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**LIVING WITH RISK: EXPLORING THE CONCEPT OF RISK
WITH ADULTS WITH LEARNING DIFFICULTIES**

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Abstract

Key Words: learning difficulties, risk, challenging behaviour, participatory research, reflexive research, ethics, grounded theory, disability theory, voice, standpoint epistemology.

This study explored the perception of risk of adults with learning difficulties who had been assigned reputations for challenging services. Adopting a standpoint epistemology the research sought to give voice to the alienated knowledge of adults with learning difficulties who had experienced exclusion from the community on the basis of the perceived risks they posed to themselves or others.

The concept of risk was used as a lens through which to uncover the situated knowledge of research participants and to consider the extent to which this knowledge was reflected in risk and disability theory and practice.

The research was informed by a broad range of theoretical approaches to risk ranging from the technico-scientific tradition exemplified by the psychological school and socio cultural perspectives drawn from the disciplines of anthropology, philosophy and sociology. Influences were also drawn from the range of academic disciplines that inform disability theory.

The research was undertaken within a social constructionist framework and adopted a participatory methodological approach. Data collection and analysis spanned a two year period and processes of constant comparative analysis (Charmaz 2006) were applied to explore underlying concepts and relationships. The study evolved over its duration and the reflexive processes that informed the emergent methodology are incorporated in the findings. Consideration was given to the ethical dilemmas associated with adopting the dual roles of a practitioner and researcher.

Through the core themes of voice, harm and relationships the views of research participants challenge the existing hegemony and offer an alternative perspective on the concept of risk. Participants provided an alternate rationale for behaviour as a form of communication rooted in a context of oppression and resistance. Reframing behaviour as actions of resilience and resistance offers valuable insights that should inform the development of risk and disability theory and practice.

Table of Contents

Abstract	2
List of Tables	6
List of Figures	7
Chapter 1: Introduction - scoping the journey	11
1.1 Introduction	11
1.2 The original itinerary	12
1.3 Reflective Practice	13
1.4 Researcher / Practitioner	14
1.5 Overview	15
1.6 The importance of language	18
Chapter 2: Risk theory - providing direction	20
2.1 Introduction	20
2.2 Overview	21
2.3 History of risk as a concept	22
2.4 Theories of Risk	26
2.5 Technico-scientific approach - cognitive sciences	26
2.6 Socio cultural perspectives	34
2.6.1 Weak social constructionist perspective - 'Risk Society'	35
2.6.2 Cultural/symbolic perspective	39
2.6.3 Strong social constructionist perspective - 'Governmentality'	44
2.7 Conclusion	47
Chapter 3: Learning disability- history and theory.	49
3.1 Introduction	49
3.2 Overview	49
3.3 Learning Disability: Historical Development	51
3.3.1 Normalisation	55
3.3.2 Challenging Behaviour	63
3.4 Disability: Theory	71
3.4.1 Theory: Power	71
3.5 Theory: Medical Model	75
3.6 Theory: The Social Model	76
3.7 Conclusion	95
Chapter 4: Research design- a journey through ethics	96
4.1 Introduction	96
4.2 Overview	96
4.3 Background	97
4.3.1 Robust services project	98
4.4 Original research design	101
4.5 Ethics in practice	103
4.6 Obtaining Consent	105
4.6.1 Vignettes	105
4.6.2 'Case studies'	107
4.7 At a crossroads	108
4.7.1 Initial field work: vignettes	109
4.7.2 Initial fieldwork: 'case studies'	110
4.8 Ethics and Theory	111
4.9 The road less travelled	114
4.10 Conclusion	117

Chapter 5: Exploring methods - intentions, experience, reflections and revisions.	119
5.1 Introduction	119
5.2 Overview	119
5.3 A theoretical guide	120
5.4 Case studies or conversations	129
5.4.1 Learning to listen	130
5.4.2 Learning to converse	131
5.5 Pilot conversations: help me learn	134
5.5.1 Rules of engagement	135
5.5.2 Mr Purple	137
5.5.3 Ms Gold	138
5.5.4 The learning	139
5.6 Our first conversation	140
5.6.1 Conversation Guide	140
5.6.2 Graphics Facilitation	141
5.6.3 Have I heard you correctly?	144
5.7 A lighthouse moment - am I speaking a foreign language?	145
5.8 Our second conversation	147
5.9 An introduction: who are you?	148
5.10 Learning together	149
5.10.1 How to say no?	151
5.10.2 Mr. Grey	151
5.10.3 Ms. Silver	152
5.11 Data analysis	154
5.11.1 Audio recordings	154
5.11.2 Research diary	156
5.11.3 Graphic facilitation	156
5.12 Conclusion	156
Chapter 6: Findings - traversing terra incognita	158
6.1 Introduction	158
6.2 Overview	159
6.3 Risk and Danger	161
6.3.1 Key finding- concept of risk	166
6.4 Risk and Voice	167
6.4.1 Reputation	167
6.4.2 Becoming 'other'	184
6.4.3 Communication	191
6.4.4 Key findings - risk and voice	196
6.5 Risk and Harm	197
6.5.1 Abuse	197
6.5.2 Resilience and resistance	204
6.5.3 Home	207
6.5.4 Key findings - risk and harm	212
6.5.5 Additional Areas	213
6.6 Conclusion	214
Chapter 7: Discussion - theoretical cartography	215
7.1 Introduction	215
7.2 Risk and disability in a social context	216
7.3 Reflections on the research process	220
7.3.1 Reflective Practice	228
7.4 Conclusion	230
Chapter 8: Conclusions - the rear view mirror	231

Appendix 1.....	236
Appendix 2.....	240
Appendix 3.....	245
Appendix 4.....	248
Appendix 5.....	255
Bibliography	257

List of Tables

Table 1: Number and location of meetings	150
--	-----

List of Figures

Figure 1: Key components of classic grounded theory	125
Figure 2: Ms Scarlett picture conversation 1	142
Figure 3: Ms. White graphics conversation 2	143
Figure 4: Mr. Green graphics conversation 1	144
Figure 5: Journal entry 1 - Ms. Lilac	145
Figure 6: Mr. Orange graphic self description	149
Figure 7 Voice - sub themes	167
Figure 8 : Mr. Pink self description	168
Figure 9: Mr. Purple self description	169
Figure 10: Journal entry 2 - Mr. Green	186
Figure 11 Journal entry 3 - Mr. Green (b).....	187
Figure 12 Harm- sub themes	197

Preface

The Road Not Taken

Two roads diverged in a yellow wood,
And sorry I could not travel both
And be one traveller, long I stood
And looked down one as far as I could
To where it bent in the undergrowth;

Then took the other, just as fair,
And having perhaps the better claim,
Because it was grassy and wanted wear;
Though as for that the passing there
Had worn them really about the same,

And both that morning equally lay
In leaves no step had trodden black.
Oh, I kept the first for another day!
Yet knowing how way lead on to way,
I doubt if I should ever come back.

I shall be telling this with a sigh
Somewhere ages and ages hence:
Two roads diverged in a wood, and I -
I took the one less travelled by,
And that has made all the difference.

Robert Frost (1874-1963)

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And finally, I owe a huge debt of gratitude to the participants in this research who gave of their time and knowledge and without whom this thesis would not have been possible.

Thank you

Author's declaration

I declare that, except where explicit reference is made to the contribution of others, this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signature _____

Printed name _____

Chapter 1: Introduction - scoping the journey

1.1 Introduction

The focus of this study was an exploration of the perceptions of risk of adults with learning difficulties who had been assigned reputations for challenging the services that supported them. The overarching research question considered was:

“To what extent do the personal perceptions of risk of adults with learning difficulties, who have been assigned reputations for challenging services, inform theory and practice?”

However, this was not the original starting point for this research endeavour. This thesis details both the practical activities undertaken in the course of the research and also the ongoing reflective considerations that informed the development of the study.

This research can be best described using the metaphor of a journey. Along the way there were a number of what I have chosen to call ‘lighthouse moments’; critical junctures when previously held assumptions and perceptions were put in the spotlight and challenged. On a number of occasions long held understandings were dashed upon the rocks of new found academic knowledge, at other times when I was more open and reflective the ‘lighthouse moments’ guided the research around hazards and sent it in a different and unexpected direction of travel. This emancipatory process (Habermas, 1971) of developing self awareness has been described by Mezirow (1981, 6) as ‘perspective transformation’ when,

‘becoming critically aware of how and why the structure of psych cultural assumptions has come to constrain the way we see ourselves and our relationships, reconstructing this structure to permit a more inclusive and discriminating integration of experience and acting upon these understandings’.

This thesis charts the journey undertaken to complete this research, it provides warning of the hazards experienced and should by the end provide more detailed maps of the subjects charted. These maps are available to be used by other researchers/explorers to navigate the areas I have focussed on in this research. In addition I have detailed in the final chapter the many fascinating areas that were sighted and noted but were not, due to the constraints of time, fully explored. These should offer up to other academics and activists inspiration for further research and exploration. This chapter provides an overview of this thesis, a 'rough guide', to what to expect from the subsequent chapters and concludes with an exploration of the significance of language in disability theory and research. In order to fully understand the distance travelled during the course of this research journey it is necessary to first outline the original point of departure and proposed itinerary of this research venture.

1.2 The original itinerary

The intention at the outset was to explore professional perceptions of risk research as applied to adults with learning difficulties who had reputations for challenging behaviour. It was to be based upon original research by Giovannoni and Becerra (1979), partially replicated by Fox and Dingwall (1985), which explored differences of risk perception among professionals involved in child mistreatment work. Giovannoni and Becerra (1979) suggested that differences of professional perception in relation to risk were expressed in one of two ways; through published writings reflecting the policy stances of the different disciplines and through decision making in the actual work setting. They developed a methodology based upon the use of vignettes to explore the latter. It was this approach that I originally sought to adapt and use to explore the perceptions of risk of professionals working with adults with learning difficulties who had reputations for challenging behaviour.

At this point I had a clear itinerary for the journey ahead; there were several key milestones that I knew I had to pass such as literature reviews, gaining ethical approval, data collection and analysis. However I had failed to take account of the fact that undertaking these research activities would affect the direction of travel of the research itself. I discovered that the research journey

does not necessarily follow a straight road, a point I have subsequently had confirmed by other researchers such as Alasuutari (1992, 161),

‘This process, in which we chewed over the main problems of our project and made false starts and rethought it all over again, is hardly an exceptional beginning for a research project. It’s just that researchers rarely report on all of this’.

The deviations from the original research route I had mapped out occurred for a number of reasons, both practical and principled, and this aspect of the journey became as important as the end point, as although clichéd, it became a voyage of intellectual discovery. These developments are therefore reflected in the format of this thesis which attempts to combine a description of the research process, exploring the perceptions of risk of adults with learning difficulties, with a focus upon the evolutionary nature of the journey from its original starting point.

Changing research direction resulted in a radical paradigm shift from a research proposal unintentionally rooted in a positivist methodology of the medical model of disability to a participatory approach to disability research theoretically located within a social constructionist perspective. This process brought further concepts to the fore that have had a profound influence on this research; the process of reflective research practice and the role of the practitioner as a researcher. I will provide a brief outline of each of these in turn.

1.3 Reflective Practice

Finlay (1998) describes two approaches to reflexivity; methodological reflexivity, the process by which the researcher reflects upon the action of undertaking the research and personal reflexivity, whereby the researcher evaluates their own contribution to the research.

The basic tenets of action research are planning, acting, observing and reflecting (Carr and Kemmis, 1986). McNiff (1988) highlights two different perspectives on action research. The first involves an eclectic approach to a self reflective programme utilised to solve a problem or a ‘loose set of activities’

McNiff (1988, 2). The second is a more actively defined process for undertaking these activities utilising particular methods and techniques based upon the four key themes of collaboration, participation, reflection and reflexivity. In terms of reflexivity Carr and Kemmis (1986, 187) define a cycle in two phases, the constructive phase during which the researcher plans and acts and the reconstructive phase during which they observe and reflect. This 'self-reflective spiral' links the reconstruction of the past to the construction of the immediate future through action.

This thesis is constructed on the premise of the 'self-reflecting spiral' with chapters concluding with observations and reflections and discussion of the 'lighthouse moments' that illuminated opportunities that informed the next stage of the research journey. This approach underlines the importance of chronicling the genesis of this research regardless of the level of deviation through gradual evolution; the 'self reflective spiral' locates the process in history and enables the researcher to become 'aware of themselves as both the product and the producer of history' (Carr and Kemmis 1986, 187).

1.4 Researcher / Practitioner

Undertaking this research I occupied two distinct roles, that of practitioner and of a researcher. My role as a practitioner changed during the course of this research project. I moved from being a Commissioner of Learning Disability Services working in a joint local authority and health team to start up and become the Executive Director of a Supported living organisation called C-Change for Inclusion, working for adults with learning difficulties who had been assigned reputations for challenging behaviour. The duality of roles as a researcher and practitioner had a significant influence on the development of this research.

The shift of focus for this research from an analysis of professional perceptions of risk to an investigation of the personal perceptions of risk of adults with learning difficulties, who had been assigned reputations for challenging, brought with it a whole new range of possibilities and challenges. One of the most significant factors was my dual role as researcher and practitioner. The

implications of this duality were compounded by the fact that all but one of the adults with learning difficulties who participated in the research was supported by C-Change.

There is much debate within qualitative research about the merits and downsides of the position of the independent researcher (Barnes, 1996; Bury, 1996; Shakespeare, 1996; Goodley 2001). Edwards (2002, 71) coined the term 'deep insider' research which he defined as 'research undertaken by a person who has been a member of the organisation or group under research for at least five years'. At first reading the relevance of this concept to the study of the perceptions of risk of adults with learning difficulties, who have reputations for challenging, might seem tenuous; for as a researcher, I have been assigned none of these labels. However the 'deep insider' approach has been interpreted to include the knowledge that a researcher can bring of the culture and history of the 'organisation' (Kincheloe, 1991). In addition it may include an awareness of 'body language, semiotics and slogan systems operating within the cultural norms of the group' Edwards (2002, 72), in which case my knowledge and understanding of long stay learning disability hospitals, 'service land' (Sanderson, 2002) and the culture of the organisations supporting the research participants may be regarded as an invaluable resource. Ethical considerations were highlighted by the practitioner as researcher duality and they developed an increased prominence in the research project; Chapter 4 charts the journey through ethics.

1.5 Overview

Chapter 2: Risk theory - providing direction, details the historical evolution of the concept of risk. It provides an analysis of the major theoretical positions from the technico- scientific theories exemplified by the psychological tradition through a range of approaches reflecting the socio cultural school of thought. The works of the major social theorist on risk Giddens (1990; 1991; 1994); Beck (1992a; 1992b); Douglas (1982; 1985; 1990; 1992) and Foucault (1972; 1973; 1977; 1980; 1988; 1991) are discussed in order to explore the theory of risk as a social construct, with the focus on the 'meaning' of risk. This approach sets to challenge the applicability of what could be described as the 'objective'

quantitative analysis of probabilities and predictions expounded by physical and biological sciences and adapted for use in the field of the social sciences.

Chapter 3: learning disability - history and theory, starts with a brief exposition of the history of the development of the concept of learning disability from the medieval societal response in the form of the 'ship of fools' (Foucault, 1973) through the major legislative and policy changes to an analysis of the current political and policy positions where there is an increasing focus upon individualisation and self direction (Duffy, 2003). International perspectives on learning disability are considered only in respect of their relevance and impact upon the United Kingdom experience. The purpose of this research is to explore the perceptions of risk held by adults with learning difficulties who have reputations for challenging the services that support them. The term 'challenging behaviour' has been in widespread use since its incorporation into the influential document 'Facing the Challenge' (Blunden et al, 1987). Despite the fact that it is part of the everyday terminology in use in learning disability services there is no consensus over the definition or its use. Chapter 3 includes a brief analysis of differing approaches to the concept of challenging behaviour. The chapter then goes on to detail the development of disability theory locating it within a wider cultural and social context. The theories of Gramsci (1971) and Luke (1974) are considered in a brief in order to analyse the relationship between social policy and power. This analysis is then refined to focus upon the development of the medical model and social models of disability and the applicability of these approaches to the lives of people with learning difficulties. The role of normalisation theory and the impact that this had upon the development of services for people with learning disabilities is critiqued.

