering positive praise after some answers were given. Staff had a marked influence over the answers which were eventually written down for the official audit. In the context of a service audit that aims to evaluate the

care that is received, if questions have not been asked in a standard way, what is recorded is not necessarily a true reflection of the reality. More recently Antaki and Kent (2012) conducted a study which focuses specifically on the sorts of questions that are used by staff in order to facilitate exchanges with people with learning disabilities that allow a conversation to flow. This study was part of larger ethnographic research which videoed staff and service user interactions in 3 differing locations (2 residential services and 1 voluntary sector service). The authors provide adequate details of participants and information relevant to their communicative abilities. However they do not explicitly illustrate the theoretical framework which guided the interpretation of the analysis. Results of the study suggest that if conversation did not flow it often came to a premature end or staff would end up taking a more influential role in its direction. Antaki and Kent (2012) identify seven different strategies that staff utilise in order negotiate between these two unwanted outcomes, these included simplification of a question format and repetition and expansion of the original question. These findings highlight the active but sensitive role that staff members are required to take if conversation is to be appropriately supportive.

In a different study (again focusing on interactions between staff and service users) Jingree, Finlay and Antaki (2006) examine how empowerment played out within 2 residents meeting for people with learning disabilities. These meetings were set up with the specific aim of encouraging expression of preference and empowering people with learning disabilities. Data was collected over 2 months from 2 different privately run organisations. While the study gave very little description of the participants involved and only some details of the process of analysis, there is substantial evidence from extracts that enables a clear understanding of the findings. Indeed conversational analysis is applied to the data which enables close inspection of the power inherent within the exchanges between staff and service users. This study illustrates how staff led and controlled discussions through attending to certain voices and ignoring other utterances. Jingree et al.

(2006), note that this practice conflicts with the overall objectives of the meeting; to empower people with learning disabilities. Indeed it was also acknowledged that service users were persistent in expressing their preference for example a woman expressed 14 times that she did not like the idea of retiring. This was acknowledged only twice by staff and one of these times the staff member reframed her predicament -forced retirement as the day service was closing- into something more positive. This meant that her concerns were left unheard. Staff tended to position themselves as more knowledgeable than service users and preferences were only taken up if they were endorsed by staff. This research is incredibly valuable in terms of highlighting the ways in which disempowering practices can remain unquestioned because they are so subtle and routine.

Further research around the enactment of choice is examined by Finlay, Antaki and Walton (2008) in a study involving people with learning disabilities who had limited communication. Data for the study formed part of the same ethnographic research mentioned earlier; data was collected from 3 different services over a 9 month period. Within this study Finlay et al. (2008) used conversational analysis in order demonstrate how staff are often faced with a dilemma regarding the implementation of conflicting service objectives. The research provides adequate detail of the services involved and demonstrates how data was generated through video and audio recordings. Nevertheless there was little information included about the stages of analysis which were applied to the data. The complexity of the data gathered was acknowledged by the authors and an effective strategy of reducing the data into a manageable format -through the presentation of only two episodes which illustrated the relevant themes- was successfully applied. This worked very well with the inclusion of extensive ethnographic detail to bolster the readers understanding. Importantly this research highlights two conflicting service aims: firstly, the need to provide care and health checks through the routine procedure of weighing service users, and secondly to acknowledge and respect individuals' choices not to get weighed. Staff

demonstrated a persistence to achieve the former goal. This research is particularly fruitful in that the analysis takes into account both verbal and embodied action. This is important given that some service user participants within the study had little communicative skills. It demonstrates how research with people that have higher support needs can be done in a positive way and emphasises the use of video in order to capture embodied action present in communication. The use of video will be discussed further in relation to the current research.

As noted previously policy documentation places huge emphasis on the need to encourage people with learning disabilities to have more choice and control in their lives (DoH 2001; 2009). Nevertheless research suggests that it is not easy to translate these values into practice. Issues of communication between staff and people with learning disabilities (Antaki and Kent 2012) can create barriers to enhancing choice and control. Antaki, Finlay and Walton (2009) highlight that providing real choice to people with learning disabilities is a complex and often difficult process. This research focused on choice interactions between staff and service users within two residential homes. Importantly the analytical stages were omitted from the analysis- perhaps in order to save space within the publication-nevertheless its inclusion would have been useful in determining a more valid evaluation of the research. Extended extracts to illustrate conclusions drawn were presented in the appendix. Essentially this research details the discrepancy between 'big' choices for example where to live and who to live with and 'smaller' but arguably no less significant, every day choices. Indeed Antaki et al. (2009) revealed that discourses around the 'big' choices encapsulated in public policy bear little to no resemblance of the choices which are actually offered and negotiated in real world practice. In order to close this gap between official discourses and everyday practice, Antaki et al. (2009) highlight the potential use of feedback sessions where staff can reflect on their own practice in real time, though watching back video-recorded interactions. Indeed the use of video recall, where service users and staff have an

opportunity to watch and reflect on their interactions, is incorporated within the current research design. It is hoped that video recall sessions will alert staff to the importance of their own interactions in helping facilitate self-determination through more empowering practices.

Given the pertinence of everyday interactions and the difficulties that are continually identified in research concerning self-determination and choice, there is scope for new research to consider these issues further. The current study proposes the use of discourse analysis as informed by principles of discursive psychology in order to examine everyday interactions concerning the negotiation of self-determination.

1.5 Summary of the literature and the current research

The evidence base relevant to the current research highlights various disempowering discourses which surround people with learning disabilities. Indeed research also highlights the difficult and often helpless position that staff find themselves in when attempting to implement policy goals pertaining to increasing choice, autonomy and empowerment for people with learning disabilities. Within this, research highlights the complexities involved in the basic facilitation of everyday choices, the notion of which is made more complex by the multiple and often conflicting agendas faced by frontline staff. Finally, research indicated the use of video as an important tool to encourage staff reflection on their practice.

Despite the aforementioned research, there remain few studies that employ the use of video to record staff and service user interactions within this research field. The evidence base focusing on choice in everyday interactions remains small and some of the studies reported above do not include a full account of the analytical steps applied during the analysis. This makes it problematic in terms of evaluating the quality of available research. Despite such restrictions these studies are included due to their relevance to the

current research. Research in this area is notably split between using interview data or data more akin to naturalistic interactions. In recognising the merit of both, the current research uses naturalistic data as its primary source and data generated through video recall as a secondary or supplementary data source. No study in relation to this area of research has utilised this dual methodology before.

The current research employs discourse analysis as informed by discursive psychology; as a result there is a strong focus on the small but significant exchanges that go on between people with learning disabilities and staff members. It is hoped that in highlighting how self-determination is negotiated in everyday interactions, and how opportunities for self-determination are opened up or closed down within the talk, new knowledge and understanding may be developed. The current research may therefore be useful in terms of identifying ways in which staff might develop their awareness of particular ways of interacting that may have more empowering effects. More broadly the application of the findings are hoped to be useful to staff working in frontline services for people with learning disabilities.

1.5.1 Research Question

- How is self-determination negotiated in everyday interactions between staff and service users?

1.5.2 Research Aims

- To examine how opportunities for self-determination are facilitated or closed down in interactions between staff and service users with learning disabilities.
- To examine self-determination in relation to the position each participant occupies within the discourse.
- To examine how participants reflect on the recorded interaction and how these reflections relate to the primary analysis.

CHAPTER 2: METHOD

Within this chapter the theoretical rational for the chosen method is discussed and an overview of its background is given. Following this the ethical issues related to this research are considered. The practical method is then described, looking at sample selection and the application of the two-part recruitment process. The process of the analysis is then described, including the stages of reducing the data into a manageable format. Finally, a brief commentary on quality assurance, the researchers' own position and reflections from the research process are presented.

2.1 Theoretical rational for the methodology

Firstly it is important to situate this research within its wider qualitative methodology. This study does not look to quantify data or verify predetermined hypothesis which would more appropriately be addressed by a quantitative methodology. Instead, this research has an exploratory focus looking in detail at participant interactions in order to make sense of and extrapolate meaning of these exchanges. Qualitative research methods have thus been chosen. These methods more generally seek to engage with data in order to develop new insights into the way in which participants make sense of their experience within the world (Elliott et al, 1999). Qualitative discursive approaches differ in that there is an explicit focus on language or discourse and on the construction of accounts given. The researcher may openly focus on the function or effects of using particular discourses. Within this study there is a focus on staff and service user interactions; the context to these interactions is important in understating how language is used to construct or indeed obstruct opportunities for self-determination. Qualitative methods- which capture the context, quality and richness of these exchanges- were considered most appropriate in addressing the research questions.

A range of qualitative methods were considered for their suitability in addressing the current research questions. Three key epistemological questions guided the choice of method:

- What knowledge are we looking to produce
- What are the assumptions of the methodology
- How is the researcher and her experience conceptualised within the methodology (Willig, 2008).

The research questions prioritise discourse (with a specific focus on both its interpersonal construction and function) discourse analysis (DA) was considered most appropriate. Importantly, within the current research there is an explicit focus on everyday micro interactions; therefore the analysis was guided and informed by principles of discursive psychology (DP). These approaches to discourse are explored in greater detail within the following sections. Other qualitative methods would answer different questions and focus on different elements of the data; for example, thematic analysis would look to establish patterns or themes associated with understanding a particular phenomenon (Braun and Clarke, 2006). Interpretive Phenomenological Analysis (IPA) might answer questions related to the participant's experience and sense making (Reid, Flowers, & Larkin, 2005). DA is preferable to other qualitative approaches as it is well suited to the research questions that explicitly focus on language and interaction rather than participant cognitions or experience.

2.1.1 Theoretical background of discursive psychology

The current research is situated within a discourse analytic context; however, it is important to clarify that it is the ideas from discursive psychology (DP) which have influenced the analytical process and the research as a whole. DP is not a prescriptive method of analysis, but rather a set of analytical principles which can be applied to guide interpretations of discourse (Potter, 1992). DP can be used to examine how people negotiate meaning and use language to achieve particular goals within social interaction (Willig, 2008). It is important to examine some of the key

assumptions underpinning DP in order to demonstrate how it might guide the analysis of discourse within the current study.

In contrast to Foucauldian discourse analysis, DP evolved out of conversational analysis with its specific focus on everyday interactions (Potter, 2001). The early influence in the development of ideas credited within DP came initially from the works of Wittgenstein (1953) on the philosophy of language. Wittgenstein developed a new way of looking at language, as a counterbalance to the dominant understanding at that time: notably that language was simply a unified system which enabled abstract reasoning. Wittgenstein posited that language was more like a 'tool kit', fragmented, practical and varied in its usage (Potter, 2001).

In later years, the ideas of the philosopher John Austin (Potter, 2001) came to influence the development of DP. Austin's most notable idea is his 'general theory of speech acts', this theory postulates that words allow the performance of certain actions, for example persuading, denying or accusing. Further to this is his idea of 'illocutionary force,' here there is an understanding that when different forces are applied to words their meaning can change. Austin (Potter, 2001) also highlighted the importance of societal and historical conventions as well as the current context in which language is produced all of which are important in the development of meaning from discourse. Potter (2001) suggests it is Austin's 'general theory of speech acts', which was notably influential in the transformation of the study of language. Indeed, discourse analysis has been shaped by these ideas as it underscores the importance of psychology, social context and social structures when attempting to understand language and its application (Potter, 2001). Austin's theory is influential, nevertheless it has not endured without criticism, Potter and Wetherell (1987) highlight shortcomings regarding its application to everyday discourse and its failure to consider the complexities of interaction within talk.

Potter and Wetherell's (1987) seminal book, *Discourse and Social Psychology: Beyond Attitudes and Behaviour*, provides a critique of the traditional perspectives within social psychology and examines the subsequent evolution of DA. It is perhaps important to draw attention to the ways in which psychologists traditionally understood language in order to illustrate the reorientation within social psychology to the idea that language is functional and 'action-orientated' (Potter and Wetherell, 1987). Indeed it is ideas from Potter and Wetherell (1987)- derived initially from conversational analysis- that influenced the development of discursive psychology. The traditional view within psychology was that language is a conduit to access our inner cognitions. It was seen as a way in which we could represent our inner thoughts, feelings and attitudes to others. DP moves away from this view and emphasises the constructive and action-orientated qualities of language. DP therefore looks to examine how people negotiate and achieve interpersonal and social functions by drawing on their available discursive resources (Potter and Edwards 2001; Willig, 2008). In examining dominant and counter discourses, we can begin to develop an understanding of the personal and social objectives being played out in the talk (Potter and Wetherell, 1987; Willig, 2008). Willig (2008) agreed with this view and notes that people use language to construct themselves in a particular way, for example in order to validate their claims in an argument, or position themselves in a favourable light. Edley (2001) suggests that there are numerous ways in which we can construct an event or object, but states that some constructions - due to their cultural dominance - may be more accessible and therefore more easily said than others. The term 'construction' also infers a conscious selection or exclusion of certain discourses or ways of talking; it reemphasises the functional aspect of language (Potter and Wetherell, 1987). The analytical focus within DP is therefore on how discursive resources are employed and with what consequences (Willig, 2008).

Edley (2001) identified three significant concepts that may guide analysis; interpretive repertoires, ideological dilemmas and positioning. I will discuss each in turn, in order to highlight how these concepts will influence the current research. *Interpretive repertoires* are linguistic tools, metaphors and figures of speech that are used flexibly in order to construct a perspective or particular position. Recognition, identification of these repertoires and their functions facilitates a deeper understanding of a participant's linguistic agency, as discourse or talk is negotiated. The notion of *ideological dilemmas* are captured in our 'common sense' views of the world which are often contradictory (Edley, 2001). People frequently hold concurrent opposing discourses about the same topic, as an example a service user might hold a view of services relating to wanting more support from others but also wanting to be independent. Identifying these dilemmas will facilitate an understanding of action within its social context (Potter and Wetherell, 1987). Furthermore it is important to consider the *subject position* of the participant in relation to the available discourse, in order to establish the meaning and function of the language used (Edley, 2001). In considering language as purposeful action used to co-construct our own social reality we can begin to understand how available discourses can promote or limit action according to conscious or unconscious objectives (Davies and Harre, 2001).

In answering the research questions the analysis focuses on the action-orientation of the talk, specifically the way in which the participants constructed themselves in order to negotiate and achieve particular aims. Where relevant to the research questions, *interpretive repertoires*, *ideological dilemmas* and *subject positions* are commented upon. Further to this, Wetherell and Edley (1999) advocate the use of a more fined-grained analysis –akin to what you might find within conversational analytic studies– when applying discursive principles to a text. With this in mind, the current research also pays particular attention to the rhetorical devices used within talk, which enable interpersonal goals to be met or accounts to be

strengthened (Edwards and Potter, 1992). An overview of the steps which were taken as part of the analysis can be found in section 2.5.

2.1.2 The use of naturalistic data

The importance of using naturalistic data is emphasised within discursive psychology, as naturalistic talk is thought to allow insight into the phenomena that is studied directly as a result of a particular setting. Edwards and Potter (1992) suggest that this is important as it allows identification of the action-orientation, constructed and situated nature of talk (Edwards and Potter, 1992). Within discourse analysis, interview data has at times been considered a poor substitute for naturally occurring talk as it has been noted that participants may orient themselves to the interview context and therefore present themselves in particular ways (Hammersley, 2003). Potter and Hepburn (2005) suggest that by using naturalistic data, you are able to capture the phenomena that are present, irrespective of the researcher's interest, thereby reducing the influence of the researchers on the data. Nevertheless, in utilising naturalistic data, it remains important to acknowledge the influence of the researcher and the agenda they bring to the process of analysis (Griffin, 2007) - reflexivity is particularly important here and will be addressed within later sections.

Within the current research the primary data set is most akin to naturally occurring data, although it is acknowledged that the interactions captured on video are not entirely naturalistic as participants were aware they were being filmed and selected the focus of the discussion that would be recorded. The secondary data generated through video recall is more akin to interview data.

2.1.3 The use of video recall/ interview data

The secondary data used within this study were gathered through the use of video recall. This section considers the use of interview data and acknowledges some of the difficulties associated with interview data.

Finlay and Lyons (2001) noted many difficulties when reviewing the literature relating to interviewing people with learning disabilities. Their review highlights the complexities in conducting interviews with people with learning disabilities and recommends that other more naturalistic methods are used to supplement the data. In line with this, the current study draws from naturalistic methods as its primary source of data and uses secondary recall interviews only to support and or enhance the primary findings. Sigstad (2014) suggest further methodological considerations when interviewing people with learning disabilities. Perhaps the most pertinent to the current study is having an awareness of the tendency for people with learning disabilities to acquiesce. Acquiescence is defined as a tendency to respond to questions in the affirmative and is often regarded as being motivated by a willingness to comply or please. Finlay and Lyons (2002) note that acquiescence occurs more often when participants do not understand the question. In the current study, it was important to be aware of acquiescent responses between staff and service users. At the same time during the secondary recall stage of data collection it was important to give participants extra time to understand questions that I asked of them.

Furthermore Potter and Hepburn (2005) note the difficulties associated with the researchers interpretation of what is said and what the participants actually mean when data is collected via interview procedures. In the current study the findings are grounded within the discourse that is generated. However it is noted that the researcher contributes to and influences the talk that is produced. The involvement of the researcher, in particular the prompts or questions used to facilitate recall, will have an impact on what

and how certain topics are approached and discussed. Given the presence of the researcher, participants may have censored or adapted what they said in line with what they felt was appropriate or acceptable to say (Willig, 2008). In this instance steps were taken to make each participant feel as relaxed and comfortable as possible when participating in the recall session.

2.1.4 The use of video

Within the qualitative research field of the learning disability literature, the use of video is reasonably novel as a method of data collection. There are only a handful of studies where video has been used to look at choice and self-determination in people with learning disabilities. Over the course of 9 months, Antaki Finlay and Walton (2009) utilised video and audio recordings from 2 residential homes in order to examine how policies around choice were actualised in practice. In a related study Finlay, Antaki, Walton and Stribling (2008) discussed the principles of empowerment, inclusion and independence by examining two episodes of video recordings of a staff member instigating playing a verbal and non-verbal 'game'.

The use of video material has long been identified as a medium in which training and service development can be facilitated back in 1995 Couchman identified its uses in educating staff in responding to nonverbal behaviour. This method of data collection has also been employed as a means to promote staff development when working with children with learning disabilities (Van Vonderen, Didden and Beeking, 2012). They found that video feedback was effective in improving care staff responses to the children. Video has also been employed as a method by which to promote staff reflection on their practice. In Sweden, Antonsson, Graneheim, Lundstorm and Astrom (2008) noted that professional carers can have difficulty interacting with people with learning disabilities. This study notes the effectiveness of using video as a method to prompt recall and open up discussion on practice, this has potential implications for strengthening the competence of care staff and the quality of care given.

Video recording allows the capture and subsequent examination of subtle exchanges -within interactions - which may empower or disempower service users towards self-determined action (Finlay, Walton and Antaki 2008). With this evidence in mind, this study intends to use video to capture both verbal and embodied action present in interactions between staff and service users. The video material will also be used to generate secondary data; here the video will be played to each participant in order to assist recall and promote commentary on their thoughts at the time. This will form what in educational literature has traditionally been termed a 'simulated recall interview' (Calderhead, 1981).

When using video in research, a number of decisions need to be made prior to data collection. There are two prominent approaches to video recording; *etic* and *emic*. An *etic* approach requires that the researcher remain distanced from what is occurring in front of them, whereas an *emic* approach advocates that the researcher take more of a participant perspective approach (Ratcliff, 2003). Using an *emic* approach it may be expected that the participants be included in the running of the camera and editorial processes (Collier and Collier, 1986). As the current research focuses on interactions between staff and service users, it requires that both are captured on film; an *etic* approach is most suitable. This approach is unobstructive allowing the researcher to set up and run the video and blend into the background as much as possible.

2.1.5 The consultation group

Prior to developing the current research protocol, a consultation group was set up in order to find out what might be important to research for people with learning disabilities. This group met initially to generate ideas about what mattered to people with learning disabilities and what areas might be prioritised to research. As well as informing the research topic, this group acted as a source of support throughout the research process, meeting a number of times prior to data collection.

Initially a shared understanding of the notion of research was developed before moving to discuss ideas about what might be important to investigate. After the meeting, themes from the group were collated; these informed the area of investigation around choice.

The consultation group also looked at the information sheets and consent forms which would be given out to potential participants. This was to ensure that the information provided to participants was accessible and meaningful. The group gave feedback on the draft information (Appendix 2) and consent forms (Appendix 3) and clarity of the diagrams and language used. They also suggested the inclusion of the 'information letter' (Appendix 4) which could be given to both staff and service user participants to pass on to their parents, carers or managers in order to inform others of their involvement in the research.

This group was incredibly helpful with regard to the development of the current research; my final meeting with them involved sharing the progress of the research and the final findings.

2.2 Ethical Considerations

Ethical approval was sought and granted by Yorkshire and Humber (Leeds West) ethics committee (see appendix 5). The research was also approved and registered with the relevant NHS Trust's Research and Development department (see appendix 6). REC approval was dependent upon careful consideration of a number of ethical issues which are detailed in the following sections.