The implications of the medical and social model of disability are considered with particular emphasis given to the impact of emancipatory and participatory approaches to disability research and their applicability to learning disability research. The influence of feminist theory is explored through a review of the narrative approach to disability research and the development of standpoint epistemological approaches. The final section of this chapter provides an opportunity for reflection upon the original research design and the developments that took place as a result of the literature review and the influence of disability theory.

The ethical dilemmas involved in undertaking research with people with learning difficulties are discussed in Chapter 4: A journey through ethics. The first section of the chapter details the practical and ethical considerations taken into account when planning to undertake this research. It also recounts the ethical approval process followed, detailing the challenges of undertaking research based upon a social model approach to disability whilst seeking ethical approval from an ethics committee with views firmly based in the medical model of disability. The learning from this process and the dilemmas that it raised are discussed in detail. The chapter goes on to review the literature available on the ethics of disability research generally and the issues specific to learning disability research in particular including issues of consent.

Of particular relevance in this chapter is the discussion on the ethical implications of being a practitioner and a researcher and the Foucauldian concept of ethical agency (Koro-Ljungberg, et al. 2007) . The chapter concludes by summarising the paradigm shift that had taken place in part as a consequence of ethical considerations and signposts the methodological way forward.

Chapters 5: Exploring methods -intentions, experience, reflections and revisions, focuses on the theoretical and methodological influences that informed the development of this research project. It provides a brief outline of grounded theory as a counterpoint for the subsequent discussion of the emergent methodological approach undertaken. Chapter 5 then charts the practical aspects of adopting a participatory research approach with the research participants in this study; the process of piloting the research conversations; the use of graphic facilitation; participant's self descriptions and the process of data analysis.

Chapter 6: Findings - traversing terra incognita, details the outcome of the analysis of data drawn from conversations with research participants. The findings are presented through analysis of the emergent themes of 'voice', including the sub themes, reputation, becoming 'other' and communication and the second theme 'harm', which includes the sub themes, abuse, resistance and resilience and home. Chapter 6 also includes a brief reflection on the process of attempting to undertake participatory research and the limitations of the research methods adopted.

Chapter 7: Discussion - theoretical cartography, draws together the findings detailed in chapter 6 and explores the extent to which the perceptions of risk of adults with learning difficulties are reflected in current risk and disability theoretical formulations. The ethical implication of undertaking participatory research with adults with learning difficulties is discussed with a particular focus on the ethical challenges of occupying the dual roles of a practitioner and a researcher. Chapter 8: Conclusions - new horizons, signposts potential areas for further research exploration in this interesting field of study. The chapter highlights questions and clarifications that require further academic attention but which fell out with the remit of this current study.

1.6 The importance of language

The power of language cannot be underestimated. As Walmsley (2001, 189) pointed out,

‘linguistic change is important, the term ‘mentally handicapped’ semantically aligned issues relating to learning difficulty with ‘mental illness’. Intellectual and learning disability made a clear statement that it should be considered under the disability agenda with consequent implications in terms of researchers looking at the applicability of the social model of disability’.

Specific words and phrases have been used throughout this thesis. Oliver and Barnes(1998,14) suggest that definitions of disability can be divided into two groups,

‘Official definitions produced by professionals and academics, and those developed by disabled people and organisations controlled and run by them’.

The term learning difficulties has been used in this thesis to describe people who have been labelled at some point in their lives as requiring specialist ‘learning disability’ services (Walmsley, 1993). The term learning difficulty was chosen instead of other synonyms such as ‘intellectual impairment’ or ‘learning disabilities’, because it is the term preferred by many in the self advocacy movement (Harris 1995). As one self-advocate puts it, ‘If you put ‘people with learning difficulties’ then they know that people want to learn and to be taught how to do things’ (quoted in Sutcliffe and Simons 1993, 23).

I have used the term learning disability when referring to services and research, as in learning disability services, and learning disability theory, as this is the terminology utilised in the dominant discourse in these areas. When referring to adults with learning difficulties who have additionally been labelled as having challenging behaviour, I refer to their status as individuals who have been 'assigned reputations for challenging behaviour' or who have been 'assigned reputations for challenging services'. The former term may apply generally to all those so labelled, the latter term refers specifically to the participants who took part in this research.

Chapter 2: Risk theory - providing direction

‘.....To live in the universe of high modernity is to live in an environment of chance and risk’.

(Giddens 1991, 109)

2.1 Introduction

The concept of risk is broad, complex and multifaceted (Mitchell and Glendinning 2007). In late modern society risk, as a conceptual category, informs a wide range of academic disciplines as diverse as mathematics, engineering, anthropology, psychology and sociology. As broad as the range of disciplines, is the range of meanings and interpretations applied to the concept of risk. Jaeger, Renn and Rosa (2001) proposed a typology of approaches to studying risk: technical, psychological, sociological, anthropological and geographical. However while recognising the value of diversity it is necessary to define the conceptual boundaries that inform this research focusing as it does on an exploration of the perceptions of risk of adults with learning difficulties. Reference is made to the contribution of the techno scientific schools in the historical development of risk as a concept (Section 2.3) and in particular to the contribution of the psychological approach to risk perception (Section 2.5). However the main focus for this chapter is the exploration of theories of risk as a social construct; the meaning, interpretation and practice of risk in the social arena particularly as it relates to adults with learning difficulties.

The following literature review examines the historical development of the concept of risk and acknowledges the contributions of a breadth of academic disciplines including psychology, anthropology, sociology and social policy in informing the research evidence and knowledge base. The term risk is used in day to day discourse in a way that is conceptually interchangeable with the term uncertainty to denote substantial harm regardless of the estimable probability (Lupton 1999). Joseph (1993) suggests that most people have learned to incorporate risks into a ‘repertoire of chances’ they are willing to take in life. The research that forms the basis for this thesis was undertaken as an exploration of the perceptions of risk of adults with learning difficulties who had

been assigned reputations for challenging services. To facilitate the emergent nature of this exploratory research process no explicit definition of risk was selected as a starting point; instead a range of definitions of risk adopted by different disciplines and theoretical approaches are discussed throughout this chapter. These conceptual frameworks provided the theoretical background within which the perceptions of risk of those who participated in the research were considered.

2.2 Overview

Section 2.3 of this chapter walks a short path through the historical development of risk as a concept charting the various influences that shaped this fascinating area of study. Extensive literature and academic research devoted to the subject of risk exists spanning a range of academic disciplines. The development of risk specialism's within academia was described by Warner (1992, 7) in the Introduction to the Royal Society Report on Risk as the 'risk archipelago' warning that this could lead to the compartmentalisation of ideas and variations in terminology and approach. A comprehensive literature review of risk research across disciplines is beyond the scope of this current work due to amount of the literature available. The focus of this literature review is risk in the social sphere. A review of literature relating to risk and adult social care, between 1990 and 2007, uncovered one hundred and fifty one references (Mitchell and Glendinning, 2007). The review found that only ninety four of the one hundred and fifty one references were for empirically based studies leading them to conclude that the actual research evidence in this field of academic study was smaller than the number of references would suggest. They also concluded that 'the views of 'service users' and carers were noticeably absent' (Mitchell and Glendinning 2007, vi).

The structure of this chapter follows the model suggested by Lupton (1999, 35) for mapping the different theoretical approaches to risk. The theoretical discussion starts with the 'realist' position expounded by proponents of the 'technico-scientific' traditions, Section 2.5, exemplified by the contributions from the discipline of psychology. There follows a discussion of the theoretical approach described as a 'weak constructionist' position encompassing 'Risk

society' (Beck 1992; Giddens 1990;1991;1994) in Section 2.6.1 and the 'cultural/symbolic' perspectives (Douglas, 1982;1985;1992)in Section 2.6.2. Finally a discussion of the theoretical approach categorised as a 'strong constructionist' position embodied by the concept of 'governmentality' (Foucault 1973;1977;1980; 1988;1991) takes place in Section 2.6.3. Chapter 2 concludes with reflections upon the development of the research design as informed by the review of the literature on risk.

Throughout the literature review the relevance of the various approaches to the field of adult social care and in particular the experience of adults with learning difficulties is considered. In order to locate the theoretical discussions within a developmental context a brief outline of the historical evolution of the concept of risk is detailed in the following section.

2.3 History of risk as a concept

Within the literature reviewed there is no definitive agreement on the origin of the concept of risk. Grier (1980) cited in Covello and Mumpower (1985, 103) writes of the existence of a people, the Asipu, in the Tigris-Euphrates valley about 3200 B.C., whose primary function was to provide consultancy advice on 'risky, uncertain or difficult decisions'. According to Grier the activities of the Asipu mark the first recorded instance of a form of risk analysis. Jaeger, Renn and Rosa (2001) however state that the idea of risk management can be traced back to the code of Hammurabi (1796- 1750 BC). There appears to be some consensus in the literature that insurance can be considered one of the oldest strategies for dealing with risk. According to the Oxford English dictionary the word risk comes from the Italian 'risco' meaning danger, thought to have its origins in maritime insurance and originally derived from the Greek word 'rhiza', relating to the hazards of sailing around a cliff (Covello and Mumpower 1985).

Although rudimentary precursors to risk analysis date back to early Mesopotamia it was only with the advent of probability theory in the 17th century that 'the intellectual tools for quantitative risk analysis became available' (Covello and Mumpower 1985, 104). In the Middle Ages harmful occurrences such as climatic events, epidemics of disease and accidents were not attributed to human failings

but to divine or supernatural interventions (Lupton 1999). A mixture of magic and religion supported a belief system that allowed people to have some sense of control over their world and in particular otherwise unexplainable phenomena such as the weather and disease. Adherence to superstitions, rituals and practices were singular and collective attempts to assert a sense of order and ward off dangers and disease in an otherwise unpredictable world. Much of the ground work for modern quantitative risk analysis can be found in the religious ideas concerning the probability of an afterlife. Formal quantitative notions of probability were not really understood before Pascal (1623-1662) introduced probability theory in 1657 applying it to conclude that 'Given the probability distribution for God's existence, the expected value of being a Christian outweighed the expected value of atheism' (Ore, 1960 in Covello and Mumpower 1985, 105).

The Enlightenment challenged the old notions of superstition and divine intervention and replaced them with the belief that 'rational thought and objective knowledge' were the foundations of 'progress and order' (Stalker 2003, 213). These ideas were based upon the understanding that the social world and natural world conformed to laws and forces and that these laws and forces could be measured and predicted. In the late 17th century theories of risk focused upon the structure of probabilities as a whole and from this work the mathematical analyses of chance emerged. Risk in this context meant the probability of an event occurring, combined with the extent of the losses or gains entailed,

'Since the 17th century the analyses of probabilities has become the basis of scientific knowledge, transforming the nature of knowledge, of authority and of logic...probability theory has provided a modern way of thinking'.

(Douglas 1992, 23)

In the 18th century the concept of risk was still neutral; it took account of the probability of losses and gains (Lupton, 1999). During the 19th century the focus of risk theory turned to risks in economic enterprise at which point the probabilities of loss became the focal point. The notion of risk also extended beyond the realm of nature and was seen to be present 'also in human beings, in

their conduct, in their liberty, in the relations between them, in the fact of their association, in society' (Ewald 1993, 226). There is a contention that from this point in history value judgments began to inform risk debates; von Winterfeldt and Edwards (1984) assert that many conflicts about risk are at root conflicts about values. The role of values in risk discourse is particularly significant when considering societal attitudes towards people with learning difficulties; this subject is discussed in Chapter 3: Section 3.3 when considering the historical development of learning disability services. The link between the concept of risk and perceived negative outcomes has continued into the 21st century.

Despite increases in the average life expectancy and vast improvements in the general health of the populations in Western developed countries, surveys reveal that that this has not resulted in a reduction in the perception of risk in society, in fact the opposite has occurred. A Louis Harris poll (1980) found that approximately four fifths of those surveyed agreed that '....people are subject to more risk today than they were 20 years ago' (Covello and Mumpower 1985, 117). Many possible suggestions to explain this phenomenon have been posited; increased access to information through the development of computer technologies; developments in the regulation of issues seen as highly risky such as the nuclear industry and the environment; a move from mono causal determinism in scientific thinking; a change in risks from local to global phenomena and a move in the West from modern to post modern societies with the subsequent challenge to tradition and established thought and practice particularly in relation to science and medicine (Smart 1993, 12).

Contemporary Western societies have been described by Giddens (1994, 56) as 'post-traditional', in that old traditions have been called into question and the vacuum left has been filled with greater uncertainties and insecurities. A more pessimistic view of the future suggests that improved risk management capabilities will be outstripped by improved risk identification capabilities, this phenomenon has been dubbed the "Hydra effect" - for every risk problem that is resolved, two new ones are raised in its place' (Covello and Mumpower 1985, 118, citing a private communication from Baram, M). Covello and Mumpower (1985, 18) themselves conclude 'it is quite likely that the probabilistic and uncertain world created by modern science and technology will seem to many to

be an increasingly risky and uncomfortable place, even in the face of overall improved prospects for a longer, healthier life'. In this analysis the concept of risk forms a back drop to all life's activities leading to a sense that there is no place of safety. Massumi (1993) identifies the shooting of President John F Kennedy (1963) as the moment Western societies moved from modern to post modern and the concept of risk began to inform our daily lives,

'The shot could come from any direction at any time even pleasure no longer felt the same. Smoking was the insidious onset of a fatal ailment. Food became a foretaste of heart disease. The body itself was 'subversive' of the 'self'; in the 'youth culture' the very existence of the flesh was the onset of decline...'

(Massumi 1993, 10)

A more profound and not necessarily oppositional consideration is that accidents and injuries are no longer seen as acts of retribution from God to be fatalistically accepted, they are instead seen as potentially avoidable events under some degree of human control. Instead of the rituals and superstitions of the medieval period a range of other strategies to manage our feelings of threat and danger are adopted for example anti pollution legislation and pre screening for prevention of ill health. Post incident investigation and subsequent legislation such as the Dangerous Dogs Act (1991; 1997) following a number of high profile dog attacks and the Terrorism Act (2006) introduced quickly following the London terrorist attacks in July 2005, can be seen as attempts to regain control over unpredictable events or as Reddy (1996, 237) concisely states,

'Moderns had eliminated genuine indeterminacy, or 'uncertainty', by inventing 'risk'. They had learnt to transform a radically indeterminate cosmos into a manageable one, through the myth of calculability'.

The question arises; if risks can and should be controlled whose responsibility is it to protect the individual from harm, the expert, the lay person or the state and importantly how should this be undertaken? The following literature review explores a range of divergent approaches to conceptualise and consider some of these issues.

Traditionally, academic research has been divided according to the specific types of risk being investigated, notably into natural hazards, technological hazards and social hazards (Hood, et al. 1992, 135). Lupton (1999, 14) argues that six main categories of risk appear to dominate the concerns of individuals and institutions in modern western societies; environmental risks; lifestyle risks; medical risks; interpersonal relations; economic risks and criminal risks. Consideration of the relevance of this argument to the lives and perspectives of adults with learning difficulties informs aspects of this thesis and is explored in greater detail in Chapters 6 and 7.

2.4 Theories of Risk

Studies of risk have been undertaken using a range of methodologies including both quantitative (often focusing upon the probability of risk events) and qualitative (focusing upon the meaning of risk events to those affected). Traditionally risk research could be seen to fall into two main types, the physical and biological sciences, including cognitive sciences such as psychology focusing on what would be described as ‘objective’ investigation involving quantitative analysis of probabilities or predictions. The second category falls to the social sciences exploring the ‘meaning’ of risk, either in terms of subjective probabilities or the significance of the perceived consequence of risk events. The following sections of this chapter explore the contributions made to risk discourse from a variety of academic traditions starting with the psychological approach to risk, generally located within the technico-scientific perspective (Lupton, 1999).

2.5 Technico-scientific approach - cognitive sciences

Within the technico-scientific tradition risk is considered a definable objective category, ‘the product of the probability and the consequences (magnitude and severity) of an adverse event (i.e. a hazard)’ (Bradbury 1989, 382). Warner (1992, 2) described risk in the introduction to the Royal Society (1992) as,

‘The probability that a particular adverse event occurs during a stated period of time, or results from a particular challenge’.