2.2.1 Capacity to consent

The service user participants within this research are people with a learning disabilities, and therefore constitute a group of individuals who are considered amongst the most vulnerable within society (DoH, 2001). Throughout the study I was aware of the potential power difference between my position as the researcher and those participating, in this context the issue of coercion was considered and efforts were made within the recruitment process to ensure that the research was carried with due consideration of ethics.

Only participants who had capacity to give informed consent to take part in the research were included. The process of establishing valid consent was informed by the Department of Health publication 'seeking consent: working with people with learning disabilities' (2001a) and the Mental Capacity Act (2005). More recently, the Department of Health have also published a reference guide when seeking consent to examination or treatment (DoH, 2009), within this there is an acknowledgement that gaining consent is a process and not a single event. As part of the research process, consent was therefore revisited and rechecked at different points.

Participants were asked to consent to a number of things:

- Initial participation in the study
- Being video recorded
- Being asked if they can be reproached for the second part of the study
- Transcription of video recorded material
- Participation in video recall session
- Being audio recorded (as part of the recall session)
- Use of anonymous quotations from video and audio recorded material

It was essential that informed consent was given freely and embedded throughout the research process (Department of Health, 2001a). In line with available research into the consenting process regarding individuals with learning disabilities, increased time for obtaining consent was built into the recruitment process (Cameron and Murphy, 2007; Lloyd, Gatherer and Kalsy, 2006). A series of different stages were devised as part of the consent process; these will be outlined in more detail in later sections of this chapter. For clarity, please refer to Appendix 7 for a brief flow chart of the consent process and the stages that were implemented.

The first principle of the Mental Capacity Act (DoH, 2005) is that capacity is assumed unless assessed to be otherwise. When assessing an individual's capacity, it should be both decision and time specific and every effort should be made to facilitate capacity. In earlier literature the ability to give informed consent was often aligned with cognitive ability (March, Steingold, Justice, Mitchell, 1997) and as a result people with learning disabilities were excluded from research that was salient to them. More recently it has been acknowledged that individuals can be supported to give informed consent, by researchers utilising more innovative ways of delivering information relating the research (Cook and Inglis, 2009). Evidently it is important that any documents relating to the research process are written in simplified accessible language, information should be repeated and visual aids or multi-media used where necessary (Hardie and Brooks, 2009).

The Mental Capacity Act (2005) requires that people make efforts to support process of understanding through alternative and adjusted communication. In a study relating to men with learning disabilities Cook and Inglis (2009) demonstrate the impact that different ways of educating or delivering information to participants has on their understanding and by extension their ability to give informed consent. They conclude with the suggestion that if *'collaborative recursive endeavour is at the heart of the engagement, understanding is more likely'*. In this respect, it is important that the

researcher invest time in meeting with participants more than once to develop some rapport, in order to build a collaborative understanding of the information pertinent to the study. Due time needs to be allocated to this process, so that the researcher can actively engage with potential participants.

Service users within the current research were supported in making their decision in multiple ways. Information sheets (Appendix 2) and consent forms (Appendix 3) were provided and information was written in clear language with diagrams incorporated to facilitate comprehension (Finlay and Lyons, 2001). Importantly the consenting process was individualised and took place face-to-face so that the researcher was able to pick up on verbal and non-verbal communication from the participant (Cambridge and Forrester-Jones, 2003). This allowed for a more detailed exploration of the participant's understanding of the research and willingness to participate. According to recommendations from Cook and Inglis (2009) the researcher met with potential participants a number of times and information was repeated, thought over and talked about. Furthermore it was made clear both verbally and within the information given to service users that they could withdraw from the researcher at any point and they did not have to identify a reason for wanting to withdraw.

2.2.2 Confidentiality and data security

All data collected for the purposes of this study were kept confidential and were accessible only by the researcher and research supervisors. All participants gave their consent to be video and audio recorded, each recording was transcribed and pseudonyms assigned to each participants. All material was transcribed by two separate professional transcribers: both were asked to sign a confidentiality agreement laid out by the University of Leeds (see Appendix 8). All potential identifying information as well as

contextual details such as names of persons, locations, and landmarks were removed during the transcription process. Within this research, care was taken to ensure that all quotations utilised were anonymous; permission to use direct quotations was obtained during the consent process. As a further precaution to protect the privacy of the participants, the researcher was not privy to any participants personal contact details. The participating service was the conduit of contact between the researcher and the participant.

All video and audio data collected were stored electronically according to the University of Leeds security regulations. All data is kept for approximately three years by the university in a secure and encrypted location. At the end of this period all electronic data files will be destroyed with appropriate software and any paper transcripts shredded.

2.3 Sample

The inclusion and exclusion criteria for both service user and staff member participants are presented within the following sections. It is acknowledged with the theoretical literature surrounding discourse analysis that it is not the aim to produce findings that represent a 'truth' that can be generalised to a wider audience (Willig, 2008). Therefore it was less important to select participants on the basis of heterogeneous qualities such as age, gender or race. Nevertheless selecting a varied sample was considered to be important in order to increase the applicability of this research to the clinical practice of practitioners who may be working in LD services. In the following sections an overview of the inclusion and exclusion criteria are presented as well as further details relating to the participants who were recruited.

2.3.1 Sample size

There are no explicit recommendations on the acceptable and adequate sample size required for qualitative research which focuses on staff and service user interactions. There are, however, a number of classic studies that have used discourse analysis (DA), these have varied in extremes with regard

to sampling. For example Woolgar (1980) focused on a single text while Gilbert and Mulkey (1984) utilised a wide range of interviews in multiple settings in order to establish patterns needed to answer their research questions.

Within more recent related literature, the number of participants or transcripts to be analysed continues to vary. Using interviews Scior (2003) explored the discourse present in talk with 5 women with LD. While Jingree and Finlay (2008) interviewed 15 professional care givers in order to examine, using DA, how choice was promoted or denied. Similarly, Wilcox, Finlay and Edmonds (2006) used DA on 10 interviews with care staff. Drawing from the literature that explicitly focuses on interactions between staff and service users rather than interview data, the number of participants is often much smaller; in a conversation analytic study Finlay, Antaki, Walton and Stribling (2008) examined 2 video recorded episodes where a staff member initiated a 'game' through interacting with a service user with profound learning disabilities.

Indeed Potter and Wetherall (1987) note that when using DA '*the success of a study is not least dependent on sample size*'. Rather, there is an emphasis on the importance of the data set being rich enough to successfully answer the research questions. Therefore within the current research it was concluded that 4 staff and service users' pairs would give a data set large enough to sufficiently answer the research questions. The time limited nature of this research as well as the labour intensive two-part recruitment process was also a factor in the decision to recruit no more than four pairs of participants. These four pairs form the four case studies presented within the analysis chapter.

2.3.2 Participant selection- Inclusion criteria

In order to participate in the research, all staff and service user participants had to be adults (18 years or over) and have English as their first language or

as a language in which they could communicate. This was given as an initial caveat for recruitment as this research focuses on adults with learning disabilities and utilises a method of analysis which requires participants to have some form of verbal ability. Individualised criteria for staff and service user participation are given below.

The principle inclusion criteria for service user and staff participants were as follows:

- Service users and staff to be over the age of 18 years
- Service users had to have a learning disability (BPS, 2000)
- Service users had to have capacity to consent to participation in this research
- Service users and staff members had to speak English and have sufficient language ability.

An addition inclusion criterion was also set specifically for staff member participants:

- Staff participants must provide some sort of supportive arrangement to the service user participant with more than monthly contact.

The sample was required to be homogenous with regard to the above criteria. Within the pairs that were recruited, both service user and staff member participants varied in age and gender. However all participants were white British and therefore ethnic diversity was not captured within the sample for this research. As the sample is small and the research does not intend to produce generalisable findings, this was not considered a concern.

2.3.3 Participant selection- Exclusion criteria

The exclusion criteria for both staff and service user participants echo the reverse of the inclusion criteria and are presented below. Participants were excluded from the research if the following criteria were met:

- Service users or staff members who were under the age of 18 years
- Service users do not meet the criteria for a learning disability (BPS, 2000)
- Service users who are assessed as not having capacity to consent to participation
- Service users or staff members who do not speak English or those who do not have sufficient language ability for the analysis to be feasible.
- Paid staff members who do not provide supportive arrangements to the service user participant with at least monthly contact.

Given that staff member participants must provide a supportive arrangement to the service user participant, with at least monthly contact; it was front-line support staff that were recruited.

2.4 Recruitment Procedure

Staff and service user participants were recruited via a Service User Involvement Team. Service user participants were recruited first so that they were able to have some influence in identifying potential staff member participants. The recruitment process is described in detail below.

2.4.1 Service user recruitment

In order to recruit potential service users, the researcher met with the service lead of the Involvement team (a learning disability service). He was the identified conduit of contact between the researcher and participants. He was given an overview of the research along with participant information sheets (Appendix 2), consent forms (appendix 3) and information letter

(Appendix 4). Potential service user participants who met the inclusion criteria were identified by the service lead. The service lead met with potential participants in order to explain the research and find out if they wished to take part. In total, 4 service user participants were recruited to take part, a further 3 were given the research information but declined interest; 1 expressed specifically that they did not like the idea of being video recorded. During the early stages of recruitment a staff member approached the researchers expressing an interest in participating; however they had not yet been identified by a service user as someone they wanted or felt comfortable with doing the research. Furthermore, the willing staff member did not fully meet the inclusion criteria and therefore was not included in the research as a participant. All participating staff were chosen or identified by the service user participant.

Service users who expressed an interest in participating were asked by the Involvement lead to confirm that they would meet with the researcher to discuss the research in more depth. The researcher did not have personal contact details of any participants. Arguably this was to guard against any manifestation of feeling coerced into taking part. The introduction to the research was therefore done by the service lead that had no vested interest in the research themselves.

The initial meeting between the researcher and service user took place in a location preferable to them. Some service users opted to have their key worker or other support staff present during this meeting. This was encouraged in order to make the meeting as comfortable as possible. The consent and information sheets were revisited at this meeting and the idea of being video recorded was discussed. Service users were also given the opportunity to ask any questions about the research. After the initial meeting, all participants were given a week to consider whether they wished to participate, before the researcher would meet with them again.

In a second meeting, once service users had confirmed they were still interested in taking part, the researcher met with the service user in order to assess their capacity to make an informed decision about participating in the research. This assessment is explored in more detail in section 2.4.4 relating to obtaining consent. All participants had capacity to make an informed decision about participation.

2.4.2 Staff member recruitment

After establishing capacity to consent to the research, service users met with the researcher again. Here they were asked to identify a staff member who they thought might like to participate with them. The researcher used various questions to guide service users in identifying a staff member who met the inclusion criteria. The following are examples of questions used to guide this process:

- Does anyone support you often on a weekly basis?
- Are there any staff at home or day services who you like working with?
- Is there any staff members you are closer to than others?
- Who would you like to participate with you?
- Who do you think might want to participate with you?
- Is there anyone you would like to be videoed with?

In this meeting service users were encouraged to attend alone without their keyworkers who had the option of being present in the previous meetings. This was encouraged in order to reduce any potential coercion or pressure to choose their current keyworker to participate. However due to the close relationship often fostered between keyworker and service users, it was acknowledged that this choice would not be unusual. Only 1 service user chose a keyworker who had been present in the earlier consent stages. All 4 service users chose staff from organisations specific to them. 1 chose his keyworker from home, 2 chose a keyworker from day services and 1 chose a

support worker whom she saw for work related support. Once potential staff members were identified by the service user, the service user then became the conduit of contact to recruit the staff. All were given information sheets, consent forms and information letters to give to the potential staff participants. Once the service user participants had informed the staff about the research, staff were contacted by the researcher. All staff, chosen by the service users were willing to participate.

A joint meeting with the staff member and service user then took place, in a location convenient to both such as day services, home. This meeting had two parts: firstly to give the staff member time to ask any questions about the research and to sign consent forms, and secondly to discuss what the pair might like to record.

The following caveats to the recording were made clear at this point:

- The situation chosen must capture some interaction between the staff and service user. An example of this might be where they are planning a task or engaged in a task together.
- Filming should only include the two consenting participants, so recording needed to take place in a private space.

The focus on interaction was stipulated in order to give richness to the data set but also to capture moments where people may be 'doing' self-determination for example making choices, negotiating goals, changing their minds. The second caveat was given to protect others from being unwillingly recorded. To guide the decision making process and to create a discussion about what to record, the researcher asked a number of questions, the following are given as examples:

- Is there anything that you would like to record?
- What do you do together that might be interesting to record?
- What would you be comfortable in recording?
- What do you do day to day together?

- How do you plan what you do together?
- When do you think you talk to each other the most?
- At what times of day do you see each other most?
- Are there times in the day where no one else is around?
- Are there times where you might do something just the two of you?

These questions were used to scaffold the process of decision making for staff and service users. The researcher encouraged staff and service users to think of times where they might be on their own doing things together. Different scenarios were chosen; 2 pairs chose to record a support plan review session, 1 chose to record the time they spent together making sense of documents for a service users work commitments and one chose to record a weekly planning session. Video recording took place in a location convenient to all participants. More detail relating to the context of each recording is provided within the pen pictures of chapter 3.

2.4.3 Secondary data collection: video recall

The secondary data was generated through a video recall session this occurred after the primary data set was generated. Participants were asked to meet with the researcher separately in order to watch the video material recorded in part 1 of the data collection. As noted earlier, consent to participate is a process and not a single event, therefore participants were asked to provide their consent again; this time to participate in the video recall session. The capacity of each participant to consent to this second part of this research was also considered again (see section 2.2.1 for details). All participants were able and willing to consent to the second part of the analysis and they signed consent forms accordingly (see appendix 3).

The researcher was keen to minimise the amount of time between initial recording of the video and the recall session. Video recall sessions were therefore completed within 6 weeks of the primary recording. Research using video-recall suggests that it can be effective even up to 3 months after the

event (Antonsson, Graneheim, Lundstorm and Astrom, 2008). During the recall process, the video acted as a contextual prompt to participants who were encouraged to reflect on the video.

The researcher met with each participant and watched the video at a location that was convenient to them. The setting was important to consider in order to help participants feel comfortable and more able to participate confidently. The video recall session was audio recorded and later transcribed. The video recall session was set up in a similar way to Interpersonal Process Recall (IPR). IPR is a qualitative interview approach which uses video in order to promote self-review (Larsen and Flesaker, 2008). It is based on the idea that replaying video provides contextual prompts in order to facilitate reflection and recall of thoughts and feelings that occur during interactions. The current study drew on this model of data collection. It is important to note however that the secondary data in this study was used to provide a reflective commentary on the primary data. Therefore the current study does not make any claims in terms of applying the particularly specialised qualitative interview procedures that you would find in an IPR study.

In the recall session participants were encouraged to stop the video in order to provide their reflections at any point. The researcher also stopped the video in order to promote reflection from participants, through asking questions. A prompt sheet provided the researcher with exploratory questions designed to promote reflection (Appendix 9). This helped provide some structure to the recall session, particularly where participants were less confident at offering their views.

Below is a table which details the number of times that each participant stopped the video themselves to provide comments and how many times the researcher stopped the video.

Table 1: Number of times video was paused for reflection

Participant Pseudonym	No of times the researcher stopped video	No of times the participants stopped video
Roy (SU)	15	16
Martha(SU)	7	5
David(SU)	4	8
Kris (SU)	11	3
Simon (SM)	15	10
Pam (SM)	10	2
Julie (SM)	15	8
Jenny (SM)	11	21

2.4.4 Obtaining consent

It is acknowledged that there can be some benefit to having someone who knows the service user well in the initial consent session (Walmsley, 2004). Thus, participants were encouraged to bring a staff member or person to support them. The decision to participate remained voluntary; therefore the researcher was mindful that if a person accompanied the service user, their role was to support only and not to influence the overall decision regarding participation (Freedman, 2001).

Capacity to give informed consent was assessed under the guidance of the Department of Health publication '*seeking consent: working with people with learning disabilities*' (2001a) and the Mental Capacity Act (2005). These key documents suggest that capacity to consent is demonstrated if an individual can:

- Understand and retain the information they are given in relation to the project
- Use, retain and weigh this information to make a decision about participation
- Communicate that decision back to the researcher.

In order to check capacity, the researcher informally explored participants understanding of the accessible information they had been given and asked them to describe the information back in their own words. The researcher used a variety of open and closed questions. For example:

- “Can you tell me about what you have to do if you are taking part?”
- “What do you think might happen if you don’t want to take part?”
- "How will I know if you don't want to take part?"

Participants were then asked to confirm if they were still interested in taking part. Assessing capacity to consent was embedded throughout the research process; if the researcher thought that a participant had lost capacity to consent at any point, they would be withdrawn from the study. Information sheets were given and consent forms signed at 2 key points: directly before commencing video recording for part 1, and again before commenting the recall session for part 2. All participants were able to give their informed consent.

2.5 Analytical steps

The process of data analysis is illustrated in the following steps which are informed by the principles which define discursive psychology. The steps outlined initially by Potter and Wetherell (1987) *Discourse and Social Psychology*, were employed in order to analyse the current data set. Importantly the analytical process was not always linear with different stages revisited on numerous occasions. The presentation in a sequential format is for the benefit of the reader’s clarity.

1. All video data was transcribed- due to the volume of data gathered and the lengthy transcription process, professional transcribers were employed. The researcher then watched the videos and added into the transcript any embodied action that was present. For example [laughs], [nods].
2. The researcher began by watching part 1 of all participants. Part 1 was watched back a number of times. The aim here was to gain an

overview of the primary data set and note down initial impressions or strong feelings that the video evoked.

3. Transcripts for part 1 were then read and reread. The data was coded for interactions that linked to the research questions. This involved identifying sections of text which broadly concerned self-determination [looking at how service users asserted themselves, where choices were offered, issues negotiated, etc] or text which prompted a strong personal reaction for example feeling sad/angry.
4. Following the identification of salient extracts, these were examined in more detail in the context of the research questions. Preliminary ideas around what was happening in the text, what was being negotiated or implicitly talked about were noted. Initial ideas relating to the interpretive repertoires that were drawn on, ideological dilemmas and positions that participants occupied within the talk were recorded.
5. The data was then refined further, by revisiting how self-determination was represented within the data. Here I asked myself different questions which helped me guide the selection of data:
 - What does self-determination look like here?
 - What are the components of self-determination?
 - Are there different ways in which it is enacted/ inhibited?
6. Analysis then moved to look at what was occurring within the talk, what rhetorical devices were being used and to what end, who was in control of the talk and how this related to the construction of self-determination. The identification of conflicting roles or values systems informed the recognition of various ideological dilemmas that were present within the talk.
7. A list of main points from the transcript for each participant pairing was then made, these were clustered into the main actions within the talk, the orientation and the position that participants took in the talk.
8. Part 2 data was looked at after steps 1-7 had taken place. Part 2 data was cross referenced with the extracts that were chosen to illustrate the main findings from the primary data source. This was done in order to pinpoint reflections which linked to the selected extracts from the primary data source.
9. Reflections from the secondary recall data were included where they were thought to add to our understanding of the initial video-recorded interaction. Recall comments were also included where the data was thought to be particularly relevant to answering the research

questions. The recall or secondary data is therefore scattered throughout the analysis and presented in boxes entitled 'facilitated reflections'.

Importantly, within the literature the term 'interpretive repertoire' is almost used interchangeably with 'discourse'. While there are similarities between the two concepts Edley (2001) notes an important distinction. The term 'discourse' is often used to describe wide ranging structures such as science or masculinity, while 'interpretive repertoires' are used by researchers who wish to highlight the importance of personal agency and refers to smaller more individual discursive constructs. Furthermore these terms are often used to signal different analytical perspectives, with a Foucauldian approach adopting the term 'discourse'. As the approach to the current analysis is guided by the principles of discursive psychology with a direct focus on self-agency, the term 'interpretive repertoire' has been chosen to refer to the discursive constructs identified within the data.

2.5.1 Researchers position

In this section I share some of my own experiences which led me to be interested in the area of self-determination. Following this I share some of the reflections that occurred in the analytical process.

It is important to reflect on my own position when conducting qualitative research (Elliott, Rennie, and Fischer, 1999). Reflections were incorporated into the process of research by keeping a reflexive log and open discussions with my research supervisors. In this log I noted any ideas about how I found the process of data collection and how these feelings might influence the results. During the analysis I also became increasingly mindful of the assumptions that I might make in interpreting the data, this too was noted in the log.

This research, as well as being an area of interest noted by the consultation group, was also informed by my own personal experiences and interests. This is of importance when thinking about my role in the analysis and interpretation of the data set. Having worked in learning disability services as both a support worker and an assistant psychologist I noticed very early on that the policies that guided and informed my practice were dominated by the ideas of choice, self-determination and autonomy. I also experienced how difficult it was to translate some of these ideals into practice.

Initially as a front-line member of staff, my efforts were focused upon interacting and building up positive relationships with people with learning disabilities in order to support them in the best way I could. Perhaps naively, I initially thought this would be quite straightforward. However, as a staff member I was faced with multiple dilemmas; at times it felt difficult to know how to support individuals who were, to some extent, dependent whilst providing them with opportunities for the promotion of their own self-determination. My experience of this dilemma was played out through my own -and colleagues'- inconsistent practice, sometimes supporting too much and offering too few opportunities for self-determination and vice versa. I often felt frustrated and in conflict as to what to do for the best. I learnt that the role of frontline staff is not straightforward. I was made aware of the relevant policies pertaining to people with learning disabilities but at the time I felt unsure about how to bring these principles alive and I found little guidance on how to do this on a practical level.