The Royal Society Report distinguished between ‘subjective’ and ‘objective’ risks on the basis that ‘objective’ measurable risks exist, this phenomenon is subject to ‘subjective’ scrutiny by individuals and social groups. In this technico- scientific approach the hazard was considered to be the independent variable, people’s responses to the hazard are seen as the dependent variable (Douglas 1985). Risks according to this model are therefore seen to be,

‘Pre-existing in nature and are in principle able to be identified through scientific measurement and calculation and controlled using this knowledge’

(Lupton 1999, 18)

Within the technico-scientific approach the discipline of Psychology has made significant contributions towards the development of understanding of risk perception. The psychology profession has also played a key role informing the development of learning disability services. This factor is particularly relevant to the research undertaken for this thesis given the primacy of the psychology profession in risk debates relating to adults with learning difficulties, and particularly those assigned labels for challenging services, within post industrial western societies. The historical development of the medical model of disability within which much psychological research relating to adults with learning difficulties rests is discussed in greater detail in Chapter 3: Section 3.5.

Many researchers from within the technico-scientific and psychological approach recognise the importance of marrying the professional and lay person approach to risk. Slovic, Fischhoff and Lichtenstein (1982, 464) detail the need for both the public and experts to be part of the risk assessment process on the basis ‘that assessment is inherently subjective, and that understanding judgmental limitations is crucial to effective decision making’. The following section of this chapter explores some of the ‘judgmental limitations’ that Slovic, Fischhoff, Lichtenstein and other researchers of the psychological tradition believe influence the perception of risk.

Much of the exploration of the perceptions of risk within the Psychological tradition has focussed upon the concept of 'heuristics' considered to be intuitive mental-rules-of-thumb or short cut judgment strategies; often referred to in technological psychological literature as cognitive heuristics (Tversky and Kahneman 1974; Lichtenstein, et al. 1978; Slovic, Fischhoff and Lichtenstein 1982; Tversky, Slovic and Kahneman 1990; Slovic 1995; Slovic, Finucane, et al. 2002).

These rules or heuristics are used to break down complex mental tasks into simpler components, Slovic, Fischhoff and Lichtenstein (1982, 464) note 'although they are valid in some circumstances, in others they lead to large and persistent biases with serious implications for decision making'. A number of heuristics could be regarded as particularly relevant to the issue of risk decision making and risk perception. Lichtenstein, et al. (1978) noted, when undertaking research into perceptions of mortality rates that respondents tended to overestimate the number of deaths from infrequent causes such as tornados and botulism and underestimate deaths from frequent causes such as cancer and diabetes. It was further noted that the types of activities where fatalities were judged to be higher were typically more vivid or imaginable, results supported by the work of Bastide, Pages and Fagnani (1989).

The results detailed were attributed to the 'availability' heuristic first noted by Tversky and Kahneman (1974). They identified, through research, that people using this heuristic utilise 'availability' as an appropriate cue in decision making and as a consequence judge an event as likely or frequent if instances of it are easy to imagine. They suggested that rare events are more difficult to recall and are therefore judged less likely or frequent. This heuristic is subject to external variables other than frequency, a significant event such as a natural disaster for example the South East Asian tsunami (2004) or the Pakistani earthquake (2005) could be seen to have the potential to seriously distort risk judgment. In relation to adults with learning difficulties high profile incidences of abuse such as the case which prompted the Borders Inquiry (The Scottish Government 2004) and hastened the introduction of the Adult Support and Protection (Scotland) Act 2007 may be seen to influence the perception of vulnerability of adults with learning difficulties and their informal and formal

carers. A significant potential implication of the ‘availability heuristic’ is that frequent discussion of a low probability risk could increase its ‘memorability and imaginability’ and therefore distort the perception of actual riskiness, regardless of the data available. The so called ‘moral panics’ that gain a high profile in the mass media and therefore in the public conscious, such as ‘dangerous dogs’ could be seen to fall in to this category.

Another proposed influential heuristic, particularly relevant to health research and Health and Safety risk research is the noted tendency for people to consistently underestimate their own individual vulnerability to risk, for example ‘the great majority of people believe themselves to be better than average drivers’ (Slovic et al, 1982, 470). People believing in their own personal immunity from risk despite the data that ‘proves’ otherwise may have significant implications for the way that health authorities target health promotion campaigns such as drug harm reduction programs etc.

The perceived passivity of the lay public expounded by this approach does not stand uncontested. If the role of the ‘expert’ in this formulation is to calculate the risks based upon the ‘objective facts’ and that these risks are then contrasted with the subjective understandings of lay people, there appears to be an assumption that there exists a direct, linear relationship between risk and knowledge. This assumption leads Douglas (1992, 13) to conclude that,

‘Humans are presented in this context as hedonistic calculators calmly seeking to pursue private interests. We are said to be risk averse, but, alas, so inefficient in handling information that we are unintentional risk takers; basically we are fools’.

It could be argued that this position would be exacerbated for adults with learning difficulties many of whom may already experience disadvantage through the medicalisation of their lived experience and the imbalance in rank and power dynamics inherent in the professionalised world of social care support. This issue is considered further in Chapter 3: Section 3.5 and Section 3.6 in the context of an analysis of the impact of the medical and social models of disability on the history and development of learning disability as a construct.

A further criticism of the personal invulnerability heuristic is that it is reliant upon too narrow a view of rational action and that anything outside of this becomes viewed as irrational. Bloor (1995) criticises the 'health belief model' claiming that this approach dominates ideas of risk perception in the field of health promotion and health education and is based upon the assumption that all human action is volitional and rational. This leads to a further determination that risk avoidance is rational and therefore risk taking is irrational, 'So instead of sociological, cultural and ethical theory of human judgment, there is an unintended emphasis upon perceptual pathology' (Douglas, 1985, 3).

Another interesting outcome of psychological research into risk decision making is reportage that generally people have greater confidence in judgments based upon them. The reasons for this appear to be complex. However one aspect seems to be that respondents are unclear that their judgments are based upon tenuous knowledge (Tversky and Kahneman, 1974); in other words people do not know what they do not know. Equally concerning (or reassuring) is that this over confidence appears to be equally prevalent among perceived 'experts' (Kahneman, et al. 1982).

Findings from psychological research appear to indicate that the presentation of risk data has a significant impact upon the perception of the risk and then subsequent behaviour. Presenting information on the probability of an accident on a single car journey basis had less of an effect on influencing attitudes towards seat belt and air bag use than presenting it cumulatively over a lifetime (50 years) of driving (Slovic, Fischhoff and Lichtenstein 1982). Another contributing factor in risk perception draws upon a psychological approach termed 'prospect theory' Kahneman, et al. (1982) which details that outcomes that are perceived as probable are underweighted when compared with outcomes that are obtained with certainty. According to this theory unconditional protection from a limited number of hazards is regarded as more attractive than partial cover over a wider ranging number of hazards, this aspect of 'prospect theory' has been labelled 'pseudocertainty'. This approach has potentially significant implications for, among others, health professionals and insurance companies in terms of the way that harm reduction strategies such as vaccination programmes and insurance policies are presented. Using the 'anchoring' heuristic respondents view judgments in the light of or 'anchored

on' initially presented values (Tversky and Kahneman 1974; Lichtenstein, et al. 1978; Slovic, 1995).

Developing the 'laws of acceptable risk' detailed by Starr (1969), Fischhoff, et al. (1981) concluded that people were willing to tolerate a greater level of risk for activities that rate more highly in the following categories: voluntariness; controllability; familiarity; immediacy of consequences; threat to future generations; the ease of reducing the risk and the degree to which benefits are distributed equitably by those who bear the risk (Rescher 1983, 123). This research could have interesting and positive implications for people with learning difficulties in areas such as the design of support services based on the ideals of self directed support as individuals often find themselves marginalized from society and consigned to segregated services that offer few of the opportunities detailed above. Heuristic theory (for a more comprehensive analysis see Kahneman, Slovic and Tversky, 1982) may inform how individuals arrive at judgments of subjective probability, however it does not provide a theoretical explanation for the motivational and emotional factors associated with risk perceptions and risk-taking behaviour (Johnson and Tversky 1983).

Vlek and Stallen (1981) conducted research into group differences in a national population; their conclusion was that the differences in risk acceptability that they encountered were less dependent upon perceived risks than on perceived benefits. Their research also highlighted the fact that the dimensions on which their respondents disagreed tended to involve socially controversial issues. Wynne (1989) expanded upon this work noting that the dimensions where disagreement arose were ones with contested institutional or political implications. There is some evidence that occupation might predict levels of risk acceptance; 'specifically lower risk acceptance is reported for 'professional' groups such as medical, social, scientific and arts related occupations, higher for business, industry workers and farmers' (Vlek and Stallen, 1981, 269). There is also a small amount of evidence that gender and age may affect perceptions of risk. Pidgeon, et al. (1992, 109) reference a number of studies (Schmidt and Gifford 1989; Pilisuk, Parks and Hawkes 1987; Fischer, Morgan, Fischhoff, Nair and Lave 1991) when suggesting that women perceive there to be a greater threat to the environment than men. There was no evidence from the psychological

tradition that similar research on the perception of risks of adults with learning difficulties has been undertaken.

Increasingly, the view that a separation can be maintained between 'objective risk' and perceived or 'subjective' risk has come under attack. Watson cited in Pidgeon, et al. (1992, 94) describes the contention that such a separation can exist as the 'phlogiston theory of risk,' caricaturing the notion of 'objective risk' existing as a discrete substance emanating from physical processes and that can be counted. It is contested that even the most seemingly uncontroversial 'statistical' estimates involve a range of judgments determining the parameters of the issue and it could be argued that 'the most fundamental point at which judgment is needed is during the qualitative structuring of a risk model' (Pidgeon, et al. 1992, 96). Slovic, Fischhoff and Lichtenstein (1982, 463) use the example of the complex theoretical analyses involved in drawing up 'fault trees' to illustrate this point stating that,

'Despite an appearance of objectivity these analyses...include large components of judgment. Someone, relying on educated intuition, must determine the structure of the problem, the consequences to be considered, and the importance of the various branches of the fault tree'.

This approach raises a question about what hazards are deemed worthy of consideration and analysis and what influences inform this judgment. Pidgeon, et al. (1992, 90) suggests that one of the most significant trends in the study of risk perception has been to look beyond,

'Purely individual psychological explanations of human responses to hazards. Social, cultural, and political processes are now acknowledged as all being involved in the formation of individual attitudes towards risk and their acceptance'.

This approach proposes that there comes a point where, regardless of the amount of 'hard fact', human judgment is required in order to formulate policy and this becomes an even more important area to consider if 'public policy is our collective response to risk', as suggested by Peter Taylor Gooby (2000, 1). On this basis it could be suggested that the distinction between 'actual' and 'perceived' risk is misconceived, because at a fundamental level both aspects

inevitably involve human interpretation and judgment, and hence ‘subjectivity’, to a greater or lesser degree.

Blockley (1980 in Pidgeon, et al. 1992) analysing risk in the field of structural design refers to two distinct types of uncertainties: parametric uncertainties associated with ‘random behaviour’ and measurement error and systemic uncertainties due to the completeness or correctness of the model itself. Putting these terms in the language of the lay person Green, Tunstall and Fordham (1991, 228) characterise parametric uncertainties as ‘what you know you don’t know’ and systemic uncertainties as ‘what you don’t know you don’t know’. These categories of uncertainty are as relevant to risk research relating to the field of social care as they are to the world of structural design and natural disasters.

Heyman and Huckle (1993, 1558) argue that the psychological approach which requires ‘experts’ to provide ‘pragmatic prescriptions in the face of uncertainty’ based upon the ‘subjective estimate of risk and assessment of an individual’s propensity to partake in high risk behaviour’ is ‘culturally innocent’ in that it fails to take into account the influence that cultural norms may have on risk perception or that hazards may be socially constituted. Heyman (1998) challenges The Royal Society definition of risk and other ‘objectivist formulations’ on the basis that they ground risk as a property of the world rather than as a concept bound up with values and based upon knowledge. Bradbury (1989) contends that an epistemological uncertainty exists in the cognitive science approach to risk which confusingly vacillates between risk being an object reality and subjective when based upon perception and that this dualism results in much psychological and psychometric research providing ‘a subjectivist interpretation within a realist paradigm’ (1989, 384).

It could be argued that the technico-scientific concept of risk, exemplified by cognitive sciences, approaches risk from a reductionist viewpoint limiting perception to the functionality of human beings to process their understanding of the world through their senses and brain functioning. By excluding the influence of cultural conceptual categories in the mediation of judgment the

technico-scientific approach places individuals ‘outside the cultural and political frameworks, relationships and institutions within which they construct their beliefs and engage in behaviours’ (Lupton 1999, 23).

Having provided a brief outline and critique of risk theory from a technico-scientific perspective through discussion of the contribution of psychology to the development research and theory the next section of this chapter moves on to a discussion of the Socio Cultural approach to risk perception.

2.6 Socio cultural perspectives

There has been a growing recognition within the social sciences of the reductive nature of risk theories that constitute humans as rational actors acting in isolation from social and psychological influences. A continuum of theoretical approaches to theorising risk exists ranging from the technico-scientific approach based on ‘objective realism’ encompassing the cognitive sciences as detailed in the previous section of this chapter to the relativism evidenced in the work on ‘governmentality’ by Foucault and exemplified by Ewald (1991, 1999) when stating,

‘Nothing is a risk in itself; there is no risk in reality. But on the other hand, anything can be a risk; it all depends upon how one analyses the danger, considers the event’

The next section of this chapter examines the socio-constructionist theoretical approach to risk reviewing the work of key theorists in the field. There follows in Section 2.6.1 a discussion of the theoretical approach described as a ‘weak social constructionist’ position encompassing ‘Risk society’ (Beck 1992; Giddens 1990;1991;1994) with a subsequent discussion on the ideas emanating from a ‘cultural/symbolic’ perspective in Section 2.6.1 (Douglas, 1982;1985;1992). Finally in Section 2.6.3 there is an examination of the theoretical position categorised by Lupton (1999) as ‘strong social constructionist’ and as exemplified by the work of Foucault (1973;1977;1980;1988;1991) particularly his concept of ‘governmentality’.

2.6.1 ***Weak social constructionist perspective - 'Risk Society'***

A social constructionist approach to risk assumes that risks are never fully objective and that they are constituted from existing knowledges and discourse. The concept of risk is not regarded as neutral as it exists within and evolves from belief systems and moral frameworks. Therefore although the material and social world may be experienced by individuals as a pre-existing reality, it is in fact the product of a dialectic relationship in which each creates the other, 'these realities involve the reproduction of meaning and knowledges through social interaction and socialization and rely on shared definitions' (Lupton 1999, 29). Key to this approach is an understanding that late modern society is characterised by reflexivity. Unlike traditional, hierarchical societies where authority rested at the top and was relatively uncontested, in late modern societies there is a broader diffusion of knowledge and,

'Not only do we know more about the material world, we know more - and are more confident in our knowledge - about the workings of our own society'.

(Taylor-Gooby 2000, 8)

Although material levels of security in the Western world have generally increased sources of uncertainty and the mechanisms to deal with them have fundamentally changed and this has led to what some theorists call a 'risk society' or 'risk culture' (Beck 1992; Giddens 1991). Modernity in this analysis is not regarded as an unquestioned period of continual progress as it has heralded 'a period of change, dislocation and uncertainty that has undermined traditions and a sense of security' (Stalker 2003, 214). A consequence of this development is what has been described as the 'paradox of timid prosperity - growing uncertainty among rising mass affluence' (Taylor-Gooby 2000, 3). Two key academics Anthony Giddens (1990; 1991; 1994) and Ulrich Beck (1992a; 1992b) are proponents of what Lupton (1999) described as the 'weak social constructionist' position and have provided significant theoretical contributions to the understanding of risk as a modern phenomenon. A brief discussion of these contributions follows.

Giddens (1991) argues that societal preoccupation with controlling risk is a modern phenomenon replacing the previously held belief in the will of God or fate. He describes one of the key features of modernity as being,

‘An increasing interconnection between the two “extremes” of extensionality and intentionality: globalising influences on the one hand and personal dispositions on the other’ (1991, 1).

The interplay between these two phenomena and the implications for societal responses to risk form the basis of his theory on ‘risk culture’ (Giddens 1991, 3).

Giddens argues that globalising influences have undermined traditional habits and customs and individuals are required instead to place their faith in the belief that the state or at least self-professed experts will keep danger at bay. This process is based upon the expansion of ‘disembedding mechanisms’, or mechanisms that take social relations out of their specific time/space contexts and apply them in wider locales’ (Lupton 1999, 73). An example of this might be seen in bodies of expert knowledge that have ‘validity independent of the practitioners and clients who make use of them’ (Giddens 1991, 18).

In tandem with the development of globalisation there has been an erosion of social distance between experts and non-experts, as ‘trust in the former weakens and sources of knowledge become more accessible to the latter’ (Giddens 1991 in Heyman 1998, 18) leading to a ‘world of clever people’ (Giddens 1994, 7). A practical example of this phenomenon may be seen in the expansion of global internet access and the development of ‘lay’ information resources such as Wikipedia, an online encyclopaedia composed of submissions made by professionals and ‘lay’ internet users. The combination of globalisation and the development of ‘disembedding mechanisms’ such as standardised time zones and the global economy, alongside an increased awareness of the ‘contingent nature of expert knowledge’s and social activity, their susceptibility to revision and change’ (Lupton 1999, 75) has led to a sense of greater uncertainties within late modernity. Risk analysis in this context is about reducing the unknown and limiting the unexpected or as Giddens (1991) eloquently stated, it is about the ‘colonisation of the future’.

As a consequence of increased reflexivity people have become increasingly cynical about the claims of progress offered by traditional modernity. Another unsettling consequence of the 'late modern' society Giddens describes is the continuous changes in social structures such as family, welfare systems and work organisation, leading to a sense of personal insecurity and an increase in anxiety about the risks of modernisation. This anxiety is, in turn, exacerbated by the sense of the self as a reflexive project, with the consequence that individuals feel a greater sense of responsibility for their life trajectory. The self is less prescribed but is rather subject to individual manipulation, 'the self like the broader institutional contexts in which it exists, has to be reflexively made' (Giddens 1991, 3). It is important to note that Giddens does not suggest that individuals face greater levels of risk in late modern society merely that as a consequence of heightened sensitivity there is a raised awareness of risk as a phenomenon.

Ulrich Beck, author of *Risk Society: Towards a New Modernity* (1992, 55) one of the seminal texts in risk discourse suggests that 'it is not clear whether it is the risks that have intensified or our knowledge of them'. He argues that there have been three distinct periods that characterise social change; first pre-modernity, then simple modernity and finally reflexive modernity and that modernity is linked to the industrial phase of development and reflexive modernity with the risk society.

The axial principle of industrial society is the distribution of goods, while that of the risk society is the distribution of 'bads' or dangers.

(Beck 1992, 3)

Beck does not share the 'utopic evolutionism' of Marx et al but instead concerns himself with the darker side of societal development, particularly the 'constitutive role' assigned to science and knowledge. He contends that a product of modern industrial and scientific development is a set of risks and hazards not previously experienced and that these dangers are no longer limited by time or geography. Modern risks do not respect or adhere to national borders or political jurisdictions. Similarly they do not neatly follow the stratifications

of traditional societies such as class and gender and will ultimately affect those who produce or profit from them,

‘Reduced to a formula: poverty is hierarchic, smog is democratic....Risk societies are not exactly class societies’.

(Beck 1992, 32)

Another consequence of the magnitude and imperceptibility of these risks is that no one can be held accountable. Beck maintains that the risk society remains an industrial society because the creation of risks lies mainly within the domain of industry, in conjunction with science. Risks are defined as the probability of physical harm due to technological or other processes. In this formulation knowledge has a key role to play as technical experts are in a position to define agendas and impose bounding premises *a priori* on risk discourses. So although the passage from tradition to modernity was meant to result in a social world based upon rational self interest, Beck (1992, 3) contends that,

‘The post modern critique has exposed how modernity itself imposes constraints of a traditional kind - culturally imposed, not freely chosen - around the quasi-religious modern icon of science. Its cultural form is scientism, which sociologists of science argue is an intrinsic element of science as public knowledge. The culture of scientism has in effect imposed identity upon social actors by demanding their identification with particular social institutions and their ideologies, notably in the constructions of risk, but also in definitions of sanity, proper sexual behaviour, and countless other ‘rational’ frames of modern social control’.

Beck maintains that the logic of modern western society has changed from one based upon wealth distribution in a society of scarcity to risk distribution in late modernity. The sole focus of society is no longer on harnessing nature to meet direct material need as was the case within traditional societies but is now aimed at overcoming, ‘the problems resulting from techno-economic development itself. Modernisation is becoming reflexive; it is becoming its own theme’ (Beck 1992, 19). Beck suggests that in the transition from traditional to modern society there has been a significant change in the underlying basis upon which hazards are experienced. In traditional societies hazards were the result of the lack of available technology, such as sanitation. In modern western

societies hazards are the consequence of over production and will only intensify with globalisation. In this respect the concept of risk is,

‘directly bound to the concept of reflexive modernization. Risk may be defined as a systematic way of dealing with hazards and insecurities induced and introduced by modernisation itself’

(Beck 1992, 21).

Beck argues that the calculation of risk as it has been established by science and the legal establishments collapses under the globalisation of the risks associated with such industrial and scientific developments as nuclear power plants, ‘the latency phase of risk threats is coming to an end. The invisible hazards are becoming visible’ (Beck 1992, 55), one could cite the risks associated with the Chernobyl nuclear power plant disaster as a case in point.

Another key feature of Beck’s theorising on risk involves what he calls the process of individualization where individual agents become decreasingly constrained by social structures resulting in greater decision making in all aspects of life, ‘free of structures individuals reflexively construct their own biographies’ (Beck, 1992, 3). Individualization is the private side of globalisation in reflexive modernisation. It affords a proliferation of opportunities for choice over areas once assumed to be prescribed such as sexual identity, family relations and work opportunities. However as this increased choice coincides with the breakdown of traditional certainties structured through age, gender, social class and family a plethora of new risks are generated with the consequence that life becomes less certain even while it is placed under one’s control’ (Lupton 1999, 71). In the ‘risk society’, the emphasis on inequalities moves away from social processes and focuses upon individuals as agents of their own destiny. This approach has profound implications for adults with learning difficulties and the social model of disability as detailed in Chapter 3.

2.6.2 ***Cultural/symbolic perspective***

Cultural/symbolic theories of risk are less focussed upon the realist aspect of risk although not denying that ‘real risks’ exist. The main emphasis is on an examination of the processes by which some dangers are identified as risks and

others are not. One of the main proponents of the cultural/symbolic theorising on risk is Mary Douglas who approaches the subject from an anthropological tradition. For Douglas risk is a contemporary western strategy for dealing with danger and otherness (Lupton 1999, 36).

According to Douglas and Wildavsky (1982, 10) modern individuals are afraid of, 'Nothing much...except the food they eat, the water they drink, the air they breathe, the land they live on, and the energy they use'. 'Risk' as a concept has acquired a new prominence in western society, becoming a central cultural construct (Douglas, 1990). Sapolsky (1990, 90) suggests that the political system in industrialised societies is responsible for the current obsession with risk as the general public do not have information they require to make risk decisions about technology without relying upon 'expert' intermediaries whom it is considered may distort the information to suit their own agenda. Most industries devoted to the quantification of risk place great emphasis upon risk assessment, risk management and risk evaluation and risk in this context is defined as 'the probability that a potential harm or undesirable consequence will be realised' (National Research Council on Risk Perception and Communication 1989, 321). However, Douglas (1992, 24) suggests that the meaning assigned to 'risk' has changed in contemporary western society and that it can no longer be seen as a neutral term; it has become synonymous with danger, and 'high risk means a lot of danger'. The concept of risk has evolved as a result of a global cultural requirement for a 'common forensic vocabulary to hold persons accountable', and that the term 'risk' to mean danger is preferred in professional circles because 'plain danger does not have the aura of science or afford the pretension of a precise possible calculation' (Douglas 1992, 25).

Douglas (1985) reports on the difficulty in providing a standard literature review on the subject of risk perception. In her view the most interesting aspect of the social influence of risk perception is often overlooked with the emphasis being placed upon the view of risk perception as an individual rather than a social phenomenon. Heyman and Huckle (1993) support this position, arguing that the analysis of hazards from a psychological perspective, with the focus upon the subjective estimate of risk and particular individual propensities for high risk behaviour, fails to explain why certain human actions are regarded as high risk and others are not. A focus on risk perception as an individual rather than a

social phenomenon does not explain the prominence given to concerns around such issues as the number of deaths through train crashes over and above the far greater numbers killed on the roads every year. Nor does it explain why more people are concerned with becoming a victim of violence at the hands of a stranger when they are more likely to experience violence perpetrated by someone they know.

The rational view of risk perception would suggest that the level of concern about risk would be defined by the probability of an event occurring with the value of its outcome however this does not appear to be the case. Some high probability risks with a predictably negative outcome are to a greater or lesser extent socially acceptable; compare for example the societal response to cigarette smoking as to that of marijuana use. The focus on certain risks as high profile necessitates that some others are overlooked, this can either be seen to be wholly random or as a function of the organisation that is being developed.

Douglas (1985) argues that moral judgments focus upon particular risks and that these risks serve to legitimize certain moral principles. Expanding upon this argument she suggests that the sociology of perception is as much about what information is not readily available, what does not draw attention and what fails to make the headlines as it is about what does,

‘Persistent short-sightedness, selectivity and tolerated contradiction are usually not so much signs of perceptual weakness as signs of strong intention to protect certain values and their accompanying institutional forms’

(Douglas 1995, 3)

Some theorists suggest that it is fruitless to look for an objective way of defining risk as doing so ignores the values that are drawn upon to define the problem in the first instance (Fischhoff, et al. 1981). Parallels can be drawn between the position put forward by Douglas and that that expounded by Durkheim (1964) with his analysis of the social function of crime. This theoretical position suggests that perception of risk could provide a social function in securing compliance from the group membership,

‘...blaming the victim is a strategy that works in one kind of context, and blaming the outside enemy works in another. Victim blaming facilitates internal social control; outsider blaming enhances loyalty’

(Douglas 1995, 59)

The identification of external risks serves the dual function of categorising individuals or groups into ‘those at risk’ and those ‘posing a risk’. Lupton (1993) summarising Douglas suggests that in modern society risk has come to replace the old-fashioned (and in modern secular society, now largely discredited) notion of sin; as such risk is a term that,

‘runs across the gamut of social life to moralise and politicise dangers.....the neutral vocabulary of risk is all we have for making a bridge between the known facts of existence and the construction of a moral community’

(Douglas, 1995 4,5)

Scott and Williams (1992) pursue this line of reasoning further stating that by ignoring or overlooking the origins of public health risks those in positions of power and influence are able to control the health agenda; by blaming the individual, attention is diverted from criticism of the whole system. By stating that, ‘consequently, some recognised risks are written into the constitution along with common goals.....Since a focus on one kind of danger directs attention away from others, it follows that perceptual monitoring will not be random, but will be a function of the kind of organisation that is being achieved’ Douglas (1985, 55) clearly places the context for the analysis of risk perception in the wider social arena.

If danger, now labelled as risk, is used to protect individuals against the activities of others, this process can be viewed as part of a system of thought that upholds a type of individualist culture that is present in a post modern industrial society. The valued institution that requires protection in this formation is the liberty of the individual. Within this theoretical framework the discourse of sin/taboo could be seen to conserve solidarity whereas risk discourse aims to disperse it (Douglas 1992). There are serious implications for marginalised societal groups, including people with learning difficulties, within

this analysis of risk. Douglas (1992) argues that each type of culture discriminates; hierarchies do it overtly by labelling different groups, individualistic cultures do it by ignoring the powerless. Douglas concludes that it is inherently difficult for the views of 'minority groups' to influence the agenda in a society organised on the basis of competitive individualism, suggesting that,

'it must be harder to become a vote to be reckoned with in a system that withholds overt recognition to minority segments....an individualist society finds ways of making its disadvantaged members disappear from sight'

(Douglas 1992, 35, 36).

How much more difficult if one does not even have a vote as is the case with significant numbers of adults with learning difficulties.

The rather passive view of the individual portrayed by Douglas is challenged by Frankenberg (1992) who argues that 'the body is not just a flat pool, onto which the norms of society are reflected,' it can also be a sight of resistance and creativity in which new perspectives can be generated. It could also be argued that social life is not merely the acceptance without challenge of cultural norms, that individuals deconstruct these norms and reform them and that the body makes and is made by a deconstructed world. Fried (1970 in Douglas, 1985) developed a moral theory of risk based upon the notion that society operates a 'common risk pool' and every member of society has a personal risk budget. He suggested that societies operate a system of mutual accountability based upon a balance of whether any individual is withdrawing from the risk pool more than they are contributing, i.e. whether they are exposing others to more risk than they themselves are being exposed. By introducing social probabilities to the discussion of risk aversion it broadens the debate from questions about acceptable levels of risk to include questions about what kind of society is desirable. What this theory fails to address is whether each person starts from a position of equality. Do some people, such as those with a label of learning difficulty, experience a lower starting balance due to societal expectations, than others?

Exploring the link between risk and blame Douglas (1992, 61) suggests that organisational cultural has a key role to play, stating that,

‘...protecting from criticism and victim-blaming, when they go with a strong communal organisation, lead to less risk aversion. A community can take a bold public policy decision in favour of risk seeking if it is strong enough to protect the decision maker from blame’.

The example given to illustrate the point is a comparison between the medical profession in the United States of America and Britain. In the USA greater individual liability and professional accountability exists which, it is contested, leads to greater risk aversion. In Britain where there is greater protection from blame through strong communal organisation such as the British Medical Association, there is less individual liability and it is proposed greater scope to take risks (Douglas 1992).

Within cultures based upon individualism an ideological transformation has taken place that has resulted in a shift from a position where individuals expected their health to be protected by the state to a position where it is the responsibility of individuals to protect themselves from risk (Green in Scott et al 1992). An inherent danger is that the review of systemic risk issues can be avoided by blaming the victim, ‘for blaming the victim is effective for silencing indictments of the whole social system. Blaming the victim is a hand washing ploy good for all sorts of occasions (Douglas 1985, 56).

2.6.3 ***Strong social constructionist perspective – ‘Governmentality’***

Unlike weak social constructionist theories that regard risks as cultural mediations of ‘real’ hazards and dangers strong social constructionist theorists view hazards or dangers as socially constructed, coming into existence when human actors recognise and label them as such. Analysis of risk in the social sciences has been considerably illuminated by the work of Foucault (1926 - 1984). Central to Foucauldian theorising is ‘the way that discourse, strategies, practices and institutions around ‘risk’ serve to bring it into being, to construct it’ (Lupton 1999, 85). Another key aspect is an understanding of the government

of populations or as he labels it 'governmentality', or the 'apparatuses of security' (Foucault 1979). 'Governmentality', involves processes by which particular populations are first defined and then subjected to definite political strategies (Kendall and Wickham 1992, 8).

For Foucault there is no single or simple embodiment of power, neither in the 'state', nor even in the more widely recognised apparatus of government. He argues that the prime motive of security is achieved through the regulation of behaviour. Some strategies for the regulation of behaviour are aimed at improving the medical health of the population, others at making the population more economically healthy (Millar and Rose 1990; Rose 1990), more mentally healthy (Millar and Rose 1986), or more educationally healthy (Hunter 1989). Foucault argues that in order to regulate behaviour a distinction needs to be drawn between 'normal' and abnormal' behaviour; a distinction that can only be made by those members of society with 'specialist knowledge'. In this way power is invested in bodies of expertise, including: professions and institutions such as medicine, psychiatry and education; employers; and even more diffusely, the family.

Through historical analysis, Foucault asserts that the concept of normality is socially constructed and that the distinction between normal and abnormal behaviour reflects the concerns and motives of society at any point in time,

'It's the body of society that becomes the new principle in the nineteenth century. It is this social body that needs to be protected, in a quasi-medical sense. In place of the rituals that that served to restore the corporal integrity of the monarch, remedies and therapeutic devices are employed such as the segregation of the sick, the monitoring of contagions, the exclusion of delinquents'

(Foucault 1980, 55).