Providing the 'right' support is a complex process influenced by a multitude of factors, including, but not limited to: conflicting demands within services, our own interpersonal relationship with the service users, and indeed understanding of individual capabilities and problems in communication with the people we supported. My reflections on these experiences has led me to be interested in what new understanding might be gained by

examining the phenomena of self-determination more closely, through a focus on staff and service-user moment-to-moment interactions.

Goodley (1996) suggests that it is important to reflect on your position both when collecting data and during the analytical process. It is important to note my position as a non-disabled trainee clinical psychologist with the intention to use the data as part of my doctoral research thesis. During data collection I introduced myself as a trainee psychologist and highlighted my role as a researcher. It is likely that some participants will have understood my role as a psychologist rather than a researcher and this may have had potential influences on the data that was collected. This may have been more present for part 2 where I had a more active role as someone to help facilitate reflection.

2.5.2 Ensuring quality

The aim within this research is to produce valid conclusions, grounded within the data, whilst acknowledging that this may not be the sole way to interpret the dataset. In the following section I will first reflect on my experiences when analysing the data. The section that follows reveals my personal orientations, it is hoped that these reflections enable greater transparency for the reader to understand my position with regard to the research and the conclusions that have subsequently been drawn. I will then go on to review some of the ways- specific to discourse analysis- in which quality was checked within the current research.

There are a number of different ways in which rigour is checked to ensure that the research makes a valid and defensible contribution to the evidence base. What I present in the analysis will certainly have been influenced by my experiences and current beliefs (Elliott, Fischer and Rennie et al, 1999). During the analysis I paid attention to *why* I might be interpreting a text in a particular way. In reflecting on this I asked myself whether there might be other ways of interpreting the data. Antaki, Billig, Edwards and Potter (2003)

note that in discourse analysis it can be easy to under-analyse by identifying with a participant's view within the text and taking that persons side. During the analysis I noted when I felt I was taking sides. An example of this is when I felt that I would have done things differently or communicated differently with the person with learning disabilities. To minimise the potential of my own personal views and maintain the rigor of the analysis, it was important to re-analyse the text at these points. Furthermore I discussed these sections of the transcript with my research supervisors who conducted validation checks by offering challenges to my own interpretation of the data.

Within discourse analysis, situating the sample in context is considered particularly important (Antaki, Billig, Edwards and Potter, 2003). Sections of transcript have been provided to illustrate the analytical findings and the discursive context of each extract is highlighted, so that valid conclusions are drawn. Further to this, Potter and Wetherell (1987) note the importance of presenting the research to the reader in a coherent and understandable manner, such that the reader is aware of the ways in which the discourse is constructed, if there are parts of the data left unexplained it is less lightly to be thought of as trustworthy.

2.5.3 Transcription Conventions

Any significant embodied action was also included in the transcript.

- (.) - Indicative of a short pause
- [nods] - Information on embodied or non-linguistic action
- [???] - Section of text which was inaudible
- [italics]* - Italicised text demonstrate speech that is read by the participant
- [...] - Missing speech in order to allow transcript to read easily
- ↑ - Indicative of rising intonation in the voice

CHAPTER 3: ANALYSIS

Within this chapter, staff and service user demographics are presented. The analysis is then split into four separate case studies, with each case representing one participant pairing. A case study structure was adopted in order to capture the essence of each case and give voice to the individual.

Pen pictures of each pair are given in order to provide information about how the staff member participants were chosen and how the pair came to choose the interaction they recorded. My early impressions of these exchanges are included here in order to situate the data and give insight into the way in which decisions are made between each pair. Additionally, reflections of the verbal abilities of each service user are provided. This is included as it is likely that communicative abilities will affect the process of negotiating opportunities for self-determination.

The main findings are then structured around the dominant actions within each pair. In highlighting the actions particular functions are identified and the rhetorical devices used to achieve the action are highlighted. Furthermore, where relevant to the research question, interpretive repertoires and ideological dilemmas are explored. Examples of actions that appear across pairs were combined and presented together at the end of the chapter, in order to avoid overlap and repetition. Each example given was chosen for its representativeness of the concept it is illustrating. Equally, examples of uncommon or unusual cases are also included. In doing so the analysis is as transparent as possible and the reader gains a good sense of the interactions which occurred within each pairing.

Data from the video recall sessions are presented in separate boxes entitled 'facilitated reflections' throughout the analysis; these are linked to extracts from the original interaction. These data were included in order to extend our understanding of the initial recorded interaction. Finally the main

findings from all pairs combined are presented in a summary at the end of the chapter; these findings are linked back to the initial research aims.

3.1 Staff and Service User Demographics

The table below gives brief demographic information of the staff and service user pairings. Pseudonyms and only approximate categories of age are used to protect individual identities.

Table 2: Table depicting demographics of staff-service user pairs

	Pseudonym Service User	Age	Gender	Pseudonym Staff Member	Service User Age	Service User Gender
Pair 1	Roy	20-30	M	Simon	40-50	M
Pair 2	Martha	50-60	F	Pam	30-40	F
Pair 3	David	40-50	M	Julie	50-60	F
Pair 4	Kris	50-60	M	Jenny	30-40	F

3.2 Martha and Pam: a pen picture

Martha (SU) lives in independent supported living accommodation. She has a staff team who help her at home with routine activities.

Martha told me that she has a job as a governor for a large organisation, this is an unpaid role. Part of this role is for her to attend corporate meetings as a representative for people with learning disabilities. She told me that she takes this job very seriously and attends all the meetings and conferences that she can. Every fortnight she will receive post from the organisation which contains information for the next event or meeting that she is asked to attend. She told me that she likes attending these events as it keeps her busy and she attends in order to represent her views and the views of others with learning disabilities. Martha told me she is keen to do her job well. She is supported in doing this job by Pam (SM).

Pam (SM) has known Martha for over 6 years, she has worked with her in different capacities but at present she supports Martha with her work commitments. Pam is not a direct support worker for Martha. Pam told me that she took over the role as someone who supports Martha with her work commitments by chance and it came about in a very 'ad hoc way'. As part of supporting Martha in her role as governor, Pam attends the events and meetings with Martha. She also helps Martha attend these events. Pam meets with Martha every few weeks in order to go through Martha's work documentation. These documents are often minutes of previous meetings and agendas or reports for the upcoming meetings. They are lengthy and written in complex language. When I first saw these documents I had wondered if there was an accessible summary produced in order to facilitate the understanding of lay people and people with learning disabilities. Pam told me that part of her role is to support Martha in understanding these documents so that she might follow and contribute to the meeting. At the time, with the complexity of the documentation, I reflected that this must be a very difficult task.

Deciding what to record was done in a very opportunistic way with little discussion. Martha told me that when she saw Pam it was most often to go through paperwork and this is what they wanted to record. Although this recording is qualitatively different from the other pairs (largely because of the complexity of the content they are discussing) it was still thought to be useful as they are both engaged in a task that is focused around increasing Martha's ability to attend and contribute in her role as governor. The recording is therefore based around Pam supporting Martha with her understating of specific work documents. The video recording of Pam and Martha was 45 minutes long. During the video recording Martha is fluent, although occasionally she does pauses between words. Nevertheless in the video recording the speech between Pam and Martha is markedly unbalanced, with Pam doing the majority of the talking in the transcript.

3.2.1 Using constructions of competence and incompetence

A key feature of the talk between Martha (SU) and Pam (SM) is the idea of knowing or not knowing; this links directly to interpretive repertoires of competence and incompetence. On occasions Martha constructs herself as incompetent in order to negotiate a position that evokes support from Pam. However, what is most interesting is the way in which Pam negotiates her own position of competence and how this functions to close down opportunities for Martha to self-determine.

Pam is put in a position of competence and authority as she occupies a supportive role as a staff member, with the dual goal of helping Martha understand her work documents and helping her participate more fully at the meetings she attends. Pam is drawing on the voice of the service as she reads the complex documents that have been sent to Martha in advance of a meeting they will both attend. These documents provide a focus for Martha and Pam's interaction, which is inevitably structured by the documents content. Furthermore the document is powerful in that it dictates what is relevant for governors (Martha) to know. Pam is thus positioned as a mediator; her goal is to translate the language of the service into something more accessible for Martha.

In my reflections I noted that Pam's task here is challenging as the documents, which she is attempting to make accessible for Martha, are complex, difficult to understand, and littered with jargon and terminology. I argue here that Pam struggles to maintain a position of competence as she herself does not fully understand the content of the documents. This position of incompetence is uncomfortable for Pam whose goal is to help Martha understand the documents more fully. This makes Pam's goal difficult to achieve. Through the imbalance of knowledge, competence and status, power dynamics become evident within the interaction.

The transcripts presented below depict examples where Pam struggles to maintain her competence as a knowledgeable staff member. In these instances where Pam's competence is called into question one of two actions are performed: Pam disguises her incompetence or acknowledges it. The following extracts illustrate these actions along with the function they serve and how each impact of Martha's self-determination.

The extract below demonstrates Pam's struggle with explaining some of the documents terminology to Martha:

- 1 Pam: Um, oh, this is to do with the constitution of the council of governors. . .
2 Martha: what's constitution?
3 Pam: constitution: it's just all the rules that you've got as governors and how
4 many there should be. Every so often they need to make little changes to it
5 and Ros is saying you need to approve the – she wants you to approve the
6 changes um, that she's, she's gonna put towards you and to the council
7 governors
8 Martha: oh
9 Pam: it's just probably just a little change, yeah, and it's just that there's been a
10 new Act introduced um, and it, the Health and Social Care Act 2012. It's just
11 made a little change to, to the um, the constitution and they need to send the
12 new constitution to Monitor...

When Martha asks what the word '*constitution*' means (line 2) Pam attempts an explanation (lines 3-7). Pam's initial attempt to explain the word constitution to Martha appears to fail, indicated by Martha's minimal response in line 8. Pam then begins to divert the conversation by talking about what changes are being made to the constitution rather than offering any further explanation of what '*constitution*' means (line 9-12). In drawing on the rhetorical device of minimisation, using the word '*little*' 3 times (line 4,9 and 11) and '*just*' a total of 5 times (lines 3, 9, and 10), Pam is able to de-emphasise the importance of understanding the word and the changes that the document proposes. This casts Martha's questioning as unimportant. In doing this Pam is able to deflect attention away from her own struggle - indicated by her hesitation '*um and it,*' (line 10) and '*to, to the um*' (line 11) - to understand the information. In minimising the need to understand the information Pam holds onto her position of competence. In this way she

disguises her own incompetence which allows her to maintain control over the conversation and continue to occupy the more powerful position within the talk. Importantly, Pam ultimately decided what is and isn't important for Martha to understand. The outcome, while not intentional, is that Martha does not gain any new understanding and is left no more empowered towards being able to self-determine or contribute at the meeting.

In a later extract we see a similar exchange: Martha asks Pam a question which she again struggles to answer. However in this instance Pam acknowledges her incompetence as Martha persists in her questioning.

- 1 Martha: well, what, what this mean then? [Points to a different page]
- 2 Pam: there's lots of them
- 3 Martha: I don't know what they mean?
- 4 Pam: um,
- 5 Martha: what they supposed to mean?
- 6 Pam: do you know what, I don't know, but they've got lots of them in there. I think
- 7 it's just their current trendy way of showing things.

Martha asserts her interest in a different page of the report and is forthright in declaring her need to understand through questioning Pam. What Martha points to when she asks well, '*what, what this mean then?*' (line 1) is not visible on the video. Nevertheless, in asking the question Martha positions Pam as someone who is knowledgeable and who might be able to provide an answer. She also demonstrates her own unknowing position. In placing the connective '*then*' at the end of the sentence Martha prompts Pam to evidence her knowledge (line 1). Pam does not respond directly rather she responds as if beginning another conversation '*there's lots of them*' (line 2). This does not answer Martha's original question nor does it divert Martha from her pursuit of an answer, as Martha continues to pose the same question (line 3 and 5). Pam eventually admits that she doesn't know the answer to Martha's question and in doing so demonstrates her own powerlessness (line 6). The consequence of acknowledging her difficulties here is the notion that neither Pam nor Martha can move forward; with Pam being unable to help and

Martha being no clearer in her understanding. Both are left in helpless positions.

In order to encourage self-determination through empowerment and giving Martha an opportunity to express her voice, the wider service demonstrates its good intentions in employing Martha in the role of governor. However these extracts demonstrate the difficult position that staff are faced with when helping to translate service goals -in this case service user involvement within high level service meetings- into tangible practice. Importantly, empowerment does not end with the duties encapsulated in the role of the governor; rather it is more readily seen and negotiated within the everyday mundane interactions between people.

Facilitated Reflections

At this point in the video recall session I paused the video and asked Pam:

- 1 *Researcher:* ... I guess I'm wondering how you feel when Martha asks
- 2 You questions like this
- 3 *Pam:* um. Obviously because it's the governor's minutes, they're
- 4 quite complex so you just hope that you can kind of give
- 5 some sort of answer um, sometimes some of the questions are
- 6 easier to deal with than others. And sometimes you've just
- 7 got to hope that you can answer it!
- 8 *Researcher:* yeah I guess it might be more difficult sometimes...

Pam is clear in her reflection that the task is difficult. She indicates this by stating that the documents are 'quite complex' (line 4). In using the word 'Obviously' (line 3) Pam draws on the device of extreme case formulation (Pomerantz, 1986) which emphasises the factual nature of her account that the document is complex and by extension difficult to explain.

In a later reflection Pam again notes her difficulties in understanding the document:

- 1 *Pam:* um, I mean you can see from the video that I'm kind of skim
- 2 reading it to try and work out what's happening. And sometimes it's
- 3 quite easy for me to grasp and other times it's just . . . a bit of a
- 4 nightmare really. So you just kinda hope that you're giving the right
- 5 information

Pam's reflection highlights a wider issue here, in terms of considering the accessibility of these documents to lay people more generally. After all this is an impossible task for Pam, if the document she attempts to explain to Martha is beyond her own understanding.

3.2.2 Restricting and encouraging a voice

Within this section I argue that Pam both restricts and encourages Martha to have a voice at the conference. These two actions are tied up with an ideological dilemma that is experienced through the implementation of different, potentially conflicting agendas. As a supportive staff member, one of the agendas that operates on Pam is the need to assist Martha in contributing to the conference in an autonomous and self-determined way. A second agenda evidenced within the talk is that needing to look after or protect Martha from contributing in an embarrassing or 'wrong' way. These two agendas have the potential to conflict; it is within this conflict that the opposing actions of restricting and encouraging a voice are demonstrated.

In the first instance the action of restricting Martha's voice in the meeting is evidenced. Martha and Pam are discussing how Martha might interject within the conference at an appropriate time.

- 1 Pam: right. Well, if it's . . . if it's . . . they only take questions at certain times,
2 don't they? Or like people to . . .
3 Martha: yeah
4 Pam: to talk at certain times. So, if it's one of those times
5 Martha: yeah
6 Pam: if it's something that you know you definitely want to say, then put your
7 hand up like other people do
8 Martha: yeah
9 Pam: and then somebody'll see you and they'll bring you the microphone ...

Pam begins to explain the conference etiquette, one rule being that '*they only take questions at certain times*' (line 1) and therefore Martha needs to contribute at this time. By stating the rules, the action here is to restrict Martha to certain times where she might legitimately contribute. Pam goes on to stress the importance of contributing only at specific times (line 4). Martha is therefore only encouraged to contribute if she is certain that she knows exactly what she wants to say (line 6). In using the rhetorical device of extreme case formulation (Pomerantz, 1986) the word '*definitely*' acts to discourage Martha in her contributions if she is not confident in what she

wishes to say. Whilst the action here is potentially restrictive, it may also function to protect Martha from the embarrassment of *'getting it wrong'*. Indeed repertoires of protection are often found to impede choice within interactions between staff and people with learning disabilities (DoH, 2005). While Pam may have good intentions, in attempting to protect Martha from talking or asking questions in the wrong section of the conference, she exerts control over when Martha should and shouldn't contribute. This could act to restrict Martha's overall contribution to the conference.

The extract below follows the above extract in a linear fashion within the text. In this instance we see a protraction of the above conversation where Pam and Martha continue to negotiate how Martha might express herself at the conference.

- 1 Pam: okay. So if we make sure that your hands up or if you're not sure you check
 2 with me and then we say, yeah, it's the right time and we'll get you the
 3 microphone
 4 Martha: yeah [*nods head*]
 5 Pam: okay
 6 Martha: just in case I want to say something about say the learning disability service
 7 or what, what I enjoy about the learning disability service. And I think I am
 8 learning a lot each way . . . going to the meeting but I haven't had a lot of
 9 time to say what I want because they've gone onto something else . . .
 10 Pam: yeah
 11 Martha: . . . and it's broke me . . . thread
 12 Pam: and they move on really, really quickly don't they
 13 Martha: yeah

Pam opens with a practical solution: when Martha wants to speak at the conference they will get the microphone together. The rhetorical device of footing (Goffman, 2001) is important here as by shifting footing from *you* to *we* (line1-2) Pam is able to extend a collaborative hand to Martha. Here the responsibility is shared '*if we make sure that your hands up*' (line 1). In continuing to use the plural '*...and then we say, yeah it's the right time,*' it allows Pam to retain some influence and responsibility in determining the appropriate time for Martha to interject. Indeed she also reminds Martha to check with her if she is unsure (line 1). Pam therefore maintains a position of

control within the interaction and demonstrates her powerful position as someone who might mediate when Martha will speak at the conference. This enables Pam to protect Martha from talking at the wrong point. Pam then shifts her footing back to the singular '*we'll get you the microphone*', affirming that Martha still has responsibility and autonomy in terms of what she wants to contribute. This talk suggests that Pam will guide Martha to a point where it is appropriate to speak out but what Martha says is entirely down to her.

Martha then goes on to describe how she has not had an opportunity to contribute as the conference has '*gone on to something else*' (line 9). Pam responds to this by drawing on her own category entitlement (Sacks, 1974) and proportions blame by stating that '*they*' [the conference] move too quickly. Indeed by using the rhetorical device of category entitlement and recruiting an example of the 'powerful other' Pam is able to make a more persuasive statement which builds credibility and constructs the conference (or the service running the conference) as unaccommodating of Martha's needs.

In the following extract we see a shift in the talk; I argue here that Pam fully prioritises Martha's contribution to the conference and the repertoire of protection which has the potential to restrict Martha's contribution becomes less apparent. In the extract below the action of encouraging Martha to have a voice within the conference is evidenced.

- 1 Martha: that's what I mean. I want to make sure that I've got my point across as well
2 as everybody else's
3 Pam: yeah, that's fine
4 Martha: that's what I'm gonna do
5 Pam: ... don' worry, you can pop your hand up. And if it's in the wrong bit it's just
6 tough, isn't it?
7 Martha: yeah
8 Pam: okay

Martha initially asserts to Pam some of her anxieties about doing her job properly (line 1-2). In doing this Martha does not take a passive position but is clear about what she wants to achieve. Martha refers to her wish to get her

point across as well as '*everybody else's*' here she refers to her role as a representative for other people with learning disabilities. Her contribution is important in order to increase her own sense of agency and parity with the other governors in the room. This could evidence a desire on Martha's part to be seen as legitimate and equal. This may give some insight into her motivation and commitment to having her voice heard. Pam reassures Martha and summarises what she has to do in order to contribute to the conference (line 5-6). Unlike before, Pam does not attempt to hold on to any responsibility in helping Martha speak at the right time. In this sense the repertoire of protection is less apparent as Pam suggests it's '*just tough*' (line7) if Martha contributes at time that is deemed 'unacceptable'. With this statement Pam positions herself alongside Martha. The action here is that Martha is more fully encouraged to have a voice within the conference regardless of the conference rules, this is likely to enhance her sense of entitlement to contribute.

Through these linked extracts the actions of restricting and encouraging a voice are demonstrated. The functions of these are linked to the ideals of encouraging self-determination and protecting Martha from 'getting it wrong'. To some extent these two ideologies demonstrate some of the difficulties staff face with regards to encouraging self-determination in the face of other values. It must be acknowledged here that as the conference is in the future, we can only speculate as to whether Pam maintained her supportive position during the conference. If she did, it is likely that Martha would be empowered to contribute and could experience the outcome of her own self-determined agency.

3.3 David and Julie: a pen picture

David (SU) currently lives in residential supported living. He lives with 4 other individuals with learning disabilities. David has a regular staff team that supports him at home. He attends different day services throughout the week and he also has a work placement. David told me that he liked going out

for coffee and eating cake. He also told me that he particularly liked going to Link Club (service user club) and enjoyed going to the pub when he could.

David was very keen to participate in the study and he decided very quickly that he wanted to ask Julie (SM) at home to see if she would participate with him. At the time that David decided he wanted to participate, Julie was on holiday for a few weeks. I talked to David about the possibility of asking other staff if he wanted to do the filming straight away. David decided that he wanted to wait and ask Julie when she got back from her holiday. David speaks quite slowly and sometimes it is difficult to understand his speech. Although the majority of his speech is captured on the transcripts there are parts which were noted as 'inaudible'.

When Julie was back from holiday David gave her the information for the study and asked her if she would participate. Julie was happy to participate but told David that she would have to ask the home manager to confirm that it was ok first. In discussing what they wanted to record David first proposed that he wanted to be recorded doing his chores on his 'training day'. He told me that his chores were cleaning his room and emptying his bin. Julie reminded David that this is something that he did on his own and that the video needed to have her in it too. David then suggested recording them having a chat. Julie said she thought this would be a good idea but that maybe they could record them doing their weekly 'planning' together, so that they were chatting about something specific. David agreed that he thought this would be a good idea and told Julie that he needed to plan his Christmas present list and asked if this could also be recorded.

The video recording therefore took place at David's house. David and Julie were sitting together at the kitchen table with a pen and paper during the filming. The session consisted of Julie asking David questions about his week. My first impression of the filming was that Julie and David were doing more than just a plan for the week. They did not just talk about the activities that

David was going to do but rather went step by step through David's day giving details about what he did from when he got up in the morning to when he went back to bed on the evening. I reflected here that it felt like a discussion about the routine that David already had in place. At the end of the video David did talk about his Christmas plans, who he was buying presents for and what he was going to buy. One thing of importance was that in the initial minutes of recoding David glanced at the camera on two occasions and on one of these occasions he addressed me behind the camera. At this point I did not respond and let the interaction with Julie continue. At no other points was David focused on the camera. Julie and David's initial recording was 45 minutes long.

3.3.1 Asserting independence

Central to the talk between David and Julie is the action of 'asserting independence'. David (SU) would often construct himself as autonomous by drawing on the interpretive repertoires of independence. In the extract below David asserts his own independence. Julie has just asked David what he does on a Saturday:

- 1 David: Go to, Saturday go in town on myself
- 2 Julie: See your mates?
- 3 David: Yes
- 4 Julie: And what do you do in town?
- 5 David: Do the shopping later on. Go on bus myself.

In the first line David states that he goes by himself into town. He then restates again in line 5 that he goes on the bus himself. By repeating the word '*myself*', David emphasises that he goes independently, without support into town. He demonstrates clearly an awareness of his independence and exerts this through conversation with Julie.

In the following extract David continued to assert his independence this time, constructing himself as being responsible. David explains that he takes his mum out to the pub on a Sunday.

- 1 David: We go out together
- 2 Julie: Where do you go David?
- 3 David: Go pub in town with me mam
- 4 Julie: Do you?
- 5 David: Get drink. She's half a bitter and I pint bitter. I get it for her.
- 6 Julie: Thought you liked lager
- 7 David: No
- 8 Julie: You don't like lager anymore?
- 9 David: Not much

David positions himself as taking responsibility for getting his mum a drink exemplified by '*I get it for her*' (line 5). In this instance David also demonstrates an ability to assert himself as he disagrees with Julie's comment in line 6 and confirms that he does not like lager anymore (line 9). David demonstrates that he is self-determined through actively disagreeing and positioning himself as responsible which enables him to assert his independence more fully.

While David does assert his independence on numerous occasions throughout the interaction, importantly this is also supported by Julie. This is often evidenced in the subtle but powerful exchanges between the pair. An example of this subtle support can be seen as Julie phrases her questions in a way that reinforces David's sense of agency. For example:

- 1 Julie: Do you take your mum for a cup of tea? In town?
- 2 David: Yes

The way in which the question is phrased positions David as active and responsible for his mum. If Julie had phrased the question differently; '*does your mum take you for a cup of tea in town*', the emphasis of responsibility is changed and mum would be positioned as doing the '*taking*'. As it is, Julie reinforces David's capacity for independence by assuming that he is

responsible for the action of taking his mother for tea. This is likely to reinforce David's awareness of his own capacity for independent action and David is likely to become more self-determined as a result.

3.3.2 Confirming an existing routine

The goal of the interaction between David and Julie was to negotiate a plan for David's week. However rather than videoing a negotiation between the two of them, what occurred on video was something markedly different. Rather than developing a new plan for David's week the action that was evident within the talk was that of 'confirming an already existing routine'. Within this there was very little negotiation of a new plan for David's week. This may reflect the fixed nature of routine within residential services. Nevertheless the function of this is made clearer in the following extract, where it becomes evident that David must go through certain steps before he can attend his preferred activity of going to Link Club.

In this instance as they were discussing a routine that Julie knew very well; she ended up asking David a series of questions which she already knew the answers to. As a result Julie had preconceived ideas of what David's answers would or should be. What is most interesting is when David deviates from the response that Julie expects and how Julie positions herself in order to direct David towards the response she is looking for. In the extract presented Julie asks David a series of display questions (Stubbs, 1983) these are questions that she already knows the answer to. We might speculate that this gives David the opportunity to verbally confirm his routine, reinforcing the notion that there are things he needs to do in the house i.e. 'clear dishes way,' 'do the washing up' and 'have a shower' before he can access his favoured activity of going to Link Club. In this sense the interaction is only reinforcing and confirmatory and no new planning takes place.

1 David: When I come home?
2 Julie: Mmhhmm yeah
3 David: Go to link club on Monday
4 Julie: Yeah but before link club what do you do first?
5 David: need me tea first
6 Julie: Yeah you have your tea first don't you?
7 David: yeah
8 Julie: Have your tea. Then what do you do after tea David?
9 David: When I've finished me tea?
10 Julie: Yeah
11 David: Err watch telly a bit and
12 Julie: No you clear the dishes away don't you?
13 David: Yeah
14 Julie: In the dishwasher. And then what do you do then David?
15 David: Do the washing up
16 Julie: Yeah, washing up. And then you get, what happens then after that?
17 David: Err
18 Julie: Have you forgotten? You get in the shower ready
19 David: Go in the shower
20 Julie: (laughs). You get shower don't you and
21 David: Go in shower then we go to link club.

In line 3 David responds to Julie's initial question about what he does on a Monday evening. Julie follows his response with a further prompt towards a different answer (line 4). In promoting David towards a more specific answer, Julie demonstrates that she has a preconceived response in mind. Baring in mind that in my initially meeting with David he told me that going to Link Club is something that he enjoys. Julies prompt here functions to invite David to confirm what he does or perhaps needs to do before he can attend his preferred activity at Link Club. David responds by changing his answer suggesting that he understands his first response as being inadequate or wrong. In line 6 Julie uses a confirmatory-tag question (Antaki et al, 2002) indicated by the '*don't you?*,' this strongly encourages a confirmatory answer from David. This tag question is powerful and makes it difficult for David to change his response; it also acts to sanction his response as *correct*.

The conversation continues with Julie maintaining control over what is the *right* answer (an answer she expects) vs a wrong answer (one which she challenges). Controlling the conversation to such an extent directs David towards specific responses and as a result functions to limit his freedom of expression. The consequence of this is that after 2 indications that David's

initial responses are inadequate in line 4 and line 12, David begins to hesitate, indicated clearly in line 17. After this hesitation we see Julie demonstrate the response that she is looking for (line 18). David then dutifully repeats a derivative of Julie's words (line 19), an answer which cannot be rebuked as Julie has already given it herself. The action here is that David is encouraged to confirm an existing routine, but in doing this his self-determination and freedom to express himself in his own way becomes markedly limited. It is likely that David experiences a reduced sense of autonomy and empowerment. Notice also that what this does more generally is direct the conversation away from its original goal of planning David's week. This is replaced with a stunted commentary where David is asked to confirm his existing routine. Indeed this may function to reinforce a sense of responsibility within David, highlighting the importance of the daily living tasks that are required to be completed prior to doing something he enjoys like going to Link club.

Facilitated Reflections

When watching the video back, Julie paused it and reflected at this same point:

- 1 *Julie:* *Think when I'm asking him things he's looking at me to give him the*
2 *answers*
3 *Researcher:* *OK*
4 *Julie:* *That's what I think*
5 *Researcher:* *That's interesting so he's looking at you as if to, to get the answer from*
6 *you?*
7 *Julie:* *...I think he keeps looking at me and I and he's not answering straight*
8 *away and I'm thinking does he want me to answer for him*
9 *Researcher:* *OK*
10 *Julie:* *But obviously I didn't because I mean we were videoing*
11 *Researcher:* *OK*
12 *Julie:* *So I wanted him to say it himself*

Julie states that she wanted David to answer the questions himself (line 12); her intention here are thus in line with ideas of facilitating self-determination and autonomy. However in mentioning that her actions are different or in some way modified because she was being videoed, we might conclude that under usual circumstances Julie would step in and answer for David.

Contrary to her reflection above, later Julie notices that in the video she does give David answers. The bold text indicates the footage from the video and the italics are Julie's reflection.

- 1 *Julie:* ***Then what do you do after tea David?***
2 *David:* ***When I've finished me tea?***
3 *Julie:* ***Yeah***
4 *David:* ***Err watch telly a bit***
5 *Julie:* ***No you clear the dishes away don't you? [video paused]***
6 *Julie* *No I've give him an answer there haven't I?*
7 *Researcher:* *MMmhhmm mm*
8 *[...]*
9 *Julie:* ***Yeah, washing up. And then you get, what happens then after that?***
10 *David:* ***Err***
11 *Julie:* ***Have you forgotten? You get in the shower ready***
12 *David:* ***Go in the shower***
13 *Julie:* *Yeah (Laughs) I'm doing it again aren't I?*

Julie's reflection suggests that she hadn't intended to answer for David. We might conclude that she is somewhat critical of her own practice here. This highlights some of the difficulties in noticing the subtle exchanges that influence opportunities for self-determination. Only when Julie is given the time to watch the interaction and reflect on her own practice is she able to spot discrepancies between what she hopes to achieve and what is actually achieved. In this way video-recall has been useful in highlighting aspects of Julies own behaviour which make it difficult for David to assert himself, this could open up avenues of new thinking about how she might do it differently next time.

3.4 Roy and Simon: a pen picture

Roy (SU) currently lives with his parents; although he hopes to move out one day and live with his girlfriend to whom he is engaged. Roy attends two day services over the course of a week and has a work placement for half a morning a week where he works in a café. Roy gets to and from the day services he attends using council transport. He is supported by a number of different staff at the two services he attends.

In our meetings before filming I discussed with Roy who he felt he wanted to ask to take part in the study with him, examples of the sorts of questions I asked to facilitate this discussion can be found in section 2.4.2. Roy told me that he had spoken to his parents about the study and that he thought a key worker would be the best person to participate with. He told me that he wanted to ask a key worker as they would know him well. Roy was going to see Simon (keyworker) that afternoon and told me he would ask him then. My first impression here was that Roy was keen to get involved and wanted to get a staff member involved straight away. When I asked why he had picked Simon he told me that he was funny and described how he would joke with him a lot. My impression was that this seemed to be a good match; Roy felt comfortable enough to ask Simon to participate with him. Roy's speech was clear and well-paced, on occasions he would repeat himself but he was articulate. On the video the conversational speech between Roy and Simon was unbalanced; Simon did more talking than Roy, however it was not strikingly disproportionate and Roy was fully engaged with the task.

Simon (SM) has been Roy's key worker for 6 months, but has known Roy for over 4 years as he works in the day center which Roy attends. During the consent sessions he also told me that he knew Roy's parents quite well. Simon supports Roy for 3 days a week on a weekly basis. He supports him in attending his weekly activities which consist of playing snooker, football, going to the gym and going swimming as well as other community activities.

In discussing what might be good to record, Roy suggested that he wanted to film him and Simon playing snooker together. Simon commented that this wouldn't be in a private space though and therefore would be difficult if others were captured on film. Simon then suggested recording the session where they sat and reviewed Roy's support plan together. Roy agreed this would be good as they did this in private and no one else would be captured on film. Roy also said that he thought it would be good as it would mean he could talk about his girlfriend with Simon. It seemed a timely thing to do and it is something that Simon was doing with Roy anyway over the next few weeks.

With both Roy and Simon some of what they said was difficult to capture and where there are gaps in my understanding the words are noted on the transcript as 'inaudible'. The recording lasted approximately 50 minutes long.

3.4.1 Colluding to enable choices

The talk between Roy and Simon is complex and multifaceted; one of the predominant actions identified within the talk was colluding to enable choice. This action largely relates to Simon and the constraints that operate on him as a staff member who is trying to facilitate the enactment of Roy's choices.

The action of colluding with Roy in order to enable his choice is best demonstrated in an example where Simon has been asked by his manager to establish a 'special goal' with Roy. This is an objective set by higher management for all staff to make sure that the service users they support have a goal and achieve it. Despite the fact that the term 'special goal' invokes a child-like discourse, its aim in practice is to give service users more opportunity for choice and control in their day to day activities. In the extract below Roy has been asked by Simon what his special goal might be; the parameters of this goal are not specified. All Simon has told Roy is that it has to be '*a goal that is special*' and '*not something that is routine.*' From this Roy

identified that he would like to go see a professional rugby team train. Simon endorses this and then Roy follows with the following conversation:

- 1 Roy: Yeah, yeah. I've got another one, go [The Kitchen], see Hannah all the time
2 Simon: Well you could but that's not really big is it? That's not a big deal is it?
3 That's I think I like this other one.

In line 1 Roy demonstrates a clear choice, that he would like another one of his goals to be to see Hannah (his girlfriend) more at The Kitchen, which is where she attends her day service. This does not sit comfortably with Simon and he challenges Roy's choice by minimising and giving an evaluation of his goal '*That's not a big deal is it?*' (line 2). Simon then goes on to state his own preference in terms of which goal he feels Roy should work towards (line 3). Simon demonstrates his own power within the talk here, if this goal is not endorsed by him it is unlikely to be facilitated and therefore Roy's choice is equally unlikely to be actualised. The following extract is a continuation of the conversation above. The line numbering is indicative of this.

- 4 Simon: I mean I did actually say to Georgina, you see I'm psychic, I said to Georgina
5 I know what Roy will say, he'll say I want to see Hannah.
6 Roy: Yeah
7 Simon: And she said '*oh I hope not*'
8 Roy: (laughs)
9 Simon: Which is probably a bit naughty, I did
10 Roy: And holding hands, you see
11 Simon: I did think that that was a bit poor that she said straight away you couldn't
12 do anything with [Hannah] erm unless Hannah comes to see [name of rugby
13 club] I mean I don't know
14 Roy: Hannah?
15 Simon: Well, if she shared your love of [name of rugby club] I don't know we could
16 maybe think about that
17 Roy: Yeah holding hands
18 Simon: But anyway, the special goal is to see [name of rugby club] yeah?
19 Roy: Yeah
20 Simon: Right. Erm that's simple that we can arrange, I'm sure we can think of
21 something like that. Erm

Simon uses the rhetorical device of active voicing (Wooffitt, 1992) and highlights what Georgina (a senior colleague) thinks about Roy's second goal (line 7). Quoting Georgina directly, enables Simon to reposition himself as less responsible for limiting Roy's choice. It is senior management who are

placing restrictions on Roy's choice. The fact that Georgina and Simon had a conversation where they identified what Roy was likely to say prior to having spoken to Roy about his goals, suggests that Roy's choice to see Hannah is nothing new. It is likely that he will have expressed this choice before. By openly talking to Roy about Georgina's view (line 4-5), Simon demonstrates the pressure he experiences from senior management, this may go some way to explaining why Simon is initially reluctant to put in Roy's support plan that seeing Hannah is another one of his goals. Georgina's view- although external to this conversation- create a powerful tension that constrains the enactment of Roy's choice and Simon's ability or willingness to facilitate it.

Simon struggles with the account given by Georgina (line 11 -13) and moves to position himself alongside Roy by offering a potential compromise (line 12). In suggesting that Hannah might want to come and see the rugby club training ground too, both Roy's goals are combined and have the potential to be fulfilled. Simon's suggestion of a compromise leads him to actively collude with Roy in order to facilitate his goals without senior management having to sanction, or indeed even be aware of it. Nevertheless this collusion is left as something that they can '*maybe think about*' (line 16) and what is written in Roy's support plan is that his special goal is to see his favourite rugby club train (line 18). Only the choice that is likely to be sanctioned by senior management is written down. This extract illustrates some of the complexities and tensions involved for front-line staff when attempting to facilitate the enactment of self-determination and choice. The consequences of this for Roy are speculative but this experience may lead Roy to the understanding that it is wrong for him to want to see his girlfriend that it needs to be kept secret from senior staff or it is somehow prohibited.

3.4.2 Closing down uncomfortable conversations

The theme of Roy wanting to see Hannah (his girlfriend) more often and the constraints he experiences around this runs throughout the interaction with Simon. From the extracts already presented the view of senior management is clear and restrictions may have already been placed on this before. The following extract draws attention to the action of closing conversations prematurely. This action occurs in the context of Roy alluding to the sexual relationship that he wishes to have with Hannah. In the following extract it is Simon's own hesitations around this issue which leads to the conversation being closed down prematurely. Simon and Roy are discussing where Roy would like to live in the future, this is a topic heading included in the support plan. Simon reads from the support plan (indicated by the use of italics):

- 1 Simon: ...*living in your home so 'I live with my parents, I don't want to live anywhere*
2 *else at the moment'*
3 Roy: Nope
4 Simon: Quite happy living with your mum and dad? Erm
5 Roy: I engage
6 Simon: Oh there's that as well isn't there. '*Getting a new home,*
7 Roy: Yep
8 Simon: '*I don't want to leave home yet'*
9 Roy: No
10 Simon: So that's sort of knock that on the head. Erm I mean where would you live if
11 you did I mean one day you'll have to probably live somewhere else won't
12 you?
13 Roy: House
14 Simon: Yeah where would you aim to live one day would you..
15 Roy: Me and Hannah in a house
16 Simon: You'd like to yep. Ok that's been done hasn't it.
17 Roy: Like house together
18 Simon: Erm
19 Roy: Me and Hannah engaged
20 Simon: '*Alcohol and drugs'* wow
21 Roy: Drugs?

Roy currently lives with his parents and according to his support plan he doesn't want to leave home yet (line 1 and line 8). However when asked whether he is happy living with his mum and dad (line 4). Roy states that he is engaged (line 5). This could be read as an attempt on Roy's behalf to disagree with the statement in his support plan. Indeed, given the normative view of sexual relationships that links engagement to marriage and marriage

to living together, we might expect that Roy would want to live with his fiancé. Simon only minimally acknowledges Roy's comment and goes back to reading the support plan (line 6). The action here is that Simon closes down any opportunities to explore with Roy what it means to him to be engaged and how this might shape his future living situation. Simon only peruses this conversation in a limited way and in a manner that shuts down the option of choice. By referring to the fact that Roy one day might '*have to*' live somewhere else (line 11), he suggests that Roy's parents won't be around forever to support him and he will have no choice but to move. From this Roy takes the opportunity to state his preference for the future (line 15). In expressing the normative and conventional progression for a relationship to take, Roy's preference here stands out as his choice becomes atypical in the context of his learning disability. Simon then attempts to close this conversation by specifically referring to the fact that the topic within the support plan '*has been done*' or is ticked off as having been discussed (line 16). Roy however resists this reorientation and by stating again that he would like to live with Hannah (line 17) and that they are engaged (line 19). Simon takes greater control gives no acknowledgement of Roy's comment and moves the conversation on by reading the proceeding heading in the support plan (line 20). The action here is to close the conversation prematurely this functions to move the conversation on and this issue which is conceivably important to Roy is not talked about further.

Facilitated Reflections

At this point in the video recall session, with Roy, the tape was paused in order to explore his thoughts further.

- 1 *Researcher:* *So you were saying that you'd like to have a house with*
- 2 *Hannah?*
- 3 *Roy:* *Yeah*
- 4 *Researcher:* *OK*
- 5 *Roy:* *(laughs) a bedroom together*
- 6 *Researcher:* *Yeah and have a bedroom together?*
- 7 *Roy:* *I want, want, I won't say it*
- 8 *Researcher:* *what do you want?*
- 9 *Roy:* *Sleep together*
- 10 *Researcher:* *Ok so you'd like to sleep together*
- 11 *Roy:* *Yeah in bed together*

Here Roy is more explicit in his intentions to have a sexual relationship with Hannah. However, notice how he hesitates when talking about this, indicated in line 7 when he explains 'I won't say it.' His tentative expression here suggests that Roy may consider this topic to be 'off limits' or taboo. It may also be indicative of how Roy feels, perhaps he is embarrassed if he hasn't had much opportunity to talk about this before.

Interestingly within the talk between Simon and Roy the conversation is closed before Roy has any opportunity to explicitly talk about sex. Its absence is perhaps a reflection that it cannot or should not be an issue that is talked about (Foucault, 1990). In light of this understanding Roy's persistence to talk about his relationship with Hannah, given that others do not encourage it, demonstrates strength and an ability to autonomously express himself. These factors are likely to help Roy develop more self-determination in future.

3.5 Kris and Jenny: a pen picture

Kris (SU) lives at home with his mum, dad and brother. He attends a day service 5 days a week. He told me that he enjoyed going to his day service and that snooker was one of his favourite things to do there. He told me that he had been teaching others to play snooker. Throughout the video Kris' speech is clear but minimal. He does not offer much in the way of conversation and most often his responses to Jenny were yes or no. When he did say longer

sentences, the rhythm of his speech was uneven -he would talk slowly and then moved on to saying something very quickly. On the video that balance of talk between Kris and Jenny is uneven with Jenny talking markedly more than Kris. This is not to say that he is disengaged. Kris took a long time to think and formulate what he wanted to say and often this meant that there were long pauses in the video.