Foucault further argues that it is the task of professionals to establish and promote the dominant ideas (or discourse) of the time, from which those definitions of normality can be derived and applied. For example Foucault suggests that by the 19th century problems of health were being defined 'through the relation to two sorts of dangerous phenomena: the dangerous classes and the dangerous individual' (Kendall and Wikham 1992, 11). By

adopting this historical perspective, Foucault demonstrates how the definitions of 'madness', 'illness' and 'criminality' for example have changed, and can be expected to change, over time.

Whilst Foucault's analysis applies to a broad range of institutions, two are of particular importance to this research. Challenging the focus of current psychiatric discourse on 'lack of reason', Foucault, in 'Madness and Civilisation' (1961), argues that the process of 'psychiatric treatment' can instead be seen as the oppression of those who would pose a threat, not only to other individuals, but to society as a whole by challenging its fundamental values. The figure of the 'dangerous individual' was according to Foucault, constituted at the intersection of law and psychiatry (Foucault 1988). This marked a significant development in the risk debate in that 'dangerousness' was seen as inherent to the character of the criminal themselves rather than the crime they committed, 'the correlate of the dangerous individual, the 'at risk' individual, is apparent' (Kendall and Wickham, 1992, 12). Castel (1991) developed the Foucauldian distinction between risks and 'dangerousness' to examine historical shifts in the surveillance of those experiencing mental health difficulties by psychiatrists and social workers. If dangerousness is the property of the person and can only be identified through symptoms indicating dangerousness, the challenge becomes how do to draw up preventative strategies? This paradox led to changes in practice: a move from strategies designed to prevent dangers associated with persons to strategies designed to reduce risk in entire populations on the basis of epidemiological data (Heyman and Huckle 1993, 1559).

Secondly in 'Discipline and Punish' Foucault (1977) turns his attention to the displays of power in the prison system. Foucault delineates the temporal and spatial control and restriction that is exercised over individuals who do not conform to society's expectation of normal social behaviour and who are therefore considered to represent a threat to current dominant ideology. The same strategies were applied to people with learning difficulties, where historically risk management can be traced back to the Middle Ages where people with learning difficulties (and mental health issues) were managed by being driven from the towns and cities or cast adrift on 'ships of fools', (Foucault 1973). Following this, the principal methods of management were

confinement and incarceration in private jails and madhouses. In the Victorian era incarceration remained the primary method of risk management with the important distinction that this occurred through the geographical separation of the asylums from the main body of the community. This allowed the development of psychiatric treatment as a form of risk management to go virtually unchecked for around 100 years. The focus of late 20th century service provision was on integration. However it was not until the 1970's that any real momentum for a process of deinstitutionalisation was generated (see Chapter 3 for more details of the historical development of learning disability services).

The normalising processes of late modern society mean that 'discourses on risk are directed at the regulation of the body and how it interacts with other bodies and things' (Lupton 1999, 88) These discourses are informed by increasing amounts of aggregate data on populations with a consequence that,

'As expert knowledge about risk has proliferated in late modernity, the various strategies which individuals are required to practice upon themselves to avoid risk have proliferated'

(Lupton 1999, 88)

The development of the 'technologies of the self' (Foucault 1988) in late modern society means that not engaging in risk avoiding behaviour is considered a 'failure of the self to take care of itself - a form of irrationality, or simply a lack of skilfulness' (Greco 1993). Risk avoiding can be seen to have become a moral endeavour based upon 'self -control, self knowledge and self improvement' (Lupton 1999, 91) a prerequisite of this form of self government involves the internalisation and acceptance of the norms of society. This aspect of risk theory is particularly relevant to the research detailed in this thesis exploring as it does the perceptions of risk of adults with learning difficulties who have been assigned reputations for challenging services.

2.7 Conclusion

As detailed in this chapter risk theorising ranges from the realist positions of the technico scientific traditions with the focus on quantifying 'objective' discernable risks; through the weak social constructionist positions of Beck and

Giddens and the cultural symbolic expositions of Douglas to the strongly social constructionist formulations of Foucauldian analysis. I started this research journey unconsciously wedded to the realist position strongly influenced by the psychological tradition. The process of undertaking the literature review afforded the opportunity to consider a wider range of perspectives and informed a key 'lighthouse moment' within this research process. Contemplating the range of theories available challenged the 'natural' notion of risk inherent within my original research proposal. It also called in to question the absence of the voices and perspectives of adults with learning difficulties within the risk literature available and more specifically in terms of my own research endeavour as detailed within the original research design. As a consequence of the literature review on risk the research design evolved to incorporate the views of adults with learning difficulties who had been assigned reputations for challenging services. This marked the first steps towards the development of an emergent and evolutionary research methodology.

Chapter 3: Learning disability- history and theory.

3.1 Introduction

As detailed in the previous chapter, a process of reflection during the review of the literature relating to theories of risk led to a realisation of the predominance of the technico-scientific perspective within the field of social risk research. Importantly it also highlighted implicit assumptions within my own original research design based upon the ‘natural’ conceptualisation of risk. Allied to this new understanding was the recognition of the relative absence of the voices of adults with learning difficulties within risk literature,

‘A glaring omission from much of the research to date are the voices of people using services, those who are perceived by professionals as being at risk, or as posing a risk to others. The inclusion of their perspectives must be a priority for future work’

(Stalker 2003, 229).

The culmination of this aspect of the research process led to a revision of the original research design. A similar reflective process took place as a consequence of undertaking a review of the literature relating to the historical development of learning disability services and disability theory, the outcome of which is detailed in the conclusion of this chapter in Section 3.7.

Chapter 3 explores learning disability as a historical and theoretical concept. Policies and theoretical discussions drawn from wider cultural and academic sources informed this research endeavour. However the primary focus for this chapter was historical developments and theoretical expositions relating to the concept of learning disability in western developed societies and more specifically in the British context.

3.2 Overview

The time frame for the research detailed in this thesis coincided with the final years of the learning disability long stay institution closure programme in Scotland detailed in the White paper, ‘The Same as You?’ (Scottish Executive,

2000). The original research question was designed to consider the perceptions of risk of a range of professionals involved in the hospital closure programmes. The research subsequently developed into an investigation of the perceptions of risk of adults with learning difficulties who had been assigned labels for challenging services. Details of the original research question and the evolving process of research redesign are discussed in more detail in Chapter 5.

The closure of long stay hospitals for adults with learning difficulties could be regarded as the most influential policy decision within learning disability services in late 20th Century Britain. This policy set the scene for further policies to advance the role of people with learning difficulties as full and active citizens within our communities (Department of Health, 1998; Department of Health, 2001; Department of Health, 2006; Department of Health, 2007). The driver for much of the policy development of the early 21st century has been for greater control and participation by people with disabilities, based upon the recognition that people with learning difficulties are,

‘...among some of the most the most socially excluded and vulnerable groups in Britain today. Very few have jobs, live in their own homes or have real choice over who cares for them. Many have few friends outside their families than those paid to care for them. Their voices are rarely heard in public. This needs to change.’

(Department of Health, 2001, 14)

In order to understand the magnitude of recent policy initiatives it is important to view them within a historical context, this is outlined in Section 3.3. It is important to recognise that until very recently little effort was made to document the views of people with learning difficulties or their families and carers or use these to inform policy and practice development (Twigg, 1994, 4). This situation was compounded for adults with learning difficulties who have been assigned a reputation for challenging services.

During the process of detailing the chronological development of learning disability policies and practice two minor detours are taken in order to provide a fuller explanatory context for this research. The first detour in Section 3.3.1 involves an explanation and discussion of the principles of normalisation, a key concept that had a significant impact upon the development of learning

disability policy and practice in Britain in the late 20th and early 21st Century. The second detour off the chronological path in Section 3.3.2 involves an exploration of the concept of challenging behaviour.

Learning disability was overlooked or excluded from much early disability theorising and as a consequence learning disability theory, policy and practice developed a different trajectory to that of physical disability. Section 3.4 introduces the concept of disability. Before embarking upon an exposition of contemporary disability theory, Section 3.4.1. outlines a brief overview of Luke's (1974) theory of power and introduces a discussion about the significance of language. Section 3.5 introduces the theoretical stance characterised by the medical model of disability followed in Section 3.6 by an exploration of the social model of disability and the applicability and utility of these models in relation to people with learning difficulties. Feminist perspectives on disability are considered and used to provide a critique of both approaches and to posit alternative ways of exploring the issue of disability as a lived experience. These considerations are further developed to inform discussion of the implications for disability research; reviewing a variety of approaches from medical sociology, emancipatory research, participatory research and research informed by a feminist perspective. The chapter concludes in Section 3.7 with reflections on practice outlining the evolution of the research design and research process as a result of the new perspectives developed from the information obtained through the process of undertaking the literature review process. Through a constant process of self reflection the researcher and research changed; solid became fluid, the fixed moved and the certain become questioning. Again this promoted a further 'lighthouse' moment that called into question some of the foundations on which the original research was based and signposted a new direction for the research journey.

3.3 Learning Disability: Historical Development

A brief reference to the Foucauldian analysis of origins of the development of mental health (including learning disability) services pre 20th century was provided in the context of the analysis of risk in Section 2.6.3. The following section of this chapter considers the development of learning disability policy

and practice in the 20th and 21st century. The limits of this thesis do not allow detailed exposition of all the policy decisions that have affected adults with learning difficulties during this period. Legislation that incorporated or was influenced by a particular risk perspective or that had a significant impact upon service development and or the lived experience of adults with learning difficulties has been detailed.

Chronological development in this area can be categorised as segregation 1896-1930; experts 1930-1980's; normalisation 1970-1990's; self-advocacy 1990's to the present (Atkinson, Jackson, & Walmsley, 1997, 3). Prior to the turn of the 19th century services for people with learning difficulties in Europe and North America were not, in most cases, differentiated from other people in need,

‘the number of people catered for by special schools and establishments of the time was, on the whole, very small....the vast majority of people with disabilities were still being catered for in almshouses, asylums, poorhouses, or simply not being catered for at all’

(Murray 1988, 96).

Those services that were available frequently had their basis in philanthropy, the aim being to ‘rescue’ both adults and children from destitution and abuse (Oswin, 1998). During the last quarter of the 19th century political systems were influenced by the combined forces of ‘industrialisation, imperialism, capitalism and nationalism’ (Jacobson, 1999, 333).

The implications of Charles Darwin’s theory of evolution through natural selection began to interest theorists and politicians, particularly the potential to apply it to national populations and social groups. The term eugenics was first coined by Francis Galton in 1883 and was defined as being the, “science of improving inborn human qualities through selective breeding” (Galton, 1883). Galton, unlike Darwin, did not believe that nature could be relied upon, through natural selection and survival of the fittest, to improve the characteristics of the human population. He determined that this could only be achieved by artificial means. In Britain this was to be achieved by institutionalising those it was felt would not enhance the nation’s genetic status, were they to procreate. In this climate people with disabilities were seen as both an individual and a collective

risk to society, ‘...the attention of the public is constantly aroused to the necessity for the segregation and permanent sequestration of these unfortunates...’ (Barr, 1904/1973 in Jacobson 1999, 333).

The eugenics movement had a profound effect upon the development of social policy in the first half of the 19th century resulting in the rapid growth of institutions to segregate sections of the population. In Britain in 1886, the first legal distinction was established between psychosis and ‘retardation’. The Mental Deficiency Act 1913 recognised people with learning disabilities in law for the first time and emphasised the need for institutional provision (Brigden and Todd 1993). The period between the 1920/1930’s saw a rise in ‘deficiency colonies’ to house those now recognised in law (Alaszewski 1983, 228). During this time the statutory providers of such institutions were local authorities however in 1948 with the creation of the National Health Service, long stay institutions were transferred to new hospital authorities,

‘after 100 years in which education, philanthropists, doctors and social workers had all tried to deal with the problem, the care of mentally handicapped people in residential accommodation was handed over to the health professions’

(The Jay Report 1979, 14)

There was little rationale for the transfer of the management of learning disability services to the medical professions other than the fact that they constituted a very small part of the overall mental health service, ‘the overriding factor in placing mental handicap within the health service was, in all probability, time’ (The Jay Report 1979, 14). So despite the fact that most ‘mental deficiency’ institutions at the time had essentially no health related purpose or nature ‘colonies became hospitals overnight’ (Collins, 1992, 7).

The move towards deinstitutionalisation had its origins in the 1950’s. The publication of a pamphlet by the National Council for Civil Liberties, 50,000 Outside the Law (National Council for Civil Liberties, 1951), drew attention to the shortcomings of mental handicap hospitals including ‘exploitation of patients, lack of legal rights for patients, and general inadequacies of care’ (Alaszewski, 1983, 228). This was followed shortly after by the 1954-57 Royal Commission (Royal Commission, 1957) which recommended major changes in the

care of the learning disabled including breaking down segregation and moves towards more care based in the community. Acting on these recommendations the 1959 Mental Health Act conferred 'informal' status on the majority of individuals living in long stay institutions. In reality this meant that most people were no longer certified or subject to detention in an institution, in practice little was done to offer suitable alternative accommodation and support in the community and as a result very little changed for the vast majority of people residing in long stay institutions.

Despite a number of high profile scandals such as Ely Hospital, 1969 and Normansfield Hospital, 1978, drawing attention to the poor quality services and levels of abuse occurring in long stay learning disability institutions, very slow progress was made developing community alternatives (Collins, 1992). It was not until the late 1960's and early 1970's that the call for complete closure of long stay institutions was voiced (Campaign for the Mentally Handicapped, 1972). In response to this mounting pressure the 1971 white paper, *Better Services for the Mentally Handicapped* (DHSS and Welsh Office, 1971) was produced. It recognised that there had been little or no progress towards community care and advocated a 50% reduction in long stay hospital places by 1991 (Brigden and Todd, 1993). The report proposed a significant shift away from the dominance of the medical profession in the management of learning disability services. The Department of Health subsequently established the Jay Committee to review Mental Handicap and Nursing, which produced the influential the Jay Report (1979). In addition to re-emphasising the need for local authorities to take the lead with the provision of care for people with learning difficulties the report also proposed that future developments should follow a service philosophy based on the principles of normalisation. The proposals outlined in the Jay Report laid the foundations for the development of policy and practice in learning disability services for the next thirty years. Normalisation and the variations that developed from this concept could be argued to have exerted the greatest influence over the development of community services for people with learning difficulties in this time period. The influence of normalisation in the field of learning disability is such that it warrants a minor detour from detailing the chronology of policies to discuss its origins and principles.

3.3.1 **Normalisation**

The principles of normalisation originated in Denmark in 1969, with a statement in Danish law detailing that the integration of disabled people in the community was to be the direction for services. The normalisation principle, as a concept, was initially developed and articulated by Bengt Nirje (1969) and focussed upon,

‘..making available to all mentally retarded people patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society’

(Nirje 1976, 231).

Normalisation in this original incarnation was formulated upon an ethical value theory approach (Nirje 1985, 65) that recognised that laws based upon the concept of rights alone were not enough to manifest positive change in the lived experience of disabled people.

‘Human rights consequently involve more than what is actually covered by legislation. Laws can regulate certain conditions for disabled people but they cannot completely affect the conditions of their existence and their opportunity for personal development - the realisation of human rights needs to come in to existence in the full cultural and human context’

(Nirje 1985, 65).

The initial aim of the concept of normalisation was to articulate an understanding of the lived experience of people with learning difficulties, and further, to ‘find a language for questions and answers regarding these condition, a language that was coherent, logical and meaningful’ (Nirje 1985, 65). Nirje (1976) detailed three inter related components to disability; the ‘mental retardation of the individual’ in respect of their cognitive handicap; the imposed or acquired retardation’ relating to ‘under functioning’ due to limitations created by society and ‘awareness of being handicapped’ relating to the personal implications for self worth as a consequence of the stigma attached to disability (Toogood 1993, 68). Implicit within Nirje’s articulation of normalisation was the principle that people with learning difficulties are ‘entitled to the same right and opportunities as are available to others in their

society, including opportunities to exercise personal preferences and freedom of choice' (Perrin and Nirje 1985, 69). Nirje did not regard these opportunities to be conditional, instead his formulation was based upon a 'recognition of a person's integrity', detailed as the scope 'to be able and be allowed to be yourself among others' (Nirje 1985, 67). Although Nirje (1985 66) quotes Ruth Benedict (*Patterns of Culture* 1934, 253), 'No individual can arrive even at the threshold of his potentialities without a culture in which he participates', he also proposed that normalisation was culturally neutral stating, 'Normalisation... deals with conditions of life; administrative organisation is secondary' (Perrin and Nirje 1985, 70). This aspect of Nirje's formulation of normalisation as a social science theory of disability forms one of the main areas of contention for social model theorists. A critique of the influence of normalisation on the social model of disability is detailed later in this chapter in Section 3.6.