Jenny (SM) has known Kris for 2 years and has been his support worker for two months. She told me that she feels she knows him very well. Jenny is Kris' key worker at the day service in which he attends. She was keen to participate in the research.

In this instance I actually met Jenny first, Jenny told me that she was Kris' key worker and had heard about the study from another staff member. I had told her that I was there to see Kris who has expressed an interest in the study, at this time I told Jenny that it would be great if she wanted to participate but that Kris really had to decide who he wanted to participate with him. When I met Kris he told me straight away that he wanted Jenny to participate. I had wondered whether they had had conversations previously about participating together. Once this was agreed we discussed what might be useful to record. Interestingly Kris did not come up with any ideas himself; much of the conversation was led by Jenny who asked Kris questions about what he might want to record. Jenny had to work quite hard to get Kris to think of things to record. As she got little decision out of Kris she began to suggest things, one of the things she suggested was to record the session where they review Kris' support plan. Kris nodded and agreed that it would be good. He took quite a passive role in the making this decision, I wondered if Kris was quite a passive person in general as this passivity is also reflected in the video recording.

The video recording took place at the day service which Kris attends. It consisted of Kris and Jenny sitting in a private room together with Kris' file.

Jenny read out sections of the file to Kris and asked if there were any necessary changes to be made. The session covered establishing Kris' new goals for the next 6 months. It looked at what he liked and disliked and looked at how Kris spends his days. The video recording was approximately 50 minutes long.

3.5.1 Coaching

The main goal of the interaction between Kris (SU) and Jenny (SM) was to review Kris' current support needs through updating his support plan. Jenny had never done this before with Kris, what is in the plan has been written by a different staff member. In light of this it is important to keep in mind that some of the information contained within the plan may conflict with Jenny's current understanding of Kris.

The support plan itself is as a powerful discursive device between the two of them. Importantly the document itself already operates on discursive principles established by dominant voices within the institution. For example each heading in the support plan has been included based on the dominant discourses that surround people with learning disabilities and what staff need to know in order to support people well. In this sense Jenny is limited to addressing only what the support plan and the designers of the support plan consider important. She is therefore positioned as a mediator between Kris and his own support plan.

Kris was much less confident at communicating verbally than other service user participants this is evidenced within his acquiescent responses. The predominant action identified within this pair was the action of coaching. On numerous occasions Jenny works hard to encourage Kris to give his opinions on what is contained within his plan. She begins to 'coach' Kris to contribute to a conversation which ordinarily might be viewed as too complex for him to engage with.

- 1 Jenny: you've still got diabetes, but it's type2
 2 Kris: yeah
 3 Jenny: and how are you doing with that?
 4 Kris: er . . . oh . . . er, all right
 5 Jenny: you're not on medication?
 6 Kris: no
 7 Jenny: you're managing with food aren't ya?
 8 Kris: yeah

Notice that Kris' response to Jenny's initial open question about how he is doing with his diabetes is marginally positive but minimal (line 4). Jenny then uses the rhetorical device of a candidate answers (Pomerantz, 1988). In using candidate answers, Jenny offers further detail (line 5 and 7) of specific criteria which lend to the notion that Kris is indeed managing his diabetes well; the fact that he is not on medication and he's managing it with food. This creates an account that is well-thought-out and more expressive than Kris' original version that he's doing '*all right*'. It also demonstrates to Kris the sort of informative answer that Jenny feels is necessary. Jenny is coaching Kris, to elicit a fuller response and in doing so is helping him participate in the conversation more actively. The next extract is a continuation of the conversation, here the action of coaching becomes more explicit.

- 1 Jenny: so, I don't think you need people on your back – or are you still taking
 2 sweeteners? And you tell people↑?
 3 Kris: yeah
 4 Jenny: what do you tell 'em↑?
 5 Kris: I have two sweeteners in my coffee please
 6 Jenny: yeah

The purpose of the interaction is to encourage Kris to contribute and in doing begin to develop his own self-determination through the understanding that he might influence his support plan. In line 1 Jenny uses a 'display question' (Stubbs, 1983) that functions as an explicit invitation for Kris to speak. From the video recording, the word '*people*' in line 2 is said with a rising intonation as Jenny pronounces it [indicated by the upwards arrow]. The suggestion here is that Kris is expected to finish the sentence. Edwards and Mercer (1987) note, that this is a rhetorical device commonly used in teaching or when talking with children. Kris then offers a non-preferred response (Schegloff, 2007) repeating the word '*yeah*', which does not match the

response that Jenny expects (line 3). In giving minimal and non-preferred responses Kris constructs himself as a less competent communicator; the conversation is perhaps too complex for Kris to follow. Nevertheless Jenny does not give up and continues to coach Kris towards a longer response, this time more directly (line 4). The interpretive repertoire of Kris being 'childlike' is invoked here, as Jenny uses the rising intonation in her voice once more to encourage a response. Eventually Jenny succeeds in gaining a fuller response from Kris (line 5).

These two extracts demonstrate the efforts Jenny goes to in order to help Kris actively engage and initiate contributions to his plan so that he might act as a causal agent and influence his care. This is laudable given that the task is conceivably complex and difficult for Kris to fully engage with. Nevertheless though coaching, Jenny attempts to encourage the development of the 'capacity' within Kris to exercise control in conversation.

A further example of where Jenny again coaches Kris towards an expected answer is presented below where the topic of bullying is brought into focus in the talk. This is a topic heading present within Kris' support plan. Jenny begins by reading the first person narration of what is currently written down in Kris' plan (indicated here by italics).

- 1 Jenny: *'I know if I feel uncomfortable with anybody, I can speak to staff'*
- 2 Kris: yeah
- 3 Jenny: and also you know not to bully?
- 4 Kris: no
- 5 Jenny: and if you are being bullied you know to come and tell ↑
- 6 Kris: stop . . . I tell them to stop!
- 7 Jenny: you will. That's fine.

Jenny checks that Kris knows that it is wrong to bully with a non-neutral question in line 3. An expected response here might be an affirmation of 'yes,' however Kris' response here is confusing and ambiguous. To negotiate around this, Jenny goes back to her previous method of coaching (line 5). The

rising intonation within her voice (indicated by the upward arrow) suggests that she is expecting Kris to finish the sentence, with the word '*staff*'. Kris gives his own answer, which does not fit syntactically with the sentence (line 6). Within this Kris exposes himself again as a less competent communicator and his response does feel somewhat rehearsed. Nevertheless through coaching Kris towards a specific response Jenny is perhaps reassured that he has the knowledge to keep himself safe and she accepts Kris' response indicated by '*That's fine*' (line 7). In positioning Kris as someone to be coached or instructed in some way, Jenny is able to encourage some participation from him. However if Kris is to develop a real an understanding of these issues, the risks of bullying or the values that inform reasons not to bully then coaching must move beyond the practical instruction of a response. Opportunities for wider discussion are needed to allow Kris to develop his own understanding, to a point where he might be more self-determined and able to comment independently.

3.5.2 Acquiescing or agreeing

In the exchange between Kris and Jenny, the action of acquiescing or agreeing was prominent. Indeed this may have been a result of the fact that the task they chose to video was difficult for Kris to engage with. Nevertheless the support plan needed to be updated and the service suggests this is done collaboratively. In the action above Jenny would coach Kris towards developing his responses. However in other instances coaching did not take place and Kris tended to agree or acquiesce. This brings into question the collaborative spirit in which the plan was updated.

In the following extract, Jenny has made a change to Kris' support plan regarding his support needs, in this case the changes were made without consulting Kris and his agreement is sought afterwards. In not providing Kris with an opportunity to influence and develop his support plan or say what he feels his own support needs are, Jenny positions Kris as incompetent or unable. This is the exchange that follows:

1 Jenny: And I've put this by . . . what I think. So if you in any way think that I'm
2 wrong or you want it changing, any little part, you tell me. This is what
3 I've put for what support you need, right
4 Kris: yeah
5 Jenny: *'although I like to be independent, I have very poor eyesight'*
6 Kris: yeah
7 Jenny: *'and I cannot always see obstacles'*
8 Kris: no
9 Jenny: 'or people in my way'
10 Kris: no
11 Jenny: 'when I am somewhere unfamiliar or I am outside I need full staff support'
12 Kris: yeah
13 Jenny: 'to help me walk around'
14 Kris: yeah
15 Jenny: 'so I don't harm myself '
16 Kris: yeah
17 Jenny: 'or anybody else'
18 Kris: yeah. Yeah
19 Jenny: ...I don't think there's anything else you need. It's only when you're walking
20 about ...right. Are you still at *[name of]* medical centre?
21 Kris: Yeah

In the example above it is hard to believe that Kris would or could give such detail over his own support needs. Whilst Jenny makes it clear that the changes she has made can be altered if Kris wishes (line 1-2), the way in which the conversation is structured makes it difficult for Kris to disagree. As his support needs have already been written down - in order to disagree with Jenny- Kris would have to tell Jenny directly that she is wrong. Additionally, Kris may not be confident enough to challenge these statements. He may also need support both in terms of understanding them and then in formulating what he thinks his own needs are. The changes that Jenny has made may be an appropriate representation of Kris' needs, however they are not necessarily his own representation. Indeed the way in which the Jenny writes in Kris's plan using the first person is noticeably misleading. Kris has had no contribution to the statements evidenced by his acquiescent responses. The pattern of agreement within the talk builds on itself, having got the right answer once this exchange has some pace with Kris only keeping up by spotting what he should say, following the lead given to him by Jenny. In this instance the action of agreeing allows the conversation to have pace which functions to disempower Kris. This exchange comes to an end as Jenny moves to address the next heading within the support plan and begins to clarify the

address of Kris' doctors (line 20). Indeed Jenny maintains full control over this conversation and Kris occupies an extremely passive position.

Perhaps inadvertently, Jenny encourages agreement from Kris who is struggling with the challenge of the task. Indeed the rhetorical device used here is a series of pauses from Jenny and a strong lead not to contests the nature of the statements. The only learning that has taken place here is that the conversation moves on if Kris agrees, reinforcement of this action is likely to increase a sense of learned helplessness and impede the development of self-determination in the future.

Facilitated Reflections

Within her recall session Jenny paused the tape herself and reflected that she didn't have a detailed discussion with Kris about his needs:

- 1 *Jenny: I were just, I didn't have to go into detail about that but I did let him know*
- 2 *that I still know what his needs are.*

In defending her position, Jenny may have become aware, through watching the video, that she had not involved Kris in any discussion which might allow him to influence what was included in his support needs. If Kris had been supported in a discussion, it may have created an opportunity for him to experience some autonomy in influencing his support plan. In her reflection, Jenny demonstrates that she has good intentions by suggesting that her aim was to remind and reassure Kris that she was already aware of his needs.

3.6 Actions occurring across pairs

The analyses revealed a number of actions that were present across pairs, as they are common to more than one situation they are presented together. The findings are again structured in relation to the actions occurring within the talk.

3.6.1 Recruiting the parental view

In this section examples come from 2 different pairs; Kris (SU) and Jenny (SM) and Roy (SU) and Simon (SM). Recruiting the parental view was common to the aforementioned pairs, both interactions focused on reviewing support plans that had previously been updated by a different staff member. These actions were not present across the other two pairs, potential reasons for this will be addressed later.

In the talk between these two pairs I argue that both staff recruit the view of the service user's parents in order to achieve different goals. Jenny uses this action to confirm the quality of Kris' timetable and Simon uses this action in order to manage blame.

In the context of Kris and Jenny, Jenny recruits the view of Kris' parents in order to confirm the quality of Kris' timetable. Kris' own opinion is neglected and he is positioned as less important than others:

- 1 Jenny: okay. Ooh, let's have a look: I've got here that your mam and dad are
- 2 happy with your timetable
- 3 Kris: yeah

In the context of the support plan review, changes to Kris' timetable could be made if he wasn't happy with the activities he currently accessed. However Kris is never directly consulted about this, instead Jenny cites that Kris' parents are happy with his timetable. This positions Kris' parents as important and powerful people who have ultimate control over his timetable. This is reflective of something that might more often be seen within a parent-child relationship, for example if children go on a school trip they are generally asked to gain parental approval before they are allowed to go. In order to increase Kris' self-determination the expectation would be to provide opportunities so that he might express his preference and experience an outcome based on his choice. The action of recruiting the parental view, takes away any opportunity for this. Recruiting the view that his parents are

happy with his timetable also functions to add weight to the decision to keep his timetable the same. This makes it harder for Kris' to express a preference which is counter to the more dominant view of his parents. As a result Kris remains passive and silent on the issue.

Facilitated Reflections

During the video recall session Jenny paused the video at this point and reflected:

- 1 *Jenny: 'I wish I hadn't said that: that your mam . . . 'cause really it's not about mam*
- 2 *and dad, it's about Kris. So really [...] I'd said 'that your mam and dad are happy with*
- 3 *your timetable' and really it's, I shouldn't really, I shouldn't really have said that*
- 4 *because it's not their timetable. It's his timetable, whether he's happy with the*
- 5 *timetable. So I've kinda, it makes me think now I don't realise this but does that*
- 6 *make it to him like um, 'well you must keep this timetable 'cause your mam and*
- 7 *dad like this timetable.' Do you know what I mean? Where I shouldn't really*
- 8 *have brought a second person into the equation'*

Jenny regrets bringing Kris' parent's opinion into the foreground by acknowledging the potential negative consequences on Kris' self-determination (line 6). Clearly her explicit intention was not to reduce opportunities for Kris to express himself. Evidently Jenny holds values of promoting Kris' self-determination but in practice she demonstrates that these values sometimes become compromised or are difficult to hold on to given the discourse that surrounds people with learning disabilities.

A similar example occurs in the pairing of Roy and Simon. Roy protests that staff won't allow him to see his girlfriend Hannah, Simon recruits the view of Roy's mum in order to manage blame.

- 1 Simon: Well it's not that they won't allow you,
- 2 Roy: The staff won't allow me to see her.
- 3 Simon: Well they're not really equipped to get you there that's the trouble. Erm
- 4 Roy: Jessica see her boyfriend at times
- 5 Simon: Yeah but that's on an evening isn't it?
- 6 Roy: At night times
- 7 Simon: Yeah that's nothing to do with us. I mean what you need to work at
- 8 probable soon is seeing... Hannah in the evening isn't it?
- 9 [...]
- 10 Simon: I mean is your mum not keen?
- 11 Roy: My mum loves, my mum like her
- 12 Simon: Oh right
- 13 Roy: So much. I like her family too

14 Simon: You probably need to work on your mum then don't you 'cos it's, I mean we
15 don't work evenings so you need... your mum to you know work at maybe
16 getting you to see Hannah one evening a week or something
17 Roy: Yeah

Simon uses the rhetorical device of 'making evidence speak for itself' (Gilbert and Mulkey (1980) in order to argue that staff can't help Roy see his girlfriend due to having limited resources in getting Roy to the day service which Hannah attends (line 3). In doing this Simon argues not that staff '*won't allow it*' but rather that they can't do it, making his argument as a matter of fact rather than a preference. In response Roy does not feel heard, indicated by the way in which he continues to build his argument as to why he feels he should be able to see Hannah. Roy recruits the example of Jessica, another service user who sees her boyfriend. In doing so Roy normalises his wish to see Hannah, giving credence to his argument as other service users see their partners (line 4). In response Simon gives a counter argument (line 5). The use of the rhetorical device of stake management (Potter, 1997) evidenced in line 7 '*that's nothing to do with us,*' allows Simon to reject any responsibility around facilitating Jessica's relationship. Jessica sees her boyfriend on an evening, on her terms and outside working hours; this does not require the use of service resources. This functions to undermine Roy's argument further.

Simon places the responsibility of organising to see Hannah back onto Roy by using the pronoun '*you*' in line 7. This removes the blame from Simon and by extension other staff, positioning Roy as accountable for his own predicament. In order to manage blame further, Simon recruits the perspective of Roy's mum (line 10). Simon suggests the need for Roy to '*work on his mum*' (line 14) in order to enact his choice. The action of recruiting Roy's mum is powerful, she is positioned as the person who is responsible for helping facilitate his relationship with Hannah. In recruiting the parental perspective Simon repositions the blame onto other responsible adults. The

preoccupation with managing blame, in this instance, prevents Simon from identifying useful avenues to better facilitate Roy's choice.

3.6.2 Testing, doubting and checking

The action of testing, doubting and checking were used in different ways by different pairs. Within the pair of Simon and Roy, the interpretive repertoire of protection is drawn upon as Simon tests and checks out Roy's knowledge of the fire procedure at the day centre he attends. Simon orientates to this topic as part of their support plan review. In testing Roy's understanding of a fire drill Simon, gains reassurance that Roy does know what to do if the fire alarm went off. Initially Simon reads a statement from Roy's plan in the first person (indicated by the use of italic); it suggests that Roy does know what to do if the alarm goes off (line 1).

- 1 Simon: Yep good '*I know what to do if the fire alarm goes off during my daytime*
2 *activities*'
3 Roy: Go outside
4 Simon: Right. How do we get out then?
5 Roy: Upstairs
6 Simon: Which door do we go through?
7 Roy: Upstairs
8 Simon: What from here? Oh yeah good, good
9 Roy: Go that down one, go outside the car park
10 Simon: Yeah in the car park good, good, good.

Given that Simon did not initially write Roy's plan with him, he test out the validity of this statement by asking Roy a series of questions. Initially Roy only validates this statement minimally (line 3). Simon demonstrates a level of doubt by seeking further clarity from Roy in order to ensure that he has the knowledge he requires to get out of the building. Simon's questioning here may also relate to a service requirement, that where possible, service users should have an awareness of any fire procedures. Simon aligns himself as someone who is responsible but also supportive of Roy by asking display questions (Stubbs, 1983) which scaffold Roy's answers (line 4 and 6). Finally Simon offers an evaluation of Roy's responses by giving his approval of what Roy is saying with an affirmative '*good*'. In this exchange Simon has used the word '*good*' 5 times. The positive assessment of Roy's answers has an

educational overtone. As Simon orientates to the position of a supportive staff member, Roy is free to describe in his own words, where he would go if there was a fire (line 9). This achieves two goals, firstly it reassures Simon of Roy's competence, secondly Simon provides just enough support to help Roy come to his own conclusion leading to the development of Roy's self-esteem and self-agency.

In a different example Simon doubts Roy's statement that he is no longer using computers at the day service he attends. The action of checking is also evident here as Simon checks whether this statement is true. Interestingly this is not done in a neutral way and the interaction can be viewed as potentially detrimental to the enactment of self-determination. The action of checking and doubting is evidenced as Simon repeatedly questions Roy.

- 1 Simon: ... 'I mean do you find going to [name of service] improving your computer
2 skills?
3 Roy: Computer, staff aren't using it
4 Simon: But do you do it a bit? You must use a bit as well do you?
5 Roy: Cooking forms
6 Simon: Yeah but do you do a bit? Do you use computers there at all then or not
7 when you go to [name of organisation]?
8 Roy: Typing
9 Simon: Right so you do use the computer?
10 Roy: yeah
11 Simon; Oh right
12 Roy: Little bit typing
13 Simon: Right, 'cos that's one of the reasons that you went isn't it really
14 Roy: Yeah

Simon opens this exchange with a non-neutral or leading question (line 1). Leading questions are difficult to contest and often designed to elicit agreement (Antaki, Young, Finlay, 2002). Simon repeats a variant of his initial persuasive question a further four times (line 4, 6 and 9). In response to this, Roy displays a confused series of replies as he changes his answer three times (line 3, 5 and 8). Notice how Roy is more tentative in his responses, indicated as the length of his reply become shorter at each change. Changing his answer also suggests that Roy understood the follow up questions, as meaning that his original answer was incorrect or unsatisfactory. The

exchange draws to an end as Simon repeats his question again ‘*right so do you use a computer?*’ (line 9). There is a level of persuasive force within this last question, enacted by the placing the word ‘*right*’ at the beginning of the turn. Roy finally responds in agreement conceding that he does a small amount of typing (line 12). Simon clearly doubted Roy’s initial account and continued to check this out with him. However in asking non-neutral or leading questions Simon maintained control over the conversation and shepherd Roy into an account which Simon endorsed. The motivation behind checking out whether Roy did use computers is alluded to by Simon in line 13; this is something which is made clearer in the recall session with Simon.

Facilitated Reflections

In the video recall session with Simon, he stopped the video and reflected at this point.

- 1 *Simon:* *That was a difficult bit ‘cos I mean I know he, one of*
- 2 *the reasons we suggested he went to [name of day*
- 3 *service] ‘cos we thought*
- 4 *they’d use computers and he seemed to be saying then*
- 5 *that they*
- 6 *don’t and then ...*
- 7 *Researcher:* *Ok*
- 8 *Simon:* *Because then he said oh I do typing and so I suppose*
- 9 *it’s erm it’s,*
- 10 *it was a relief to get a yes out of him really*

Simon describes feeling relieved. This relief is linked to a sense of responsibility he feels having recommended that Roy go to the day service initially because they use computers (line 1). If they did not use computers Simon may have felt responsible for giving Roy a bad advice. Simon clearly has good intentions; however he does not reflect or acknowledge the influence of his actions within the talk. Simon is not aware of the position of power that he occupies within the discourse. Indeed this example lends itself to the notion that disempowerment often occurs in the everyday subtle interactions between staff and service users. I would argue that increasing staff awareness of this is one way in which to begin to break down these practices.

The action of doubting and checking were also both present in exchanges between David and Julie. The clearest example of this was when David told Julie that he wanted to change his routine.

- 1 David: I'm not going tomorrow. Going to see me mam tomorrow
2 Julie: Did you arrange to meet your mum tomorrow?
3 David: I told her that I'm meeting down bus station tomorrow
4 Julie: On Wednesday?
5 David: Yes. Meeting her, I told her she, I'll meet you down the bus station and I
6 see her tomorrow
7 Julie: You don't, you don't usually meet your mum on a Wednesday do you?
8 David: No I go, go myself
9 Julie: Is [name of day service] closed tomorrow?
10 David: I'm not going, will you tell Sue I'm not going
11 Julie: What do you do at [name of day service]?

David tells Julie that he is going to see his mum (line 1). Julie then checks whether David has made plans to do this (line 2). David evidences his plans, however Julie's doubts around these new plans is evidenced in her asking the question again (line 4 and 7). In line 7 by placing the words '*do you*' at the end of the turn, Julie uses a confirmatory-expecting tag question (Antaki et al., 2002) and attempts to recruit David towards her view that what he proposes is unusual. David resists Julie's view and is persistent in wanting to do something different, emphasised by suggesting that he does not need support to change his routine (line 8). Here David emphasises his ability to be self-determined and positions himself as assertive and independent.

The action of doubting here could be motivated by concern for David. Julie looks for a rational as to why David wishes to change his routine, she does this by checking with David if his day service is closed (line 9). In doubting David throughout this interaction he becomes frustrated this is indicated in his repetition of '*I'm not going*' (line 10). In this instance Julie then change the subject, perhaps to avoid further aggravating David. This functions to divert the conversation and placate David. It is unclear if David managed to actualise his choice in changing his plans, however David demonstrate his own self-determination in challenging Julie as she continued to doubt him.

3.7 Summary of main findings

The analysis revealed a number of ways in which staff and service users drew on and used discourse in interactions concerning self-determination. In most instances staff maintained a powerful position of control over the interaction which served to both encourage and limit opportunities for self-determination. Rarely did a service user participant introduce a topic to be talked about and the conversation was almost always lead by the staff member. In some instances however service users were seen to assert themselves so that their concerns were heard and their needs might be met. Interestingly opportunities for self-determination were not only influenced through the actions of staff and service users, different service aims were found also to be a powerful influence on the construction and enactment of self-determination. Furthermore, outside perspectives brought in through the staff members talk were powerful in terms of disempowering people with learning disabilities.

Throughout the analysis a number of interpretive repertoires were identified and implicated in the negotiation of self-determination. Repertoires of incompetence placed Martha (SU) in a powerless position, reliant on Pam (SM) to help her achieve her goal of understanding complex documentation relating to her role as governor. Indeed a repertoire of protection was also present within the interaction between Martha and Pam. At the same time this repertoire was often noted as driving the action of 'testing and doubting' service user's knowledge and competence which occurred across pairs. Furthermore Jenny (SM) drew on the interpretive repertoire that people with learning disabilities are childlike, this functioned to help her more effectively coach Kris (SU) towards being able to contribute in some way to updating his support plan. Finally David (SU) asserted his own autonomy though drawing on the repertoire of independence.

Within the analysis a number of ideological dilemmas were identified. These dilemmas served to highlight some of the complexities faced by front-line staff. Staff are positioned as mediators between multiple and often competing service objectives. In particular Simon (SM) was faced with the dilemma of facilitating the enactment of Roy's (SU) choice to see his girlfriend vs prioritising the views of senior management which would in real terms inhibit the actualisation of Roy's choice.

Finally staff and service user participants drew on and used discourse in different ways when reflecting on the video. In some instances staff members were noted as defending or giving reasons for their practice. In most cases staff were seen to be acting with good intentions even when they noted their practice could be different. Reflections from service user participants were less tangible in nature and as a result only reflections from Roy were included.

These facilitated reflections revealed that often when staff took time to watch their own practice they commented upon the subtle ways in which their interaction limited self-determination leading to disempowerment. These results will be discussed in more detail and in relation to a wider evidence base within the discussion chapter.

CHAPTER 4: DISCUSSION

This chapter is structured around the initial research question and aims. It provides an overview of the current research findings, placing them within the context of the wider literature. Following this the strengths and limitations of the current study are addressed and the clinical implications explored. Avenues for future research are then discussed.

4.1 Current research findings in relation to wider literature

The research question in the current study was 'How is self-determination negotiated in everyday interactions between staff and service users? In order to demonstrate how the analysis answered this research question the research aims will be addressed. Within this section I intend to discuss the main features of the findings in relation to the research aims while at the same time linking them to the wider existing literature.

The aims of the current study were as follows:

- To examine how opportunities for self-determination are facilitated or closed down in interactions between staff and service users with learning disabilities
- To examine self-determination in relation to the position each participant occupies within the discourse.
- To examine how participants reflect on the recorded interaction and how these reflections relate to the primary analysis.

4.1.1 Positioning and power in relation to opportunities for self-determination

The analysis revealed a number of ways in which participants positioned themselves in order to exert influence over the talk. In most instances, staff occupied a position of power and therefore influenced the available opportunities for self-determination. For example, throughout all of the interactions, staff participants lead the discussion, chose what questions were appropriate or not appropriate to ask, and also influenced the flow of the discussion, swiftly moving away from certain topics and moving the conversation on where it felt appropriate. On occasions, service user participants did exert control within the talk, demonstrating how they would take up opportunities for self-determination when given the chance.

However staff generally had more influence over the interaction and therefore demonstrated considerable control over the available opportunities for self-determination.

Staff would often ask questions to service user participants, to open up conversation, positioning themselves as facilitating empowerment. However, the way in which these questions were asked often served to guide service users into particular ways of answering. For example, when David (SU) is asked by Julie (SM) about his general routine, rather than asking open and neutral questions, Julie uses display and confirmatory-tag questions which function to shepherd David into giving specific responses. In posing questions that invoke agreement, Julie maintained considerable control over the talk, which served to limit opportunities for David to express himself more freely. Furthermore in an example between Simon (SM) and Roy (SU), Simon uses repeated questioning which leads Roy to modify his initial answer. Indeed Antaki et al. (2002) demonstrated how staff depart from neutrality when interviewing service users which influenced and shaped their answers. They describe how staff 'helpfully' adapted questions, in an audit around participant's views of a service, in order to make the questions more accessible to people with learning disabilities (LD). However these adaptations served to construct answers which service users did not originally give. In a further study, Finlay and Antaki (2012) identified a number of ways in which staff modified questions when working with people with LD. The current research expands on this, demonstrating how opportunities for self-determination become more limited through the way in which questions are asked or phrased. Other rhetorical devices like minimisation or offering evaluation of participant responses were also found to influence the subsequent response of service users. Importantly, this demonstrates the need to attend to the subtle nuances in the talk between staff and service user participants. It also demonstrates that the language used in interactions is powerful in shaping the talk and the level of control that each individual has within the interaction.

The findings highlight that service users did not always occupy a position of passivity. In the cases of Roy and David, both demonstrated an ability to make choices and in doing so positioned themselves as in control. What is most interesting is when choices were made, service users employed rhetorical devices of persistence, protest, repetition and appeals, demonstrating that they had to work quite hard in order to be heard. In an exchange between Simon (SM) and Roy (SU), Roy was seen to justify his choice to see his girlfriend more. An illustration of this is noted when Roy recruits an example of another service user, who sees her partner regularly, in order to legitimise his own choice. This also highlights the unfairness of the inconsistency of practice. Here Roy positions himself as autonomous and displays a level of self-determination though challenging potential restrictions. Similarly, David (SU) often constructed himself as both autonomous and responsible. It could be argued that in doing this he distanced himself from constructions of deficit and need. In this way he was able to exert control over the conversation with Julie (SM) and maintained a level of influence. Research by Rapley (2004) suggests that the construction of people with LD as incompetent serves only to reinforce difference and deficit. He describes how this can become a 'toxic identity'. Therefore it is understandable that service users wish to assert alternative more positive constructions of themselves.

While I have described findings where service users were more persuasive and assertive with the discourse, most often they were positioned as less able, less competent and less responsible than staff member participants. These less powerful positions influence the level of autonomy afforded to them. Interestingly it is important to understand is that the findings also demonstrate that these positions were adopted or invoked by the service user themselves. In the example of Martha (SU) and Pam (SM), in order to invoke support from Pam, Martha positions herself as in need of support and draws on constructions of incompetence. Jingree and Finlay (2011) also

found that service users would position themselves as in need of support and would draw on repertoires of incompetence in order to express their needs. The findings also reveal that staff are sometimes uncomfortable with the position of competence they find themselves occupying. For example, Pam (SM) struggled to understand Martha's (SU) work documents and therefore found it difficult to help Martha gain an understanding of the material. In this instance both were placed in a position of helplessness and both may need support in order to move forward. This is particularly interesting in the context of services and highlights the need for greater staff support and guidance in terms of helping service users develop their autonomy in day to day situations.

Interpretive repertoires of competence and incompetence were present within each pair. Whilst the analysis demonstrated how service users might invoke these constructions, more often service users were positioned by others as lacking competence. This is evidenced in the way staff members would test and check out service users claims and knowledge or doubt their ability. The discourse revealed how constructions of competence led service users to be denied opportunities which may promote self-determination. For example within the talk between Kris (SU) and Jenny (SM), Jenny has already updated the section of Kris' support plan that describes his support needs. By not involving Kris in a discussion about how he saw his own needs, Jenny constructs Kris as lacking competence to engage with this activity. The way in which Kris gives acquiescent responses as Jenny lists what she thinks his support needs are adds to the construction of lacking competence. Within the wider literature, acquiescent responses are most likely to occur due to misunderstandings arising from the difference between the linguistic and interactional competence of service users and staff (Rapley and Antaki, 1996). Kris was less confident in communicating verbally than other participants in the study. Consequently this may have added to the complexity around increasing opportunities for self-determination. Nevertheless, if opportunities for self-determination - where Kris might

actively make choices and experience successful outcomes - are taken away, it is likely that learned helplessness will develop resulting in increased passivity (Wehmeyer and Bolding, 2001). Understanding these issues is highly relevant to services that support people with LD. The current research highlights that there are many opportunities in everyday interactions, where service users might exert themselves and experience control in their lives. Therefore, the role of staff arguably becomes more important both in terms of encouraging self-determination but also identifying opportunities for its enactment.

Finally, the analysis demonstrated how, in situations where staff felt uncomfortable with the topic of conversation, they would exert more control over the interaction in order to move the conversation on. This is particularly evident in an exchange about where Roy (SU) might live in the future. Roy is clear that he would like to live with his girlfriend Hannah and alludes to a potentially more physical relationship with her. The rhetorical device of non-uptake through giving a minimal response is demonstrated by Simon. Non-uptake of requests is a powerful device allowing staff to attend to certain voices and ignore others (Jingree et al., 2006).

The conversation around how Roy might move towards developing a more physical relationship with Hannah is closed down. This is only revisited in the recall session where Roy is able to be more explicit about wanting to sleep with Hannah. In closing the conversation down, Simon deprives Roy of the opportunity to discuss his relationship. Within the wider literature relating to sex and the sexuality of people with LD it is noted that people with LD were stopped or actively discouraged from having sex or even knowing about sex (Richards, Miodrag, and Watson, 2006). Indeed shutting down opportunities to learn about and talk about sex is likely to lead service users to the understanding that it is somehow wrong or taboo. A more recent study looking at the views that women with LD have about sex reveals that many of them thought that sex is 'bad' and they should not do it (Fitzgerald and

Withers, 2011). In order to help people with LD to feel confident in making informed choices about sex, opportunities to discuss and learn about sex need to be made available. This is a complex issue, made more difficult by the fact that service users with LD are often vulnerable to abuse or sexual exploitation (McCarthy and Thompson, 1997). Within this, repertoires of protection are invoked which often further limit the opportunities for people with LD to experience a positive sexual relationship. The current research highlights the power that staff have in terms of facilitating these opportunities, where sex and relationships might be more openly discussed.

4.1.2 Managing roles and conflicting values

Since the publication of Valuing People some thirteen years ago now, services for people with LD have been shaped by its key principles: the right for people with LD to have more choice and control in their own lives. This National service framework has been enforced in law by the introduction of the Mental Capacity Act (2005). Indeed Valuing People Now (2009) continues to reinforce the discourses of increasing autonomy, independence and empowerment. The current study demonstrates that while these values are important, staff's practice is also informed by other values and concerns, some of which maybe prioritised over values of encouraging self-determination.

The current study demonstrates how staff face multiple and often conflicting goals; these manifest as ideological dilemmas within the discourse. For example, Pam (SM) faced a conflict in relation to values of protection - protecting Martha from saying the wrong thing or talking at a wrong point in the conference she was due to attend- vs. facilitating her self-determination and encouraging contribution. The tension created here is evidenced in the opposing actions present within the discourse, when protection was prioritised opportunities for self-determination became more restricted and vice versa. Within the talk Pam struggles to negotiate and manage this

conflict. This is also noted within the wider literature where choice and self-determination are invariably surrendered as issues of protecting vulnerable adults from risk are prioritised (Antaki et al., 2009). A recent study by Hawkins, Redley and Holland (2011) demonstrated the tension that staff feel between protecting service users with Prader–Willi syndrome and promoting their independence and autonomy. Hawkins et al. (2011) found that this is an issue that is not resolved at the level of the organisation and therefore has to be managed by front-line staff. Indeed Antaki et al., (2009) also report stark differences between a literal understanding of policy recommendations at an organisational level and the lived reality of staff who find themselves in a position where they need to manage or juggle often opposing goals.

Within the current research the institutional context of the interactions is important to consider as this influenced the possibilities for the enactment of self-determination. Service user participants were encouraged to act in a self-determined way in instances which fitted with service objectives. In an example from Roy (SU) and Simon (SM), Simon is seen to test Roy's knowledge in relation to the fire drill. In the analysis, repertoires of protection were invoked in that Simon was checking Roy's knowledge and ability to talk through what he might do in the event of a fire. However, importantly, this is brought up as a topic for discussion by Simon and its direct relevance to Roy is not apparent (unless the institutional context is considered). It is a heading incorporated within Roy's support plan which has been designed by the service. In addressing this, Simon is responding to the voice of the service and the values promoted through institutional risk protocols. The task of updating a support plan was therefore used to promote institutional objectives. In accordance with the principles of discursive psychology the context in which discourse is situated is important (Potter and Edwards, 2001) the institutional setting has a fundamental influence on the talk. This research demonstrates that while services are important in the lives of people with learning disabilities the way in which they are structured

has a powerful influence on the available discourses and therefore on their lives.

In another example, the institutional context influences the talk between Jenny (SM) and Kris (SU). The analysis reveals that Jenny draws on different devices- for example asking questions in which she already knows the answers or giving candidate answers for Kris to reiterate- in order to encourage Kris to contribute to his support plan. In doing this the action of coaching is evidenced. Whilst this may help develop Kris' 'capacity' to exercise self-determination, the interaction is instructional as Kris is led by a series of purposeful pauses and changes in voice intonation towards specific responses. The instructional nature of these exchanges could be at the expense of Kris' own initiated behaviours. Within the wider literature Wehmeyer and Schwartz (1997) suggest that in order to encourage self-determination activities that match or '*optimally challenge*' the individual should be offered. In this case the challenge is somewhat miss-matched and another activity may have been more suited in facilitating the development of Kris' self-determination. Nevertheless, the power of the institutional objective- that a support plan should be updated 'collaboratively' with the service user- prevails. In this context Jenny is positioned as mediator between actualising two service goals; the first to encourage Kris to 'collaboratively' update his support plan and the second to increase Kris' own capacity to influence and self-determine. In positioning Kris as someone to be instructed Jenny exerts control over the interaction which may limit Kris' in initiating his own and giving his responses.

Managing institutional objectives are not the only ideological dilemma that may conflict or constrain the enactment of self-determination and choice. The analysis revealed that Simon was under pressure to conform to the values held by another more senior staff member (Georgina) who was less considerate of Roy's choices. The pressure to be seen to endorse the view of senior management is clear as Simon resorts to colluding with Roy in order

to facilitate his choice to see his girlfriend. Simon reports, within Roy's support plan, only the choice that fits with Georgina's view and the institutional understanding of 'special goal'. Indeed the notion of supporting service users to identify a special goal is set up as an activity which provides individuals with an opportunity for choice. However, in the example from Simon and Roy, if staff are not in agreement of the choices made by service users they are unlikely to be endorsed much less facilitated. This practice is not only disempowering, but it also conflicts with the overall purpose of the initiative: helping service users have more control and choice in being able to identify their own goals for the future. Acknowledging the influence that staffs individual and personal values can have on the enactment of self-determination is important. The current research extends our understanding of the disempowerment manifested in practices which, on paper, are seen to be providing avenues of choice and control for individuals with LD.

4.1.3 Reflection on video recorded interactions

In this section staff and service user reflections from the video recall data are discussed in relation to the primary analysis. In order to illustrate the findings in detail further reflections are given where appropriate. These are integrated into the discussion in order to contextualise and provide further evidence for the current findings.

The video recall sessions encouraged participants to look back at the interaction and think about it in more detail. This offered a space to think differently about what was described. Importantly, the secondary analysis does not attempt to confirm or disconfirm the primary findings rather it is there to be supplementary. The secondary data was useful in that it did help highlight where opportunities for self-determination were evidenced. It also demonstrates that staff participants have capacity to engage in discussion about their practice.

Within the reflections from staff it was interesting to find that on occasions some staff were quite surprised by what they noticed. For example Julie (SM) demonstrates her surprise when she recognised that she was stepping in and giving David answers rather than allowing him time to answer for himself. In a further example where Jenny (SM) has just stated to Kris (SU) that his parents were happy with his timetable she comments '*I wish I hadn't said that*'. In this instance the space provided for video recall gave Jenny an opportunity to think and evaluate her own practice. Having the opportunity to reflect on these moment to moment interactions may help staff develop more of an awareness of the ways in which certain ways of talking can be disempowering. Indeed Finlay, Antaki and Walton (2008) argue that staff need to be given the opportunity to watch their own practice '*from a distance but in detail*' in order to be able to identify exactly what they do when they interact with service users with LD. It is acknowledged that the recall session within the current study was not designed as an intervention to change practice. Nevertheless the findings reveal that the practical application of video recall may be useful for developing practice within a clinical setting.

Indeed the findings also depict instances where staff did not recognise the disempowering actions that took place and how they may have contributed to these through the discourse. In these instances staff orientated towards giving reasons as to why they did what they did, thereby attempting to defend their own practice. It is interesting to think about why they may have felt it was necessary to do this. The fact that on occasions staff did not reflect on their own influence here does not make the findings any more or less valid. It does however tell us that they are noticing something that was important enough to provide comment on. One thing that was missing from the recall data was any comments about positive practice. For example, no participants spontaneously reflected on things went well or what they were pleased with. This could reflect a tendency within staff to orientate to being self-critical. If video recall is to be used as an intervention in practice it would

be important to think about the strengths of an interaction so that opportunities to build on these might be found.

Importantly, when service users had the opportunity to reflect on the video, their reflections were qualitatively different to staff members. In all cases individuals with learning disabilities commented on what they liked about staff members and the practicalities of what they were doing. Service users did struggle to fully understand the process. They found it difficult to reflect on how they felt or what they thought at the time. This could be linked to the idea that recall was a new experience for all of them; indeed just watching themselves on video was a new experience for one participant in particular. In considering their limited experience with this process it may have been useful to give service users more time to get used to the recall experience. It is likely that in order for this to happen they would have to have the opportunity to be exposed to this process over a period of time. This may be something to consider in future research.

Interestingly, only one service user on one occasion made an attempt to disagree with what was said on the talk in the video. There could be a number of reasons why service users did not challenge or state what they didn't like about the interaction. This links back to ideas of control and self-determination. Service users may have limited experience challenging or contradicting staff. It may also relate to the nature of the relationship they have with support staff, complaining could create worries about damaging a relationship close to them. When taking into consideration the wider marginalisation and disempowerment that this group experiences, participants themselves may have internalised the 'normality' of disempowerment. This may lead people with LD to expect to be treated in a disempowering way.

Perhaps what was most salient for service user participants was the actual process of watching themselves on video. I wanted participation to be a

positive experience for service users. In the comments collected from the recall session all service users described having liked or enjoyed watching themselves back on video. Kris was particularly enthusiastic about watching himself on video, to my surprise this was a novel experience for him. Kris describes what he thought about watching himself on video:

Kris: 'it, it, it, it's wonderful! [claps hands excitedly] it's wonderful! [claps hands again]...[sighs noisily] I'm enjoying it so . . .I enjoying it watching myself like that.'

Given that Kris –from the service user participants- was the least confident in communicating, his expression of enjoyment here felt poignant. It is important to consider how service users find the process of participating; if it has been a good experience it may encourage them consider further avenues to participate in research. Furthermore, given that people with LD experience such disadvantage it was important, within the current study, that the process was respectful and positive.

4.2 Strengths and Limitations

Within this section both the strengths and the limitations of the current study are discussed. Methodological considerations are presented first followed by analytical considerations.

4.2.1 Methodological issues

Within this section I will address the following methodological issues: participant selection, challenges associated with naturally occurring data and video data and issues around involving people with LD within the research process.