In Britain the most influential interpretation of normalisation principle was that expounded by Wolfensberger (1972; 1980). The approaches adopted by Nirje and Wolfensberger differed in some fundamental aspects. Wolfensberger (1993) undertook a series of reformulations of the core principles expounded by Nirje resulting in the development of the term 'social role valorisation' which focused the definition of normalisation explicitly in terms of the creation and maintenance of valued roles for people with learning difficulties.

'Normalisation implies, as much as possible, the use of culturally valued means in order to enable and/or maintain valued social roles for people'

(Wolfensberger and Tullman 1989, in Walmsley 2001, 190).

This interpretation defines normalisation in terms of an end state as well as a means, placing much greater emphasis on the process of normalising disabled people as well as their environment. Wolfensberger's (1972, 1980a) analytical framework distinguishes two main aims of normalisation which are the enhancement of social image and enhancement of personal competencies of devalued persons (Anstey and Gaskin, 1985). This derivation of the concept of normalisation places a greater emphasis upon conformity and articulates a set of standards to which the disabled persons must adhere, explicitly stating that 'normalising measures can be offered in some circumstances, and imposed in

others' (Wolfensberger 1982, 28 in Perrin and Nirje 1985, 71). It has been argued that Wolfensberger devalues difference by imposing conformity as the condition for acceptance in society. Some theorists have likened his approach to Goffman's (1963) definition of 'passing', referring to the 'ability of members of 'deviant' groups to minimise their differences or signs of deviancy so that they could 'pass' undetected into society' (Perrin and Nirje 1985, 72).

By focusing on conformity to externally constructed values it is argued that Wolfensberger diminished the role of personal autonomy and as a consequence different standards were set for disabled people with greater store being set on appearances rather than reality (Toogood, 1993). Some theorists, including Perrin and Nirje (1982; 1985; 1990) argue that Wolfensberger applied a reductionist approach to the theory of normalisation and in doing so deviated from the original concept. Wolfensberger's version of normalisation,

'with its focus on using normative means and on establishing normative behaviour, is built upon a fundamentally different value base and conception of people, with quite different implications for how we view and treat handicapped people'.

Perrin and Nirje (1985, 71), eloquently argue that,

'Normalisation as originally defined is based upon a humanistic, egalitarian value base, emphasising freedom of choice and the right to self determination. It emphasises clearly respect for the individuals and his or her right to be different'.

Nirje's conceptual analysis locates normalisation within the formulation of society. It could be argued that the interpretation of normalisation espoused by Wolfensberger was easier to align to the predominant medical model approach to disability that dominated policy and practice in the late 20th Century, both locating the need for treatment or change within the individual.

It is clear however that it was Wolfensberger's conceptual interpretation of normalisation that predominated in the U.K. and alongside John O'Brien's 'Framework for Accomplishment' (O'Brien and Lyle, 1987) detailing five accomplishments of community presence, community participation, choice, competence and respect, formed the backdrop to social policy formulation during the 1980's and 1990's.

Throughout the 80's legislation was passed and reports published that increasingly supported the ideas of social inclusion and participation (1981 Education Act; 1986 Disabled Persons Act (DHSS 1986b.); Griffiths Report (1988) and the 1989 White Paper, 'Caring for People' culminating in the NHS and Community Care Act 1990 (Rose, 1993). The principles of normalisation significantly influenced the development of policies and its stamp can be seen on strategies as far ranging as deinstitutionalisation, the introduction of community care, integrated rather than segregated services (schools, health services and leisure facilities) and developments in Supported Living (Walmsley, 2001, 191). Relatively recent policy documents such as the White Paper, Valuing People (Department of Health, 2002) although not overtly citing the links to normalisation or social role valorisation bear the hallmarks of the influence of these principles.

The normalisation principle, based upon the Wolfensberger interpretation of the concept, also remains the underlying ethos of the learning difficulty self advocacy movement, with a focus upon the influence of negative labels and service issues rather than consideration of the disabling implications of social and economic structures (Walmsley 1997). It is worth noting that the ideas and theories of normalisation were primarily developed by non-disabled professionals and academics without the participation of people with learning difficulties, in contrast to the civil rights movements of black people and disabled people (Campbell and Oliver 1996). This subject will be revisited later in this chapter in Section 3.6, when considering a critique of the relevance of the concept of normalisation to the development of the social model of disability. The next section returns to the chronological development of policy and practice at the point at which we left off to embark on the brief detour charting the development of normalisation as a concept.

It is important to recognise in policy terms the differences that exist in application and direction between the individual countries that constitute the United Kingdom, for example there was no equivalent in Scotland of the English direction (DHSS, 1983) determining that learning disabled children should not reside in hospitals (Stalker and Hunter, 1999). Between 1980 and the late 1990's the capacity of 'mentally handicapped' hospitals in the U.K. reduced significantly although this pattern was not evenly distributed across the U.K.

Hospital closure happened more rapidly in England and Wales than in Scotland despite, or possibly due to, the fact that the latter had historically confined a greater proportion of the population to long stay institutions. Many reasons have been suggested for this delay including the initial absence of a national closure programme; funding disputes including resource transfer; poor inter-agency collaboration; opposition from parent and professional groups; and the debate over the future service configuration for those people with learning disabilities and additional complex needs such as challenging behaviour (Stalker and Hunter, 1999).

In 2000, the first Scottish Government White Paper on learning disabilities 'The Same as You?' (Scottish Executive, 2000) was published. This provided a comprehensive review of services for people with learning disabilities in Scotland and included a series of recommendations for future developments. Significantly 'The Same as You?' outlined plans for the closure of Scotland's remaining long stay institutions by 2005. This year also saw the passing of the Adults with Incapacity (Scotland) Act 2000, the first major law reform of the Scottish Parliament. This legislation was not to apply specifically to adults with learning difficulties but to those in society deemed to require safeguards to manage their property, financial affairs and welfare due to their lack of capacity to make such decisions themselves.

Despite UK wide developments there were still 750 places left in long stay institutions in England in 2004 (Ladyman, 2003) with thousands of adults with learning difficulties living in 'campus developments' and private institutions (Department of Health, 2004). The implications of this situation for people who had been assigned reputations for challenging services was significant as research indicates that people with higher support needs, including those labelled as having reputations for challenging services experience poorer outcomes from services generally (Emerson, 2001). In relation to deinstitutionalisation people with higher support needs are reported to be the last get to get out of institutions (Wing, 1989) and if their services experience difficulties supporting them they are the individuals most likely to be returned to institutional care (Intagliata and Willer, 1982).

The idea that services should be designed around the individual is now central to government policy as evidenced by the 2006 White Paper 'Our health, our care, our say', (Department of Health, 2006). There is also a growing recognition that the voices of people with learning difficulties should be listened to not just as 'service users' but also as active citizens with contributions to make to their families, communities and the services that they receive and that people with learning difficulties can inform the kind of service they receive 'if we are prepared to get to know them, to understand them and to respond to them' (Department of Health 1998, 3). The key themes underpinning these developments are human rights and notions of citizenship.

The emergence of the personalisation agenda (Scottish Executive 2000) and self directed support (Duffy, 2003) has grown alongside the development of dissatisfaction with many of the traditional group service arrangements commissioned as part of the long stay hospital closure programmes and with the second generation services that replaced them. In the early days of resettlement the services commissioned were often large residential units, these were then superseded by group home provision, 3-8 people living together with support from staff; this remains the dominant form of community provision currently available (Mansell, 2006). In recent years there has been an increase in the development of 'supported living' for adults with learning difficulties. Supported living originates in North America where it has been described as,

'a community housing option that: (a) is chosen by the individual with a disability and shared with others at the person's discretion; and (b) is not owned by the agency or service provider. Supported living also ensures that people are members of their community, that an individualized support plan is created with each person, and that this plan is flexible enough to change with his or her changing needs and abilities'

(Klein, 1994, 3).

Core components of this approach are that an individual chooses with whom they live, in houses that they rent or own and receive support from provider organisations unconnected with their housing arrangements. The latter principle being particularly important in order that that people can change the support they receive without moving home (Kinsella, 1993).

Underpinning this policy direction is a focus upon Person Centred Planning as a means to deliver personalised services that meet the needs of the individual. The purpose of person centred planning is to refocus the actions of services onto meeting the needs of the individual rather than attempting to meet the individual's needs through provision of existing services, in this respect,

‘Person centred planning challenges the thinking and practices of professionals (products of often stagnant training regimes reformulated, but inherited from, medical and institutional ways of doing things)’

(Osgood 2003, 12).

Questions have been asked about whether Government guidance on the implementation of person centred planning (Department of Health, 2002) is based upon ‘research outcomes or anecdotes’ and if the latter whether anecdotes provide a sound enough rationale for national policy. As would be expected with such a powerfully endorsed policy directive a body of research is beginning to emerge analysing the effectiveness and the impact that person centred planning is having upon the lives of adults with learning difficulties (Felce 2003; O'Brien 2004; Mansell and Beadle-Brown 2004a; Emerson and Stancliffe 2004; Towell and Sanderson 2004; Mansell and Beadle-Brown 2004b; Dowling, Manthorpe and Cowley 2007; Robertson, et al. 2007; Duffy and Smith 2008). It has been argued that person centred planning attempts to bridge the gap between strategic and personalised services ‘moving between the worlds of numbers and faces’ (O'Brien, 2002) however Osgood (2003, 4) cautions that,

‘If services focus on changing language without changing actions, relationships, finances, functions and structures, person centred planning may go the way of other innovations: lost in the more of organisational cognitive dissonance, a battleground of professional interests’.

As Lovett (1996, xiii) stated, ‘new names and phrases always run the risk of becoming spiffy euphemisms for ‘business as usual’’. The pace of change in learning disability policy and practice has been rapid over the past half century and more particularly over the last thirty years. The almost complete closure of long stay institutions has improved the lives of many people with learning difficulties however these benefits have not been experienced universally,

‘thus despite the progress that has been made for people with learning disabilities in general, there has been a failure to deliver the benefits of previous policy to people who present challenges to services’

(Department of Health 2007, 5)

Legislation associated with personalisation proposed a shift in the balance of care to enable more people to live in the community, making individual choices and taking more control of their lives. This policy objective has run parallel with the development of legislation aimed at protecting adults perceived to be vulnerable. The latest such act in Scotland was the Adult Support and Protection (Scotland) Act 2007, was implemented to assist with the identification of ‘adults at risk’, to provide them with support when they need it and provide the means to protect them from harm. This legislation was developed to augment the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) (Scotland) Act 2003. The Adult Support and Protection (Scotland) Act 2007, as legislation to better protect adults of risk of harm, became law on October 29, 2008.

Given the scope of the remit of this legislation it is conceivable that it will be utilised by professionals when adults with learning difficulties are perceived to be at risk of harm as a consequence of the challenges services experience supporting them. The key principles underlying the implementation of the legislation are that regard be given to ‘the adults ascertainable wishes and feelings (past and present)’ (Adult Support and Protection (Scotland) Act 2007). The act also stresses the importance of ‘the adult participating as fully as possible in the performance of the function’ and ‘providing the adult with such information and support as is necessary for the adult to so participate’ (Adult Support and Protection (Scotland) Act 2007). This may present some services with a considerable challenge in terms of their current processes for engaging with adults with learning difficulties who are perceived to challenge services.

The next section of this chapter discussed the concept of challenging behaviour and the implications for those who are assigned the label.

3.3.2 *Challenging Behaviour*

One of the most significant hurdles faced by Health and Social Work Services during the process of closing long stay learning disability hospitals was commissioning appropriate services for those who were perceived to challenge the services that supported them,

‘The small number of people who, in addition to severe or profound learning disability, show really serious problem behaviour present a major challenge to the replacement of large hospitals with other types of service. It is these people who are most difficult to place and who are most likely to be returned to institutions where they are likely to remain unpopular patients who are avoided by staff’.

(Mansell & Beasley 1993, 329)

The majority of long stay institutions for people with learning difficulties in Britain have closed since the report detailed above was published, however it is clear that the challenge of supporting people who require specific needs to be met has not been resolved. In October 2007, Ivan Lewis, the Parliamentary Under Secretary of State for Care Services, in the foreword to a Department of Health report (Department of Health, 2007, p. (iii)) wrote,

‘Valuing people clearly states that good quality services will ensure that people with additional and complex needs are appropriately cared for so that their needs are well managed and they lead fulfilling lives. It acknowledged that commissioning and providing services for people who present significant challenges is one of the major issues facing learning disability services’.

People with learning difficulties who have been assigned a reputation for challenging services cannot be regarded as a single homogenous entity; individuals who have been assigned this label have a wide range of needs and challenge services in many different ways including: self injury, self stimulation, physical and verbal aggression, sexually inappropriate behaviour, and property destruction (Doyle, 2004). The disparate group that display these behaviours includes people with sensory or physical impairments, mental health needs, communication needs and people who have been diagnosed as being on the autistic spectrum. There appears to be a consensus that unless services respond

well to the needs of this relatively small group of people ‘they occupy disproportionate amounts of time and money’ (Department of Health 2007, 20). ‘Challenging behaviour’ is a term used almost exclusively in learning disability services a fact that itself, raises some interesting questions about the perceived need for a ‘special’, separate and distinct vocabulary applicable to only one labelled section of our community; this issue is discussed later in this chapter in Section 3.4.1, Theory: Power. The concept of challenging behaviour is a social construct and may be seen to constitute both aspects personal to the individual and the physical and social environment in which they exist. Qureshi (1993) suggests the consideration of three different definitions of challenging behaviour;

‘First there is the abstract or conceptual definition of challenging behaviour, which reflects the fact that it is ultimately socially defined; second, there are a range of everyday or ‘rule of thumb’ definitions which are used by people on a day-to-day basis for a range of purposes; finally, there are operational definitions, which are specific attempts to construct methods of identifying and measuring challenging behaviour which can be used to provide quantitative information for use in research, evaluations and service planning’

(Qureshi 1993,11)

The fact that there is no unified position on the definition of ‘challenging behaviour’ has resulted in a wide range of meanings and applications adopted in practice (Naylor and Clifton, 1993). The term was first used in Britain by the Special Development Team at the University of Kent to describe a group of people with a disparate range of behaviours. The use of the term became widespread after an adaptation of a definition proposed by Emerson et al., (1987) was used in the influential 1987 report ‘Facing the Challenge’ (Blunden and Allen 1987, 15). In the report challenging behaviour was described as,

‘....behaviour of such an intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy or behaviour which is likely to seriously limit or delay (deny) access to, and use of, ordinary community facilities’.

The strength of this definition is in its perceived neutrality and the focus it gives to the relationship between behaviour and the environment (Fleming and Stenfert Kroese 1993). In a significant departure from the traditional medical

approach, behaviours are not considered challenging because of the potential harmful/challenging consequences for other people; rather, the focus is upon the challenge experienced by services in providing the individual with an appropriate quality of life. Behaviours are regarded as adaptive responses to other factors.

Unfortunately despite efforts implicit within this definition to avoid pathologising behaviours the failure to reference community or organisational competence and capacity has led to a drift towards the responsibility once again being located within the individual with learning difficulties (Department of Health 2007). This factor is particularly significant as 'challenging behaviour' is the most commonly cited reason for the breakdown of community living arrangements (Intagliata and Willer 1982; Beadle-Brown November 2006; Department of Health 2007). Responding to this drift in interpretation a strong argument has been proposed that challenging behaviour should be linked more firmly to service competencies than to the actions and behaviours of an individual (Toogood 1993). The impact of this shift in the definition would be to place the responsibility for development and change on those individuals and organisations paid to provide services and support rather than those who are in the position of receiving of it. Reinforcing this argument Allen (1999) proposes that a focus on individual pathologies may be less useful than examining the impact of service competence on behaviour and on the effectiveness of clinical interventions for challenging behaviour in community settings. The outcome of research by Allen (1999), exploring differences in individual and service characteristics in relation to placement breakdown seems to support this approach, the key findings being that:

- few behavioural or psychiatric differences were observed
- breakdown group significantly more able
- breakdown group had less than optimal resource utilisation
- the breakdown group were supported by services with less robust internal organisation

- carers in the breakdown group were less likely to have received training in emergency management technique.