4.2.1.1 Participant selection

This research utilised a qualitative method which used a small sample size, with this in mind the aim of the research was not necessarily to include a representative sample nor to make the results broadly more generalisable. Nevertheless there are a few important points to consider regarding participant selection. Participants were first identified by a lead person within the local Service User Involvement Team; this person was asked to think about who might be suitable for this research. In the decision around suitability, a judgement on whether potential participants would be able to give informed consent -and whether they would be likely to be interested in participating -was made. As a result those individuals who were thought to be unable to participate were not offered the opportunity. The sample was therefore limited to those individuals who might be described as having moderate LD. Within the literature, it is noted that, often due to ethical challenges people with more severe and profound LD are more easily excluded from research (Cameron and Murphy, 2007). With this in mind, future research could focus on how best to facilitate opportunities for participation for those who have more severe and profound disabilities.

A strength of this study is the way in which the sample of participants was situated in context; this was done through the inclusion of extended pen pictures in the analysis chapter. Indeed Elliot et al. (1999) suggested that situation the data is an important part of any qualitative research. While the sample did seem to encompass service users with varied language abilities (some more confident than others) it is impossible to comment with any certainty on the level or nature of their learning disability. Importantly, only one male staff member took part in the research and 3 female staff (3:1 ratio of female to male staff). This may be a result of the fact that women tend to be drawn more to work within the caring professions and therefore there are more women within these roles. While the diversity of the sample is not necessary for research of this design, it is helpful to have a sample that

represents a range of different characteristics within individuals, in order to make the research more relevant to services offering similar provision. However, the ratio within this study is likely to be close to what is found within some residential care settings.

A further strength of this study is that service user participants chose the staff member participants. The data generated from each pair provided interesting material that answered the research questions in terms of evidencing patterns within the talk that have relevance to the lives of people with LD. It is possible that as participants chose the staff member participants their relationship is likely to have positive characteristics, this may have influenced how they interacted, perhaps demonstrating more positive exchanges that go on within services. The researcher had little control over participant pairings as it was left up to the choice of each service user participant to choose their paired staff member. Each pair that participated knew each other in different circumstances. For example, Pam supported Martha in her work related commitments and only provided support to her on this basis. Julie is David's keyworker from home and therefore knows him only in his home environment. It is likely that each pair had a qualitatively different relationship given they originate from different beginnings and in different environments, this may have implications for the research and go some way to explain reasons why actions and discursive practices evidenced were not found in every case.

4.2.1.2 Naturally occurring and interview data

There are advantages of using both naturally occurring and interview data as noted in the method chapter (Potter and Hepburn, 2005) and the choice to use both in the current study is a strength.

Using naturally occurring data is likely to have improved the ecological validity of the findings (Potter and Hepburn, 2005). On the other hand the

use of interview data in order to supplement the main findings gave control back to participants and allowed the exploration of their views that would be impossible to capture in a naturally occurring situation. The secondary data is therefore more focused; however, the influence of the researcher is more difficult to negate here and is likely to affect the conclusions drawn (Hammersley, 2003). To balance this, I have tried to be as transparent as possible, in terms of illustrating the steps I went through to get to the final conclusions.

One of the potential difficulties associated with the use of naturalistic data is that it was not possible to control the focus of the interaction between staff member and service user. This meant that the researcher was unsure about how much of the data would focus on issues of self-determination. In this sense the data that were acquired was wide ranging, making the analytical process arduous in terms of refining the data in order to bring clarity to the overall conclusions.

4.2.1.3 Challenges and benefits associated with video recording

Due to ethical considerations participants needed to give their written consent; therefore, participants had to have an awareness that they were being video recorded. Efforts were made to minimise the effects of being on camera, by using a less obstructive participant perspective approach to filming (Ratcliff, 2003). While all participants were made aware of the camera only one participant acknowledged its presence by directly addressing me during the recorded interaction. It is also possible that the presence of the researcher and the filming will have had some effect on the naturalistic data that were collected.

Participants could also have been conscious of how they would be perceived on film and therefore act differently to how they may normally act. Furthermore some staff may have felt a level of anxiety about being recorded

particularly in light of the recent use of covert camera work within the serious case report of Winterbourne View (DoH, 2012a, 2013). It was essential therefore that participants were aware of the recording in order to put them at ease. Reflections from staff members reveal that some initial anxiety was present prior to filming but this diminished after the experience of being videoed.

Pam: 'I had some anxiety about being videoed. But, yeah, looking at it it's not as bad... and it probably makes me less bothered about doing it again'

Anxiety about being video recorded could affect how staff and service users drew on and used discourse in interactions around self-determination and could therefore affect the overall conclusions that were drawn. Nevertheless, the benefit of using video recording is clear, it gave considerable context to the interactions that would not have been captured using only audio equipment. Here I refer to the embodied action or non-verbal communication which, when integrated into the analysis, allowed new or different meanings to be understood within the interactions.

4.2.1.4 Involving people with learning disabilities in the research process

As discussed within the introductory chapter, there is a growing body of research which emphasises the importance of doing research *with* rather than *on* people with LD (Nind, and Vinha, 2013) Others have emphasised the value of including people with LD in the entire research process (Oliver, 1992). In line with inclusive research, the current study did make efforts to engage people with LD within the research process. This was achieved in a number of ways; firstly, through thinking of ways in which participants could be more actively involved in the process, and secondly with the use of a consultation group.

Service user participants in this study were involved in the research process in a number of ways. For example, they had control over which staff member they wanted to participate in the research with, they also had choice over what interaction was filmed and where they wanted the filming to take place. The researcher was careful to consider how participants might gain experience of being more involved in the research process.

Further to this, the current study employed the use of a consultation group. More details relating to this group can be found in section 2.1.6. Whilst this group had some involvement in the research process, they had little involvement in conducting, designing or analysing the data. In this respect, this research did not meet criteria for emancipatory or participatory research. Importantly this research was done as part of a doctoral qualification; consequently there was a real constraint in involving anybody more than peripherally in the research process as the researcher was required to have full ownership as part of gaining her qualification. I have been clear to present the overall findings as one interpretation of the data; in doing this I have reflected on the powerful and privileged position I inhabit as a researcher examining issues that are relevant to people with LD.

4.2.2 Analytical Considerations

The following analytical considerations are addressed with regard to the current research study: use of Discourse Analysis, presentation of findings and use of reflexivity throughout the analytical process.

4.2.2.1 Use of Discourse Analysis

The current research follows the analytical principles of discursive psychology in order to guide the interpretations of the talk made within discourse analysis (DA). This meant going beyond the immediate context of the talk. This approach facilitated an understanding of the broader

institutional context which framed the opportunities for self-determination that were available to both service users and staff. For example within the case of Martha and Pam the tension between protecting Martha and encouraging her to have more autonomy is obvious only when considered in its broader institutional context. In this instance, this method of analysis has been particularly useful in answering the current research questions. Additionally, it is an analytical method which is used very little with participants with LD. Using DA allowed more of a focus on the issues immediately salient for service users and staff allowing the findings from the current study to directly inform practice. The current study demonstrates how this method of analysis can be used successfully with people who are more limited in their expression and communication.

Within the current study the secondary data from the recall session provides a reflective commentary on the primary data set. It was used to demonstrate how participants reflect on video recorded material and how their reflections related to the primary analysis. Indeed the secondary data is considered to be strength within the study. The recall process gives an indication as to how material generated from video interactions could be used to open up discussion in order to begin to deconstruct what is happening in practice. Ultimately this opens up possibilities for change. One thing to acknowledge is the limit to how the secondary data was used. If a more detailed DA analysis was carried out on this data set it would likely yield new and interesting findings. Nevertheless this would lend to answering different research questions that were extra to the current research questions. It was also considered to be too ambitious to complete within the time limits of the DClin.

4.2.2.2 Use of case pairs to present findings

In order to present the findings in a way that was organised and coherent a case study format was chosen with a group summary provided to draw

parallels between the main findings from participant pairs. The fact that the findings are presented in a case study format and with actions occurring across pairs is considered to be a strength. A case study format to illustrate the results was prioritised in order to preserve the individual context of the interactions and give voice to each individual pairing. Using a case study format also allowed the researcher to present multiple examples from each participant pairing in order to illustrate the findings adequately. Using direct examples situates the talk within its context (Elliott et al, 1999) allowing the reader to understand how conclusions were reached.

2.2.2.3 Use of reflexivity

Importantly, the analytical findings presented here are developed out of my own understanding of the data as read through the lens of discursive psychology. Within the analysis, I present one way in which to understand the findings, there are likely to be other ways in which to interpret the data. Importantly, the aim of the analysis was not to make judgements about whether the actions observed within the talk are right or wrong. Nor was the aim to criticise staff members practice or their efforts to facilitate self-determination. Facilitating self-determination is a challenging task which is difficult to get right. Indeed, I have been transparent about my analysis through situating each interpretation within the data set and providing comprehensive examples. At the same time within the introduction and method I have illustrated my own position, assumptions and potential biases that could affect the interpretation of the data. In order to help identify my own assumptions about the data, I drew on supervision. In some cases supervisors alerted me to my own idealism when I saw less than perfect practice within the talk. They also challenged my thoughts with regard to the data, opening up a different perspective which allowed me to reconsider my own viewpoint. I kept a note of these discussions within a reflexive log which also contained my own my own reflections throughout the analytical process more details on how I used this log are referred to in section 2.5.1.

Throughout the research process, when watching the videos back, and reading and rereading each transcript I noted my own emotional reactions to the data. Indeed, I often felt sad for the service user participants and anger towards staff members when I felt that opportunities for self-determination were being closed down- or indeed where I felt staff took unnecessary control over the interactions. While I often felt empathy and compassion for the service users, I may not always have been as compassionate or as understanding towards staff. Sometimes with regard to staff actions I would see this as very black and white with little consideration to the wider context they themselves operate within. In continually going back to the analytical framework purported by discursive psychology I refocused my attention to the context that each participant occupies, influences and constructs and the ideological dilemmas that they found themselves wrestling. In order to keep greater check on my own judgmental biases, I reflected on my role as a clinician currently working within a LD service and the difficulties I experience day to day in relation to increasing autonomy and self-determination of the people with which I work. Indeed this awareness, through my own experience has enabled me to keep a check on the judgments I make with regards to staff practice.

4.3 Clinical implications

Within this section I highlight a number of clinical implications in order to improve practice within services offered to people with LD. Within this, the role of front- line staff as well as the role of Clinical Psychologists is considered.

The current study demonstrates the importance of paying attention to the everyday discourses that form within the talk between staff and service users with LD. The findings suggest that in practice, it is important for staff who support service users with LD to have or at least begin to develop an

awareness of the power they hold in relation to promoting or limiting opportunities for self-determination. It may be useful for staff to consider how they might adopt a more equal footing within interactions in order to enable service users to experience more control. Keeping these issues alive through reflection is likely to alert staff to be mindful of the patterns and powers within their interactions. Within this there is a role for clinical psychologists who should evaluate their own position and practice when working with service users with LD. Furthermore clinical psychologists are well positioned in terms of offering support, supervision, training and guidance to staff teams who may struggle to identify disempowering practices.

The current research demonstrates how video recording live interactions can be useful in facilitating staff reflection on their own practice. Video recall used in clinical practice is likely to be useful in order to challenge disempowering ways of working. Staff are often immersed within a service culture and in the everyday it may become difficult to identify disempowerment. This is important as so much of what disempowers people with LD happens within subtleness of everyday interactions (Finlay, Walton and Antaki, 2008). If staff are not in a position to see this, at the time, then it is up to the service to provide avenues of training which will enable the deconstruction of disempowerment and the taken for granted assumption that occur within everyday interactions. Using video in this way would enable staff to refocus their attention inwardly onto their own style of interaction, allowing the small but significant things that shape the everyday lives of service users to be identified and improved. In practice this would have to be done pragmatically and issues of confidentiality and consent carefully considered. Importantly in order for this to work as a learning exercise staff would need to feel safe and therefore open and non-judgemental discussions about the video material would be necessary (Finlay, Antaki and Walton; 2008a). It may be useful to involve staff in the

process of setting up these feedback sessions to maximise their effectiveness and curtail the impact of negative scrutiny.

This study highlights a wider implication for the current service structure which locates choice and self-determination within the 'bigger' decisions relating to a person's life (Finlay, Walton and Antaki, 2008). If real progress is to be made then it is important to target the everyday level, where there are more frequent opportunities for choice. Therefore a focus on the everyday level -in order to enhance self-determination and the ability of service users to make their own choices -is necessary. The focus on 'bigger' decisions that are at the core of policy documentation is perhaps misleading. Fundamental shifts are likely to happen and be supported from the bottom up.

4.4 Avenues for future research

I would argue that the current analysis, with its focus on positioning, repertoires and the actions created within the talk, was well chosen in answering the current research questions. Nevertheless the current study did not capture the wider historical issues that may have influenced the talk. In order to capture and comment on this an approach more akin to Foucauldian DA (FDA) would have been more appropriate to use. Equally a more detailed or fine-grained approach facilitated by using an approach more akin to conversational analysis (CA) may allow a more intricate focus on the individualised nuances within the talk. Using different analytical principles would likely yield a different focus, answering different research questions, and potentially produce interesting alternative findings. This could be an interesting avenue for future research.

Indeed a further point to consider would be to do more extensive analysis on the secondary data. This data set was used within the current study to provide a reflective commentary using a method of data generation akin to Interpersonal Process Recall (IPR). IPR uses video and self-review to

facilitate reflection and recall of inner thoughts and feelings that happen quickly during the course of an interaction. This could be taken further into practice-based research which might facilitate training and development, helping evaluate practice in a more structured way.

A further avenue to explore might be to look at extending the current research to include video recordings that have an even more 'live' flavour. For example, service users in the current study proposed video recording things like going shopping for food or playing snooker with staff. These situations are very much representative of real-life, however given the risk of capturing others on film, this ethical caveat prevented these situations from being explored. Future research might usefully focus on more diverse situations in order to capture a bigger variety of everyday activities.

Finally, the current study focuses on adults with LD; nevertheless there is clearly value in identifying opportunities for self-determination early in childhood. Our learning experience influences the emergence of self-determination, beginning from childhood and extending across the life span (Wehmeyer and Bolding, 2001). Therefore extending the current research method to a child population may produce interesting findings and extend the research area.

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Appendix 1: Literature Search Strategy

Literature search strategy:

Initially databases PsychInfo (OVID), Medline (OVID) and EMBASE (OVID) were searched with the following terms:

- Learning Disability/ies 'OR'
- Intellectual Disability/ies 'OR'
- Developmental Disability/ies 'OR'

These searches were then sequentially filtered with the following combinations of words. Using 'AND' as a grouping.

- 'AND' self-determination
- 'AND' Choice
- 'AND' control
- 'AND' autonomy
- 'AND' Power
- 'AND' Discourse
- 'AND' Discursive Psychology

Other sources came from government websites (DoH) and further literature referenced in the initial sources were incorporated.

Recommended resources from clinicians working in the area of learning disabilities were also followed up, these were largely books sourced from Leeds University Library.

Appendix 2: Staff and Service User Information Sheet

Leeds Institute of Health Sciences  UNIVERSITY OF LEEDS
Faculty of Medicine and Health

Information


Information Sheet



My name is Philippa Brown.
I am doing some research at Leeds University.
I am learning to be a psychologist

research



I am doing some research.

finding out



I want to find out about how people help you feel in control of your life.
I want to find out about the way you choose what you would like to do.

How will I find this out?



I want to video you and a staff member.
I want to video you and a staff member doing things that you would normally do.
I will watch the tape and think about how you and staff talk to each other.
We can choose what we record together.

Service User Information Sheet Version 1.0 March 10th 2013 1

Leeds Institute of Health Sciences  UNIVERSITY OF LEEDS
Faculty of Medicine and Health

TV



I will ask to meet with you again.
I will ask to meet you to watch the video recording back on a TV.

ask you questions



I will ask some questions about the video.
There are no right or wrong answers.

consent



You can choose to say **YES** or **No** about doing this.
If you say **YES** to the research you can change your mind any time.

ask questions




You do not have to say why.
If you want I will come and meet with you before so you can ask questions.

private information




If you say I can video you and your staff member
I will keep your information private and confidential.
This means I will not tell anybody your name and other confidential information.

Service User Information Sheet Version 1.0 March 10th 2013 2


talk to  There might times where information would NOT be kept confidential. This might be because I am worried about you or someone else.

I would talk to you first before I share any information.


report  I will write a report about what is video recorded and talked about.

I will write some ideas about how to help people feel in control and make choices.


The report will keep your information confidential.


 I might use some of what you have said in the report

I will NOT use your name. So no one will know you have said it.

information kept safe  Video tapes and all information will be kept private and locked in a safe place.

I will not show them to anyone outside the research.

talk to  If you would like I will come back and talk to you about what I found out.

information  If you want I can tell you more information about this research.

get in touch  **If you want to get in touch**

This is the address and phone number to ask for more information

address  Philippa Brown
 Programme of Clinical Psychology
 Charles Thackrah Building
 101 Clarendon Road,
 Leeds,
 LS2 9LJ

phone and email  Phone: 0113 343 2732
 Email: umphb@leeds.ac.uk



complain 	If you wish to complain. You can contact: Dr Tom Isherwood
address 	University of Leeds 101 Clarendon Road Leeds, United Kingdom LS2 9LJ
phone and email 	Phone: 0113 34 32732 Email: t.m.isherwood@leeds.ac.uk

Staff Member Information Sheet



INFORMATION SHEET STAFF

Research into self-determination and people with Learning Disabilities

My name is Philippa Brown. I am a trainee Clinical Psychologist, studying at the University of Leeds. I am doing some research as part of my doctorate training.

What do I want to find out?

I want to find out how you, as staff, help people with learning disabilities feel in control of their own lives. I want to find out how you help the people you support to choose what they would like to do. I want to find out what this process is like for you and for them.

What will happen?

I want to video you and a service user that you support. This will be a video of you and a service user doing things that you would normally do. I will then watch the tape and think about how you and the service user interact and talk to each other. We can choose what we record together. There will be no secret videoing. Once we have recorded these interactions I will ask to meet with you again in order to watch the video back with me. This will form the second part of the study which is a video-recall session. I will ask you some questions about what you might have been thinking or feeling at the time of the recording. There are no right or wrong answers.

Do I have to do to take part?

You do not have to take part in the project. It is up to you to decide if you want to. If you do want to you will be asked to sign a consent form to say that you agree to take part. If you agree to the research you can change your mind at any time. If you do not want to take part it will not affect your job in any way. It is hoped that this research will benefit staff working with service users with learning disabilities and help to improve future learning disability services.

How will information be kept confidential?

If you do agree to take part in this research the information collected will be kept private and confidential. All video material will be stored on a secure access drive and only I and my supervisors will have access to this. Others outside of this research will not have access. Identifying information will be changed when the videos are transcribed, so that the data is anonymous.

The only caveat to the confidentiality agreement is in the unlikely event that issues of risk or professional misconduct are raised. If this happens I may have to talk to another person. If I have to do this, I would talk to you before I share this information.

What happens after the research?

I will write the research up into a report. This report will detail what was found through the video and video recall sessions. I will write some ideas about how support staff might help people with learning disabilities feel in control and make choices. The report will keep all identifying information anonymous. I may use some direct quotes in the report, however these will be anonymised.

If you would like, I can come back to talk to you about what I found in doing this research. I am happy to come back and tell you more information about this research. You can also have a copy of the full report.

Should you want more information, please contact me via email or at the address below:

Philippa Brown
 Programme of Clinical Psychology
 Charles Thackrah Building
 101 Clarendon Road, Woodhouse
 Leeds, LS2 9LJ
umphb@leeds.ac.uk

What if I want to complain?

If you are not happy with any of the project and want to complain you can contact:


Dr Tom Isherwood
 University of Leeds
 101 Clarendon Road
 Leeds, United Kingdom
 LS2 9LJ
 0113 34 32732
t.m.isherwood@leeds.ac.uk


Appendix 3: Service User and Staff Member Consent Forms


Consent Form (1)


Self-determination: how you choose what you want to do.


	My name is Philippa Brown.
	Please put your initials in each of the boxes if you agree to take part in the research.
	I have read and understood the information sheet. <input data-bbox="1420 767 1666 826" type="text"/>
	The information has been explained to me. <input data-bbox="1420 922 1666 981" type="text"/>
	I have been able to ask questions about the research. <input data-bbox="1420 1050 1666 1109" type="text"/>


choose
 I understand I can choose to take part in the research.
 I understand I can STOP taking part at any point.
 I don't have to explain why I want to stop taking part.
 I will get the same care.


 I agree to be video recorded.


 After the videoing I agree to be contacted again to meet with Philippa to watch the video back.




confidential
 I understand that anything videoed or said will be kept confidential.

yes
 **Yes** I would like to be contacted after the research to find out about what was found.

no
 **No** I would **NOT** like to be contacted after the research to find out what was found out.

signature
 My Name _____

My Signature _____

date
 Date _____






Name of person taking consent _____


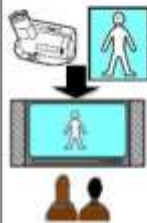


Signature of person taking consent _____

Date _____





Consent Form (2)

Self-determination: how you choose what you want to do.