Being assigned the label of ‘challenging behaviour’ is likely to have a detrimental impact on the life course of an individual with learning difficulties. The needs of people with behaviours that challenge are often neglected (Emerson 1990) and they are reported to be at significantly greater risk of physical abuse (Rusch, Hall and Griffin, 1986). Research suggests that 31% of all people with learning difficulties supported by local authorities in England are supported in out of area placements and challenging behaviour is often cited as the reason for placements, which can be very expensive (Beadle-Brown, Mansell and Hutchison 2006). The number of such placements is on the rise and in addition to marginalising increasing numbers of adults with learning disabilities these developments could be seen as a contributory factor in the disproportionate increase in social work expenditure attributed to learning disability services (Department of Health 2007, 5).

There is considerable variance in the estimates of the numbers of people with learning difficulties who are perceived to challenge services, although it is consistently reported in research that more men and boys (two thirds of those identified) than women and girls are categorised in this way (Emerson et al., 2001). The numbers of people defined as having behaviour that challenges depends on definitions, however, research suggests that 24 adults with a learning difficulty per 100,000 total population, present a serious challenge at any one time (Emerson , 2001) and that challenging behaviours are shown by 10-15% of people with learning difficulties who are in contact with educational, health or social care services (Emerson et al. 2001, 77). There is a measure of agreement over the forms of behaviour that are perceived to be the most challenging by practitioners and which attract most attention in the literature, ‘aggressive behaviour towards others; self injury; destructive behaviour; other socially or sexually inappropriate behaviour’ (Qureshi 1993, 13).

The global nature of a definition such as ‘challenging behaviour’ makes comparative studies of prevalence of challenging behaviour extremely difficult, for example variations in the prevalence of challenging behaviour range from 17% to 56%; physical aggression 10% to 28% (Beange and Bauman 1990; Jacobsen

1982; Eyman and Call, 1977, in Jones and Eayrs 1993, 5). The outcome of the Emerson et al (2001, 77) replication study reported that,

‘the most common forms of challenging behaviours reported were ‘other’ behaviour (shown by 9%-12% of all people screened), aggression (7%), destructive behaviour (4%-5%) and self-injury (4%); the majority of people identified showed two or more of these four general forms of challenging behaviour’.

In order to establish ‘operational’ definitions of challenging behaviour that attempt to impose consistency across settings and reduce the subjectivity of judgement, a variety of scales and checklists have been designed. These tools are primarily used in research and practice to provide baseline measurements from which to assess the impact of therapeutic inputs and to inform strategic planning. Attempts to study the prevalence of problem or challenging behaviour frequently rely on checklists along with ratings of frequency and severity. There are inherent difficulties in meaningfully aggregating data from such instruments and some academics question the usefulness of understanding prevalence of an umbrella concept such as challenging behaviour (Leudar and Fraser 1986). Research has also been undertaken to identify and quantify specific forms of behaviour such as self-injury (Oliver, Murphy and Corbett 1987) and aggressive behaviour (Harris and Russell 1989). However difficulties arise as research appears to indicate that individuals rarely engage in just one form of behaviour that challenges services so for example 45% of people categorised as showing aggressive behaviour also were noted as displaying self injurious behaviour (Harris and Russell 1989), at least half of those considered to have self-injurious behaviour were also assessed as having some other form of challenging behaviour (Emerson 2001). Questions have been raised about the usefulness of researching challenging behaviour itself or whether more meaningful data would be gathered focussing upon the consequences of such behaviours for example the resources that are deployed to manage or control such activity (Qureshi 1993). Again implicit dangers are located within this approach as it should not be assumed that in congregate settings every individual utilises the full range of the resources available in such provision.

Despite these reservations checklist scales inform ‘operational’ definitions of challenging behaviour, particularly within the research context. A widely used

checklist scale is the AAMD Adaptive Behaviour Scale Part 11 (Nihira, K., Foster, R., Shellhaas, M. and Leland, H. 1974). This scale was adapted for use in the British context (Thomas and Webster 1974). Part 1 of the scale details the skills necessary for independent living, Part 2 an empirically derived psychometric instrument is used to rate perceived 'inappropriate' and 'maladaptive behaviours'. Behaviours are divided into fourteen domains such as self abusive behaviour with sub domains detailing more explicit forms of the behaviour. These behaviours are then rated according to frequency. The Adaptive Behaviour Scale has been subject to much criticism and several suggestions have been made for amending the scoring system to take account of both the severity of the behaviour and the frequency of the occurrence (Clements, Boft, DuBois and Turpin 1980; Clements, DuBois, Boft and Bryan 1981; Taylor, Warren and Slocumb 1979; McDonald and Barton 1986).

It was upon recommendation from a clinical colleague, who was also an academic, that the AAMD Adaptive Behaviour Scale Part 11 was initially used within this research project, the original intent being to establish a baseline measurement for the 'inappropriate' or 'maladaptive' behaviours of the adults with learning difficulties who assisted with this research. As the research developed the inappropriateness of this approach became evident. No information obtained from this psychometric tool has been included within this thesis. The evolution of this aspect of this research is detailed in Chapter 4: A Journey through Ethics.

A social constructionist critique offers an alternative approach to defining challenging behaviour. In its most abstract form challenging behaviour could be considered to be behaviour that contravenes the prevailing norms in a given situation. The term 'ecology' is used by Hewett (1998) and Osgood (2003) to describe the importance of environmental factors both social and physical, when looking at behaviours that challenge. A body of learning disability research has been developing that rejects the 'dualism between the 'brain' (the mechanical or biochemical instigator of movement and action) and the 'mind' (the understanding, meaning, the spirit of life, that which makes humans unique)' (Slevin 1996, 625) underpinning traditional learning disability research. The personal meaning assigned to actions has increasingly becoming the focus for research with people with learning difficulties recognising that, 'behaviour is

purpose where the action of physical objects just describes motion trajectories' (Benner 1985 in Slevin 1996 625); these developments seem particularly pertinent when considering adults with learning difficulties whose behaviour is described as challenging.

The definition of challenging behaviour as activities that contravene a given norm relies upon collective agreement on accepted and agreed norms. If varying perceptions of norms exist, actors may have different perceptions of appropriateness and acceptability at which point 'questions of relative power become important considerations in determining what comes to be seen as the prevailing everyday definition of a challenge or problem' (Qureshi 1993,12). Bering et al (1993, 63) highlight the need to consider individuals who are perceived to be 'presenting challenges as, 'people first' rather than a collection of problems. They caution that services beware the latter pathological perspective, and actively organise to challenge such positions. Referencing Stark, Menolascino, Alberelli and Gray (1988), they also suggest that this approach applies equally to individuals with mental health issues, 'whose long-term support needs will not be adequately addressed by purely health-focused, clinical interventions' (Bering et al. 1993, 76).

Social theorists draw attention to the reasons why certain behaviours are considered problematic. Becker (1963), a leading proponent of labeling theory suggests that behaviour in itself is not deviant, rather it is the interaction between those displaying the behaviour and those who respond to it that makes a behaviour deviant. This approach parallels the critique of the concept of risk espoused by Douglas (1982; 1990; 1992) and outlined in Chapter 2 Section 2.6.2 . The same process could be seen to apply to individuals who are regarded as presenting behaviours that challenge; they are assigned the label and by the process of social interaction, the difficult behaviour and the person become a 'socially established phenomena' (Slevin 1996). This process has implications for the lived experience of those who are in the receipt of the label. There is an increasing body of work highlighting the importance of considering self esteem when working with adults with learning disabilities (Clements 1997, Stenfert Kroese, 2007). This aspect of learning disability research was an important consideration when undertaking the research for this study particularly when considering whether the individuals I worked with understood, recognised and

acknowledged that they had been assigned a label of presenting behaviours that challenged.

Hewett (1998) expresses a preference for thinking about peoples (challenging) behaviour in terms of the thoughts and feelings that generate them. Recent research on the subject of challenging behaviour has highlighted the importance of communication (Osgood 2005) and viewing the behaviours that challenge others as a form of “exotic communication” (Ephraim 1998). An emphasis on challenging behaviour as a form of communication once again tries to place the onus of responsibility on those providing the support and who should be listening more clearly to what is being conveyed. This approach has major implications for research, policy and practice and reflects the debate about the utility of person centred planning for policy development and strategic planning previously outlined in this chapter. Challenging behaviour viewed as ‘exotic communication’ challenges and asks questions of traditional research approaches. How do researchers quantify and aggregate the many different ways that adults with learning disabilities articulate their pain and distress in a service land where quiet commentary goes unheard?

This approach to challenging behaviour also has profound implications for practice development. It refocuses the subject of challenging behaviour back clearly in the arena of community capacity and service competence and away from misleading pathology. It charges those professionally involved in the support of adults with learning disabilities to suspend their pre judgment and attune their hearing to listen for,

‘Those minor behaviour problems, those low level agitations that may signal that the person is preparing to engage in something serious. These precursors might be understood as whispers of behaviour....It seems to us that we are requiring that the person not whisper to us; and it is the “shout” we then call severe and challenging behaviour’

(LaVigna and Willis, 1997,14).

This social constructionist perspective of challenging behaviour underlines the importance of viewing the powerful and highly contentious issue of risk from the perspective of those whose lives are often dominated by this subjective and abstract concept. It is this latter approach that I ultimately adopted in my

conversations with those who kindly agreed to participate in this research, a perspective informed by consideration of the range of theoretical approaches to disability studies as detailed below.

3.4 **Disability: Theory**

In order to gain a full understanding of the learning disability policies and practices, as detailed in the preceding sections of this chapter, it is useful to consider them within their wider societal context. To assist in this exploration it is helpful to review the theoretical frameworks that exist within wider disability studies and their applicability to the field of learning disability. Setting the scene for these discussions the next section of this chapter lends brief consideration to the concept of power and how this influences movement and developments in society.

3.4.1 ***Theory: Power***

In Section 3.3 I detailed the historical evolution of learning disability policy and practice. These developments have taken place within a wider cultural and social context and the social policies they represent are symptomatic of shifts in power relations.

Gramsci (1971) used the doctrine of hegemony to explain the relationship between power and social policy and although it is beyond the scope of this literature review to explore this concept in detail it is useful to use as a backdrop to the medical and social models of disability expanded upon later in this chapter (Gramsci, Hoare and Nowell Smith, 1971). Hegemony describes ‘the ability of a class or group to translate its own world view into a pervasive dominant ethos’ (Gramsci et al. 1971, 14) and thereby achieve ascendance. Within this framework one could consider the medical profession’s dominance of the learning disability agenda, particularly in the post war years, and the disproportionate influence it has extended over the policy and research in this field.

Luke (1974) suggests a three dimensional view of power that seems particularly relevant to the discussion of disability. Firstly the direct exercise of power may

take the form of direct decision making, through the exercise of authority or use of force; an example could be considered to be the segregation of learning disabled people in institutions following the 1913 Mental Deficiency Act. Secondly, power may manifest itself in ‘deliberate non-decision’ which results in suppression of ‘latent or manifest challenges to the values or interests of the decision maker’ an example of which could be the lack of momentum in support of the move to community care following the 1959 Mental Health Act. Luke describes his third dimension, most closely resembling Gramsci’s hegemony, in the following way,

‘Is it not the supreme and most insidious exercise of power to prevent people, to whatever degree, from having grievances by shaping their perceptions, cognitions and preferences in such a way that they accept their role in the existing order of things because they can see or imagine no alternative to it, or because they see it as so natural and unchangeable, or because they value it as divinely ordained and beneficial’

(Lukes 1974, 24)

An illustration of this dimension could be seen as the options available to parents of children with learning difficulties prior to 1971 when their children were excluded from the education system. This was the norm and at such an early age it underlined the fact that disabled children and by default disabled adults were not considered valued members of our society, entitled to the same rights as others.

The medical or personal tragedy model of disability can be seen to be sustained by sociolinguistic mechanisms that present inequitable relations and processes as inevitable, ‘power differentials provide the underlying semantic for the system of ideas encoded in language structure,’ (Luke 1974, 16). The politics of the concept of ‘care’ could be used to exemplify this point, ‘it has not played a neutral role in the lives of disabled people. On the contrary it is socially and politically loaded. It locates power with the caregiver rather than the recipient’ (Watson et al. 2004, 335).

Terminology applied to people with learning difficulties and those who have been so labelled as having behaviours that challenge provides interesting insights into the value loaded nature of language used in ‘service land’

(Sanderson 2002). For example the same behaviour may be described using different terminology dependent on the primary diagnostic label applied; mental health or learning disability. Self injury is the preferred term in learning disability services to describe,

‘Any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm will be considered to include bruising, lacerations, bleeding, bone fractures and breakage, and other tissue damage’

(Murphy and Wilson 1985).

In learning disability ‘service land’ this form of activity is generally regarded as ‘operant’ behaviour, as it is interpreted as behaviour used to get or avoid doing something. In mental health ‘service land’ the same behaviour would be described as ‘self harm’ and would be ascribed a pathological origin, for example as ‘a method of mitigating psychological distress’ (Osgood 2005, 3).

The terminology adopted affects a powerful influence on the practices adopted to ameliorate these behaviours and it could be argued that such practices are steeped in assumptions about the emotional capacity of people with learning difficulties. There is a danger that the emotional needs of people with learning difficulties are overlooked and behaviours expressing these needs are assigned the label challenging behaviour, despite the fact that research appears to indicate an increased prevalence of emotional health difficulties experienced by people with learning difficulties (Gravestock 1999). Notwithstanding the fact that there are significant numbers of people with learning difficulties who have a dual diagnosis, ‘most sources cite a 25 per cent minimum rate for the prevalence of mental and behavioural disorders among people with mental retardation...applied to populations of a variety of industrialised nations’ (Jacobson 1999, 342).

Another term worthy of consideration is ‘challenging behaviour’. The term was originally conceived with the laudable aim of placing the focus on challenge experienced by those providing the support in an effort to avoid ‘pathologising’ behaviours. However the language of research on challenging behaviour frequently utilises such words as ‘maladaptive’ behaviours when attempting to

aggregate and quantify behaviours that challenge services. This language is value laden. For a particular individual, in the social and physical environment in which they find themselves the behaviour they engage in may be entirely coherent and meet needs that are not easily ascribed by others and this scenario may be even more likely where the individual relies on non verbal forms of communication. A relevant question to ask of policy makers, practitioners and researchers is the rationale for the behaviour of people with learning difficulties being described in terms such as 'generalized noncompliance; temper tantrums; repetitive pestering; screaming; running away; over activity; other challenging behaviour; stealing; inappropriate sexual behaviour; stripping; smearing faeces' (Emerson, et al. 2001, 85). Without a social, cultural and physical context when detailing these behaviours the descriptions provide very little useful information with no scope to understand the merit, purpose or intent of the actions taken. To illustrate this fact consider that the behaviours that are detailed, taken in isolation, could be ascribed to teenagers, political prisoners and other groups in society.

Learning disability is a contested domain, as will be illustrated by the following discussions of the medical and social models of disability. Learning disability research is still heavily influenced by the medical paradigm, centred around the concept of diagnostic categories, no matter how euphemistically these are applied, for example mild moderate and severe learning disability. In the case of challenging behaviour these categories are then subdivided into subcategories defined in terms of specified symptomatology or behaviours as illustrated by the Emerson (2001) research categories detailed above. Replicating these processes by grouping people together in categories or bureaucratic entities when they are as dissimilar as they are similar has significance beyond semantics.

Such a prevailing and all pervasive power imbalance subtly creates an environment where the subordination of a disadvantaged group, in this case people with learning difficulties, appears to be natural, so natural that it can create 'quiescence' amongst the subordinated group. When quiescence is not achieved, as in the case of adults with learning difficulties who challenge services that support them, the challenge becomes pathologised and the individual often experiences greater degrees of authoritarian power, restraint

and clinical intervention. The relevance of the Lukesian model of power to this research is the emphasis upon the process rather than the mechanisms of subordination, 'power shapes not just discrete events to a measurable degree but also perceptions, understandings and beliefs' (Lukes 1974,18).