	My name is Philippa Brown.
	Please put your initials in each of the boxes if you agree to take part in the research.
	I have read and understood the information sheet. <input type="checkbox"/>
	The information has been explained to me. <input type="checkbox"/>
	I have been able to ask questions about the second part of the research. <input type="checkbox"/>

	I understand I can choose to take part in the research. I understand I can STOP taking part at any point. I don't have to explain why I want to stop taking part. I will get the same care. <input type="checkbox"/>
	I agree to meeting Philippa to watch back the video we recorded. <input type="checkbox"/>
	I agree to being asked questions about the video recordings. I understand that there are no right or wrong answers. <input type="checkbox"/>
	I agree to be audio recorded while we are watching the video recording back. <input type="checkbox"/>



<p>confidential</p> 	<p>I understand that anything that is taped or said will be kept confidential.</p>
	<input type="text"/>
<p>information kept safe</p> 	<p>I understand that all information collected will be kept in a safe place.</p>
	<input type="text"/>
<p>talk to</p> 	<p>I understand Philippa may talk to her supervisors at Leeds University about the information from this research.</p>
	<p>I am happy for these people to have access to this information when it is connected to this research</p>
	<input type="text"/>
<p>safeguarding</p> 	<p>I understand there are times where the things I tell Philippa would not be kept confidential. This might be because she is worried about me or someone else.</p>
	<input type="text"/>



<p>report</p> 	<p>I am happy for Philippa to write things I have said into a report for others to read.</p>
	<input type="text"/>
	<p>I know my name will NOT be used in the report. Nobody will know it is me that has said it.</p>
	<input type="text"/>
<p>yes</p> 	<p>Yes I would like to be contacted after the research to find out about what was found.</p>
	<input type="text"/>
<p>no</p> 	<p>No I would NOT like to be contacted after the research to find out what was found out.</p>
	<input type="text"/>
<p>signature</p> 	<p>My Name _____</p>
<p>date</p> 	<p>My Signature _____</p>
	<p>Date _____</p>
<p>Name of person taking consent _____</p>	
<p>Signature of person taking consent _____</p>	
<p>Date _____</p>	

CONSENT FORM STAFF (1)

The Interpersonal construction of self-determination.

Name of Researcher: Philippa Brown

Please initial in each of the boxes if you agree to these statements

I confirm I have read and understood the information sheets dated 10/03/13.	
I confirm that the research and information relating to the research has been explained to me	
I confirm that I have had chance to ask questions about the research	
I understand that I do not have to take part in the research and that I can withdraw at any time without needing to give a reason.	
I agree to being video recorded and participating in the research	
I agree to being contacted again by the researcher to watch back the video, after video recording has taken place	
I understand that information recorded or talked about will remain confidential and any details which could be used to identify me will be removed from all information and study's reports.	
I understand that if I or a service user is at risk or the researcher is worried about someone getting hurt certain information may be shared with others.	
I consent to the use of quotations to help illustrate the study's results and understand these will be anonymised.	
I understand that all information collected will be kept securely in a safe place	
I understand that a report will be produced at the end of the research and that this report may be shared with other professionals and service users.	
I would like to be contacted after the research is complete in order to find out the results from the research.	

Name _____ Name of person taking consent: _____

Signature _____ Signature _____

Date _____ Date _____

CONSENT FORM STAFF (2)

The Interpersonal construction of self-determination.

Name of Researcher: Philippa Brown

Please initial in each of the boxes if you agree to these statements

I confirm I have read and understood the information sheets dated 10/03/13.	
I confirm that the research and information relating to the research has been explained to me	
I confirm that I have had chance to ask questions about the second part of the study research	
I understand that I do not have to take part in the research and that I can withdraw at any time without needing to give a reason.	
I agree to meeting with the researcher to watch the video recorded material back	
I understand that in the video-recall session the researcher will ask me questions about the video. I understand that I do not have to answer questions that I do not wish to.	
I understand that the video-recall session will be audio recorded and that this information will remain confidential.	
I understand that if I or a service user is at risk or the researcher is worried about someone getting hurt certain information may be shared with others.	
I consent to the use of quotations to help illustrate the study's results and understand these will be anonymised.	
I understand that all information collected will be kept securely in a safe place	
I understand that a report will be produced at the end of the research and that this report may be shared with other professionals and service users.	
I would like to be contacted after the research is complete in order to find out the results from the research.	

Name _____ Name of person taking consent: _____

Signature _____ Signature _____

Date _____ Date _____

Appendix 4: Information Letter



To whom it may concern [Managers/Guardian/Carer],

Re: 'Research in Services for People with Learning Disabilities.'

I am writing to inform you about a research study being carried out between the *University of Leeds* and *Leeds and York Partnership Foundation Trust*. This research is particularly salient for staff working within Learning Disability services and also for service users with learning disabilities. You are in receipt of this letter because either a staff member or service user in your organisation has expressed an interest in taking part in this study. We feel it is important to make you aware of this and inform you of what will be asked of these individuals taking part in the research process.

Rationale

The research is concerned with self-determination in people with learning disabilities. The concept of self-determination is important for people with learning disabilities who often feel disempowered and have limited opportunities for choice. Research evidence suggests that people with learning disabilities, if sufficiently supported, can become more self-determined. However, we know little about the real practice and difficulties involved in supporting and 'doing' self-determination. It is recognised that staff are often asked to 'juggle' multiple demands; some of which may conflict with each other, for example protecting people with learning disabilities whilst facilitating empowerment and self-determination. Thus facilitating self-determination in people with learning disabilities is by no means a straightforward process. By opening up this area to research and reflection, we hope to be able to make recommendations in order to improve services for people with learning disabilities and provide future support and advice for staff working with people with learning disabilities.

Informed Consent

Prior to any data collection, all participants will give their informed consent to taking part. All individuals participating must have capacity to consent to the research process. The lead researcher is experienced in assessing capacity and will therefore assess the capacity of interested participants.

What does the research involve?

The research process is split into two parts. Part 1 is the video recording; staff and service user pairs will decide on a location and time that they wish to be recorded. Video recording will take approximately 30-60 minutes and will focus on naturally occurring interactions. This video recording will be done in a private space. Only participating individuals will be captured on film and no filming will take place in secret. Part 2 is a video recall session in which participants agree to attend an individual recall session at the *Service User Involvement Team* based at St Marys Hospital, Leeds. This session will last approximately 30-60mins. This session involves the researcher and the individual participants watching some or all of the video back together. All participants will be asked to reflect on what they were thinking or feeling at the time of the video recording. This session will be audio recorded and used as part of the secondary analysis.

Confidentiality

All information collected during the study will remain confidential and no participant or service names will be mentioned. All data will be anonymised. The only caveat to the confidentiality agreement is that if participants are thought to be a risk to themselves or others; in this case,

information may be shared to protect the individuals involved. You will be kept informed should this be the case.

Who has reviewed this study?

This research has been reviewed for scientific credibility at two academic research panels within the University of Leeds. It has also been reviewed by the Trusts Research and Development team. Furthermore, it has been subject to an ethical review in May 2013 [insert name and REC approval number]. This study has been deemed to comply with all regulatory standards.

While there is no formal incentive offered to participants in return for their participation, all travel expenses will be reimbursed. It is hoped that participation in this study will be both an empowering and enjoyable process for participants and we hope that you will support their participation.

Should you want more information or have any questions in relation to the participation of staff or service users in this study please feel free to contact Philippa Brown at umphb@leeds.ac.uk or Dr Tom Isherwood on T.M.Isherwood@leeds.ac.uk.

Yours Sincerely

Philippa Brown

Lead Researcher and Trainee Clinical Psychologist

Appendix 5: Ethical Approval Letters


Health Research Authority
NRES Committee Yorkshire & The Humber - Leeds West
 North East REC Centre
 Room 002, TEDCO Business Centre
 Raising Hill Road
 Jarrow
 NE32 3DT
 Telephone: 0191 428 3651

18 June 2013

Miss Philippa Brown
 Psychologist in Clinical Training
 Leeds Teaching Hospitals NHS Trust
 Leeds Institute of Health Sciences
 Charles Thackrah Building, University of Leeds
 101 Clarendon Road, Leeds
 LS2 9LJ

Dear Miss Brown,

Study title: People with learning disabilities and the interpersonal construction of self-determination
REC reference: 13/YH/0214
IRAS project ID: 123500

Thank you for your application for ethical review, which was received on 14 June 2013. I can confirm that the application is valid and will be reviewed by the Committee at the meeting on 12 July 2013.

Meeting arrangements

The meeting will be held in the Boardroom, Leeds General Infirmary, Great George Street, Leeds, West Yorkshire, LS1 3EX on 12 July 2013. The Committee would find it helpful if you could attend the meeting to respond to any questions from members. Other key investigators and a representative of the sponsor are also welcome to attend. This may avoid the need to request further information after the meeting and enable the Committee to make a decision on the application more quickly.

If you have a disability and need any practical support when attending the REC meeting you may wish to contact the REC office so appropriate arrangements can be made if necessary.

If you are unable to attend the meeting the Committee will review the application in your absence.

The review of the application has been scheduled for 3.50pm. Please note that it is difficult to be precise about the timing as it will depend on the progress of the meeting. We would kindly ask you to be prepared to wait beyond the allocated time if necessary.

If you cannot attend, it would be helpful if you could be available on the telephone at the time of the review.

Please let me know whether or not you would be available to attend the meeting or be available on the telephone.

A Research Ethics Committee established by the Health Research Authority

Committee meetings are occasionally attended by observers, who will have no vested interest in the applications under review or take any part in discussion. All observers are required to sign a confidentiality agreement.

Documents received

The documents to be reviewed are as follows:

Document	Version	Date
Evidence of insurance or indemnity		21 September 2012
Interview Schedules/Topic Guides	1	24 April 2013
Investigator CV	Philippa Brown	14 May 2013
Investigator CV	Carol Martin	24 April 2013
Investigator CV	Dr Tom Sherwood	02 March 2013
Letter of invitation to participant	1	24 April 2013
Participant Consent Form: service user consent form 1	1	21 March 2013
Participant Consent Form: service user consent form	1	21 March 2013
Participant Consent Form: staff consent 1	1	15 March 2013
Participant Consent Form: staff consent 2	1	15 March 2013
Participant Information Sheet: service user information sheet	1	15 March 2013
Participant Information Sheet: staff information sheet	1	21 March 2013
Protocol		15 March 2013
REC application		12 June 2012
Referees or other scientific critique report		12 March 2013
Referees or other scientific critique report	1	11 March 2013
Referees or other scientific critique report	1	11 March 2013

No changes may be made to the application before the meeting, if you envisage that changes might be required, we would advise you to withdraw the application and re-submit it.

Notification of the Committee's decision

You will receive written notification of the outcome of the review within 10 working days of the meeting. The Committee will issue a final ethical opinion on the application within a maximum of 60 days from the date of receipt, excluding any time taken by you to respond fully to one request for further information or clarification after the meeting.

R&D approval

All researchers and local research collaborators who intend to participate in this study at sites in the National Health Service (NHS) or Health and Social Care (HSC) in Northern Ireland should apply to the R&D office for the relevant care organisation. A copy of the Site-Specific Information (SSI) Form should be included with the application for R&D approval. You should advise researchers and local collaborators accordingly.

The R&D approval process may take place at the same time as the ethical review. Final R&D approval will not be confirmed until after a favourable ethical opinion has been given by this Committee.

For guidance on applying for R&D approval, please contact the NHS R&D office at the lead site in the first instance. Further guidance resources for planning, setting up and conducting research in the NHS are listed at <http://www.northern.nhs.uk>

A Research Ethics Committee established by the Health Research Authority

There is no requirement for separate Site-Specific Assessment as part of the ethical review of this research. The SSI Form should not be submitted to local RECs.

Communication with other bodies

All correspondence from the REC about the application will be copied to the research sponsor. It will be your responsibility to ensure that other investigators, research collaborators and NHS care organisation(s) involved in the study are kept informed of the progress of the review, as necessary.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/YH/0214 Please quote this number on all correspondence

Yours sincerely,



Miss Sarah Dunn
 Assistant Committee Co-ordinator

Email: sarah.dunn7@nhs.net

Copy to: Clare E Skinner, University of Leeds
 Miss Sinead Audsley, Leeds and York Partnership NHS Foundation Trust

18 July 2013

Miss Philippa Brown
Psychologist in Clinical Training
Leeds Teaching Hospitals NHS Trust
Leeds Institute of Health Sciences
Charles Thackrah Building,
University of Leeds
101 Clarendon Road, Leeds
LS2 9LJ

Dear Miss Brown

Study title: People with learning disabilities and the interpersonal construction of self-determination
REC reference: 13/YH/0214
IRAS project ID: 123900

The Research Ethics Committee reviewed the above application at the meeting held on 12 July 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator, Neil McCaffery, nrescommittee.yorkandhumber-leeds@nhs.net.

Ethical opinion

Ethical issues raised by the Committee in private discussion, together with responses given by the researcher when invited into the meeting.

The Chair, Dr Rhona Brall, welcomed you, Dr Carol Martin and Dr Tim Isherwood to the meeting and thanked everyone for attending.

The committee informed the researcher that they thought that this was an excellent study that was well-prepared but there were a few queries.

The committee queried why 16-18 year olds were not included in the study.

You informed the committee that they wanted to keep it to an adult population and due to the depth of analysis required in the study. You also referenced the staff involved in the study and their experience and ability to work with children and young people.

The committee queried the consent form with regard to withdrawing participants and the use of the data following their withdrawal from the study.

You confirmed that they intended keeping and analysing the data for those participants who withdraw from the study.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

1. Addition of a title to the consent form, and removal of the need for signatures after each item. Each item should either be a Yes/No, or an initial.
2. Addition of the standard statement relating to access to records by regulatory authorities, etc. to the Consent Form. The form also requires the addition of a name, signature and date for the person taking the consent.

Reference: <http://www.nres.nhs.uk/applications/guidance/consent-guidance-and-forms/>

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Evidence of Insurance or Indemnity		21 September 2012
Interview Schedules/Topic Guides	1	24 April 2013
Investigator CV	Philippa Brown	14 May 2013
Investigator CV	Carol Martin	24 April 2013
Investigator CV	Dr Tom Sherwood	02 March 2013
Letter of invitation to participant	1	24 April 2013
Participant Consent Form: service user consent form 1	1	01 March 2013
Participant Consent Form: service user consent form	1	01 March 2013
Participant Consent Form: staff consent 1	1	10 March 2013
Participant Consent Form: staff consent 2	1	10 March 2013
Participant Information Sheet: service user information sheet	1	10 March 2013
Participant Information Sheet: staff information sheet	1	01 March 2013
Protocol		10 March 2013
REC application		12 June 2012
Referees or other scientific critique report		12 March 2013
Referees or other scientific critique report	1	11 March 2013
Referees or other scientific critique report	1	11 March 2013

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

There were no declarations of interest.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document 'After ethical review – guidance for researchers' gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National

Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website – After Review

13/YH/0214 Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely
pp



Dr Rhona Bratt
Chair

Email: nrescommittee.yorkandhumber-leedswest@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*
"After ethical review – guidance for researchers" [SL-AR2]

Copy to: *Clare E Skinner, University of Leeds*
Miss Sinead Audsley, Leeds and York Partnership NHS Foundation Trust

Appendix 6: Research and Development Letters



Leeds and York Partnership NHS
 1485 Thirsk Drive, Leeds

Our Ref: 2013/433/L

Research Development
 Nutrition, 5, May's Head,
 St James' Road,
 Leeds LS1 3QT
 E mail: research@lyp.nhs.uk

Doc Ref: 2013 065 1267
 Ref: 13/065/1267

Miss Philippa Brown
 Leeds Institute of Health Sciences
 Charles Thackrah Building,
 University of Leeds
 101 Clarendon Road,
 Leeds
 LS2 9LJ

08/08/2013

Dear Miss Brown

Project Title: People with learning disabilities and the interpersonal construction of self determination
REC Reference: 13/YH0214
IRAS project ID: 123500

Following the review of the revised documents for the above project I am pleased to inform you that the changes comply with Research Governance standards, and the MHR Permission granted by the Trust management on 30 July 2013. We now have all the relevant approved documentation relating to the above project.

The list of documents, revised to comply with the conditions of the favourable opinion granted by the Research Ethics Committee, and reviewed by the Trust, is as follows:

Document	Version	Date
Participant Consent Form: Service user: Consent 1	2	01 August 2013
Participant Consent Form: Service user: Consent 2	2	01 August 2013
Participant Consent Form: Staff: Consent 1	2	01 August 2013
Participant Consent Form: Staff: Consent 2	2	01 August 2013
REC Approval Letter		05 August 2013

This revised approval is granted subject to the conditions as previously specified.



NRES Committee Yorkshire & The Humber - Leeds West Attendance at Committee meeting on 12 July 2013

Committee Members:

Name	Profession	Present	Notes
Professor Howard Bird	Consultant Rheumatologist	Yes	
Dr Rhona Bratt	Retired Multimedia Project Manager	Yes	
Dr Michael Clarke	Senior Dental Legal Advisor	No	
Dr Martin Elliott	Consultant Paediatric Oncologist	Yes	
Dr Diane Farrar	Research Programme Manager - Maternal and Child Health	Yes	
Dr Sheila E. Fisher	NCR Associate Director for PPI	Yes	
Dr Jan Geddes	Lay Member	Yes	
Ms Sarah Kirkland	Research Governance Facilitator	Yes	
Dr Vera Neumann	Consultant in Rehabilitation Medicine	Yes	
Dr Jane Orton	Consultant Oncologist	Yes	
Professor Annie Topping	Director, Centre for Health and Social Care Research	Yes	
Mr Anthony Wamock-Smith	Retired solicitor	No	

Also in attendance:

Name	Position (or reason for attending)
Miss Laura Kirkbride	Senior Coordinator
Mr Neil McCaffery	REC Coordinator

If you have any queries during your research please contact us at any time. May I take this opportunity to wish you well with the project.

Yours sincerely,

Sarah Kirkbride
 Senior Coordinator
 REC

Appendix 7: Flow Chart of Consent Procedures

First approach

Service user who met the inclusion criteria were identified by Service User Involvement Team lead. Information sheets and consent forms were given to those interested in taking part. I made contact with potential service user participants only after they had given their consent to meet with me.

Initial introduction to the research

At a time and place convenient to the service user participant a meeting was set up with the researcher to discuss the information relating to the research. The use of video was discussed and there was an opportunity to ask any questions. Video equipment was also shown to the service user. (Support person to be present if service user wished).

Capacity assessment (1 week after initial meeting).

Further discussion of what the research involves. Capacity to consent assessed within this meeting and consent forms signed. (Support person to be present if service users wishes.)

Identification of staff member

Further discussion of what the research involves, rechecking of capacity and discussion to identify potential staff participants. Service user participants were given information sheet and consent forms to give to their identified staff member.

Initial meeting with staff member

Initial contact, by the researcher was made at least 1 week after the staff had received the information sheets and consent forms and had agreed to be contacted by the researcher. Contact was made through the organisation in which they worked, personal details were never given. The use of video was discussed and there was opportunity to ask questions. Consent forms were signed and collected at the end of this meeting and a date for a joint meeting between the participating pair (service user and staff member) identified.

Joint meeting: identifying material to record

This final meeting was facilitated in order for both parties to have a chance to discuss together what they would like to record. Participants were informed of the recording caveats and a time and location agreed for data collection to start.

Appendix 8: Transcriber Confidentiality Agreement
Confidentiality Statement for Transcribers
Ethics Committee, School of Psychology, Leeds University

The British Psychological Society has published a set of guidelines on ethical principles for conducting research. One of these principles concerns maintaining the confidentiality of information obtained from participants during an investigation.

As a transcriber you have access to material obtained from research participants. In concordance with the BPS ethical guidelines, the Ethics Committee of the D.Clin.Psychol course requires that you sign this Confidentiality Statement for every project in which you act as transcriber.

General

- 1) I understand that the material I am transcribing is confidential.
- 2) The material transcribed will be discussed with no-one.
- 3) The identity of research participants will not be divulged.

Transcription procedure

- 4) Transcription will be conducted in such a way that the confidentiality of the material is maintained.
- 5) I will ensure that audio-recordings cannot be overheard and that transcripts, or parts of transcripts, are not read by people without official right of access.
- 6) All materials relating to transcription will be returned to the researcher.

Signed.....**Date**.....

Print name.....

Researcher.....

Project title.....

Appendix 9: Prompt Sheet

Primary aim is to put participant at ease and allow them to get used to watching themselves on film.

Self-Exploration

What thoughts were in your mind at the time?

How were you feeling then?

Were there any pictures/memories or words going through your mind?

Did the setting affect you in any way?

View of the other

Do you have any feelings towards the other person?

How did you think the other felt at the time

Own behaviour

Was there anything you were not saying?

Do you know what that was about? What got in the way of you saying it?

How did you want to behave in that situation?

How did you want to come across?

Values and assumptions

Was there anything you liked about what was happening?

Anything you didn't like?

Was anything important for you there?

Hopes and Intentions

Anything you wanted to happen?

What do you think the other expected of you?

Links with past

Was that a familiar experience/feeling for you?

Has it happened before?

Did it remind you of anything else in your life?

Reflection

Do you know why you might have said that?

How do you make sense of what happened?

Closure

Is there anything else for you in the video that is important to talk about?

Do you want to think about this more or move on.