It could be argued that the processes of a significant amount of learning disability research perpetuate the pathologising of adults with learning difficulties and replicate the power differentials present within society by 'reflecting the history, culture and social and professional philosophy within which such terms are generated' (Myers et al. 1998, 392).

3.5 Theory: Medical Model

Historically the main approach to understanding disability came from what would be described as the 'medical model'. From a medical model perspective disability is viewed as the consequence of some physiological impairment due to a damage or disease process. The origins of this approach are located within the disease model used in medicine. There is a focus for practitioners on framing interventions in terms of 'conditions' which need 'treatment'. In this model the disabled person is regarded as flexible and alterable, while society is fixed and unalterable, adaptation to an existing environment is one of the underlying tenets (Llewellyn and Hogan 2000).

This approach to disability has determined the majority of medical and psychological approaches to disability generally and learning disability in particular. The underlying assumption is that disability is an aberration or difference from the norm, therefore that disability equates to abnormality. Psychology for example uses clinical diagnostic criteria such as I.Q. tests to quantify variance from a perceived 'norm' of intelligence in order to define a diagnostic category for which to find a 'cause' or 'cure'. As a consequence cognitive impairment diagnosed on the basis of performance in vocabulary, memory, mathematics and abstract reasoning are often viewed as total impairments, 'pervasively diminishing everything the those so 'afflicted' can do' (Lakin 1997, 4). This medical model approach to disability has had a profound influence on the development of learning disability policies and practices,

locating, as it does, knowledge within a very tightly defined spectrum of expert competence.

Bond (1992) writing of the implications of ‘medicalising’ the needs of individuals in receipt of services for people with dementia argues that specialist care provision is driven by the need for professional control and that medicalising individuals’ ‘challenging’ or ‘deviant’ behaviour denies the social context of disability. His arguments are applicable to learning disability services particularly when suggesting that service provision could be regarded as a mechanism for social control of behaviours defined as social problems. He further suggests that a logical consequence of this is that the service provision is oriented towards the individual rather than the family or the community; this in turn denies individuals a singular or collective voice with a consequence being the ‘depoliticalisation of behaviour’. Focusing professional perceptions of the caring role upon the ‘care receiver’ locates the problem within the individual thereby failing to take into account what Brechin (1999) describes as the enabling and disabling processes in society. This approach appears all the more relevant when considering the plight of the increasing numbers of people with learning difficulties with the label challenging behaviour who are placed ‘out-of-area’ as a consequence of service incompetence (Beadle-Brown et al. 2006).

3.6 Theory: The Social Model

Before embarking upon a theoretical discussion about the relative merits and disadvantages of the social model of disability as applied to adults with learning difficulties it may be useful to provide some historical context to the development of this approach. In keeping with disability studies generally until the early 1960’s, research relating to learning difficulties reflected the predominance of the medical perspective (Klotz 2004). The field was,

‘dominated by eugenics, psychology, educational studies and medical investigations, in which people with learning difficulties were tested, counted, observed, analysed and described and frequently pathologised, but never asked their views’

(Walmsley 2001, 188).

In the 1970's The World Health Organisation adopted a typology that distinguished the terms 'impairment', 'disability' and 'handicap' in the following ways; 'impairment' referred to an anatomical or psychological disorder, 'disability' as the impact of the impairment on everyday living and 'handicap' as the social disadvantage that accrued from disability (Drake 1999, 10). Disability activists rejected this typology for a number of reasons. Firstly it appeared to ignore disability from a disabled person's perspective as it omitted any non-medical causes of disadvantage and it also promoted the notion of impairment equating to abnormality.

UPIAS (1976) outlined the basis for the social model of disability with the document, 'Fundamental Principles of Disability' which provided direction for the social and political emancipation of physically and sensory impaired disabled people (Goodley 2001, 208). The definition of impairment proposed by UPIAS was,

'lacking part of or all of a limb, or having a defective limb or mechanism of the body', disability was defined as 'the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from mainstream social activities!'

(UPIAS 1976 quoted in Oliver 1990,11).

This definition highlighted the distinction between impairment being the functional limitation within the individual and disability being the loss of opportunity due to physical and social barriers,

'Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society'

(UPIAS 1976 in Finkelstein 2001,10).

The initial definition proposed by UPIAS in 1976 made no mention of impairments affecting people with learning difficulties. The definition was subsequently amended to include people with 'sensory', 'intellectual or developmental',

impairments (Chappell et al. 2001, 46). However failure to include all people with disabilities in the first instance left a lasting impression that the experience of people with learning difficulties was included only as an afterthought and this impression has been reflected in much of the literature generated by the social model of disability.

‘People with ‘learning difficulties’ face discrimination in the disability movement. People without ‘learning difficulties’ use the medical model when dealing with us. We are always asked to talk about advocacy and our impairments as though our barriers aren’t disabling in the same way as disabled people without ‘learning difficulties’. We want concentration on our access needs in the mainstream disability movement’

(Aspis, S: London People First, in Campbell and Oliver 1996, 97).

Assumptions about the origins of learning difficulties have had a significant impact upon the treatment of people so labelled and have significantly influenced the research undertaken. Some disability theorists question why in the current postmodern theoretical climate the personal tragedy model of impairment is considered acceptable over the social model of disability for sections of the population with particular impairments (Goodley, 2001). The focus on embodiment excludes people whose primary impairment is cognitive functioning, resulting in people with learning difficulties being excluded from social model theorising (Chappell 1997). This approach runs the risk of replicating aspects of the exclusionary and pathologising aspects of the medical model that it was designed to challenge.

‘Mental retardation is, in fact, a social-political not psychological construction. The myth, perpetuated by a society which refuses to recognise the true nature of its needed social reforms, has successfully camouflaged the politics of diagnosis and incarceration’

(Bogdan and Taylor 1982, 15).

An example of the arbitrariness of the social construction of learning difficulty can be seen when in 1973 ‘the entire category of ‘Borderline Retardation’ was dropped from the Manual of Terminology of the American Association of Mental Deficiency’, as a consequence those assigned this diagnosis and label were either

cured or re-categorised overnight (Goodley 2001, 214). Acknowledging the external, social and political origins of the concept of learning difficulty guides theorists instead to consider people with learning difficulties in terms of 'their resilience in the face of arbitrary 'scientific' categorisations that have historically denied their humanity altogether' (Goodley 2001, 213). It highlights the importance of a hitherto unacknowledged body of knowledge that sits within the experiences and expertise of people with learning difficulties themselves, individually or collectively through the relatively new political self-advocacy movement.

The social model of disability has had a profound influence on the development of disability politics and research in recent years. Providing an alternative to the medical model of disability rooted in the positivist approach to disability research resulted in the development of critical social research 'with its emphasis on emancipatory goals and its call for openly partisan and potentially committed research' (Barnes and Mercer 1997, 5). Challenging the assumptions of a value free social world and the resultant pathologising of disability, the social model argues that disability is socially produced, 'disablement lies in the construction of society, not in the physical condition of the individual' (Drake 1999, 1). Oliver (1996, 37) provides a powerful critique of the practical application of the medical model,

'The medical profession, because of its power and dominance, has spawned a whole range of pseudo professions in its own image; physiotherapy, occupational therapy, speech therapy, clinical psychology; each one geared to the same aim - the restoration of normality. And each one of these pseudo-professions develops its own knowledge base and set of skills to facilitate this. They organise their interventions and intrusions into disabled peoples' lives on the basis of discreet and limited knowledge and skills'.

An implication of the challenge to the objectification of disability is a consequent challenge to the 'social relations of research production' that sustain the distinction between the researcher and the researched and the belief that the researchers have specialist knowledge and skills.

'As disabled people have increasingly analysed their segregation, inequality and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than part of the

solution.....Disabled people have come to see research as a violation of their experiences, as irrelevant to their needs and as failing to improve their material circumstances and quality of life'

(Oliver 1992 in Swain et al. 1998, 21).

The social model response was the development of the participatory and emancipatory research paradigms. These terms are used inconsistently in the literature. At times they appear to have the same meaning however elsewhere participatory research is used to describe a transitional phase on the path towards emancipatory research. Both approaches appear to be grounded in the same three principles; that the research relationship based upon the expert researcher and the passive subject is inequitable; that disabled people have a right to contribute to the production of research that is about their lives and experiences and that the quality of the research produced is improved when disabled people are involved in the process (Stalker 1998, 6). Participatory research offers a critique of, and challenge to, dominant positivist social science research as the only legitimate and valid source of knowledge. It provides a radical alternative to knowledge production (Zarb, 1992).

Collaborative research is an attempt to conduct research with, rather than on, people. With this approach an epistemological stance is adopted that regards participants as the experts and the researcher or the enquirer as someone who learns from these experts rather than testing his or her hypotheses on relatively passive research subjects (Knox et al. 2000, 49). Zarb (1992) suggests that an emancipatory research paradigm is a set of principles rather than a set of rules for doing disability research and that these principles are based upon the ideas of 'empowerment' and 'reciprocity' (pg. 127). To fulfil the criteria for the emancipatory model research has to be characterised by rigorous evaluation of questions of control,

'Being critical about self in terms of values, presuppositions and practices is an essential part of developing a critical disability research process, particularly when reflections can be made in association with others and in relation to the voices of disabled people'

(Moore et al. 1998, 15)

It poses a direct challenge to the traditional positivist approach based upon claims to be 'objective' and 'neutral' on the grounds that all knowledge is socially constructed and culturally relative (Barnes and Mercer 1997). The social model also proposes that the external forces that drive the research agendas are based on the premise of disability as individual pathology, rather than as a social construction (Knox, Mok and Parmenter 2000, 59) and that this should be challenged.

Zarb (1992) suggests that an emancipatory research paradigm requires that the more difficult task of challenging the material relations in research also be addressed and that disabled people would play a crucial role in both establishing the research agenda and managing the research process. A key aspect of this development Barnes (1992, 122) contends, is the 'establishment of a workable "dialogue" between the research community and disabled people in order to facilitate the latter's empowerment'. Oliver (1990) suggests that research can never lead directly to the empowerment of disabled people as empowerment is not something that can be given but is something that people must take for themselves, 'Simply increasing participation and involvement will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how' (Zarb 1992, 128).

Kitchin (1999) states that a critically-formulated research process (that with an emancipatory political agenda) which adopts an expert model approach is paradoxically seeking change at one level (society), whilst at the same time reproducing unequal social relationships at another (within the research process). Stone and Priestley (1996, 706) suggest that the core principles of a reformulated research strategy should be;

'The adoption of a social model of disablement as the epistemological basis for research production;

The surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self emancipation;

The willingness to only undertake research where it will be of practical benefit to the self empowerment of disabled people and/or the removal of disabling barriers;

The evolution of control over research production to ensure full accountability to disabled people and their organisations;

Giving voice to the personal as political, whilst endeavouring to collectivise the political commonality of individual experiences;

The willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people.'

Using the term 'The myth of the independent researcher' Barnes (1996, 107) proposes that the university system perpetuates the process of 'objectification' through the nature of rarefied academic study and the funding mechanisms that support it, he argues that,

'the university system implicitly if not explicitly, compels academics and researchers to write primarily for other academics.....with regard to disability research, university based researchers are far more likely to write for other university based researchers than....disabled people'

(Barnes 1996, 108-109)

He forcefully argues that to attempt to maintain the 'myth of the independent researcher' widens the gulf between the researcher and the researched when every effort should be made to do the opposite, 'researchers should be espousing commitment not value freedom, engagement not objectivity, and solidarity not independence' (Barnes 1996, 110). It has been recognised that there exists a friction between research being academically rigorous enough to meet the demands of a Ph.D. whilst being accessible to the people it purports to be researching. This is clearly articulated by Moore et al (1998, 20) when stating,

‘We have reflected upon the extent to which those conducting disability research for a PhD or other qualification can resist demands for their projects to be shaped in ways which are not only a ‘waste of time’ (Oliver, 1992), but also oppressive, both of themselves, and of disabled people being studied’.

Other theorists suggest that although this debate has been ongoing for some time there is still a wide gap between the,

‘Rhetoric of research outputs (which promote the liberation of disabled people) and the discourses and social practices in which we (researchers) work (which shape careers in the academic world)’

(Goodley and Moore 2000, 861).

Recognising that the majority of research in the field of disability is conducted by non-disabled researchers, Kitchin (2000) researched the experience of disabled people involved in the research process. He found concerns amongst disabled research participants that,

‘non-disabled researchers can potentially misrepresent and misinterpret disabled people’s experiences and knowledge because they themselves have never experienced what it is like to be disabled’

(Kitchin 2000, 33).

Kitchin also reported the significant issue of disabled respondents withholding information from non-disabled researchers for fear of embarrassment or of not being understood and as a result advocates a role for disabled people employed as consultants in the research process. Undertaking this role would ensure that academics maintain control of the research process but disabled consultants enhance the process by ensuring the data collected is interpreted correctly (Kitchen, 2000).

Some theorists contest the position of Barnes in relation to ‘The Myth of the Independent Researcher’ (Barnes 1996), arguing that this stance is contradictory. Bury (1996, 113) cautions that ‘the idea that a particular section of the disability movement should control the research agenda on a “you are

either for us or against us” sounds like a thinly veiled threat’. Bury further cautions that this approach could limit the ability of research to deal with controversial subjects and to seek to explore a different perspective from the ‘oppression theory of disability’. This argument is developed further by Shakespeare (1996, 115) who whilst supporting Barnes’s concern regarding research that ‘reinforces rather than challenges the subordination of disabled people’ cautions against the ‘simplistic and reductionist analysis of the research process’ which he fears is being portrayed by Barnes. Shakespeare (1996) references the influence of feminist theorists and researchers in his work and in particular cites Ann Oakley’s ability to depart from the ‘traditional paradigm of “objective” and “positivist” social research and developmore equal and balanced style of interviewing’ (Shakespeare 1996, 115). He also contends that there is considerable scope for disability research to learn from within feminist work, particularly the diversity of perspectives that coexist, ‘feminists and especially post-structuralist theories have challenged the notion of a singular, unitary set of truths which are openly accessible to researchers’ (Shakespeare 1996, 116). He highlights the danger of an orthodoxy developing within disability research that marginalises dissenting voices and ignores any perspectives that challenge the received wisdom.

In addition to the proposal that disability research look to feminist research as a model of good practice, Shakespeare (1996) also takes a different perspective on the issue of accountability proposed by Barnes differentiating between accountability to ‘one’s research subjects and accountability to the disability movement or specific organisations within it’ (Shakespeare 1996, 116). He draws a valuable distinction between the accountability he feels to participants involved in research and the ethical and moral position he adopts in support of the disability rights movement, which in turn informs all activities, both personal and professional. Shakespeare argues persuasively that it is the ‘right if not the duty of academics to take an independent line’, however he qualifies this by arguing that ‘while I aim to be independent, I do not confuse this with being neutral or being objective’ (Shakespeare 1996, 117).

Thomas (2004) similarly challenges the perceived orthodoxy of the social model of disability and the separation of impairment and disability. Taking a social relational stance Thomas argues that is possible to acknowledge that impairment

and chronic illness may directly cause some restriction in activity; the point of issue is that non-socially imposed restrictions of activity do not constitute 'disability'. Thus the definition of disability that Thomas adopts is that,

'Disability is a form of social oppression involving the imposition of restrictions on activities on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing'

(Thomas 1999, 60).

At the end of the 1980's there was an increasing body of literature reflecting the potential of 'critical social research'. This included works by feminists, black writers and educationalists, who positively allied themselves to oppressed groups and valued the experiences of the subjects of the research. Standpoint theory emerged as a 'critical theory of the relations between knowledge and power' and as a guide to improving research projects - as a methodology,' (Harding 2004, 73). Standpoint epistemology asserts that,

'life experience of subordination or exclusion can give people greater knowledge about certain realities that those in positions of relative privilege and power cannot easily know about in the same way as they lack that life experience'

(Tew and Gould 2006, 8)

Harding (2004) suggests that a level of knowledge and awareness is achieved through the process of struggling against internal and external forms of oppression. This approach could similarly apply to the perceptions of adults with learning difficulties who have been assigned reputations for challenging services who would have firsthand knowledge of their experience of the risks associated with 'service land' (Sanderson 2002).

Standpoint epistemology offers the clear distinction between the feminist perspective and that of Oliver (1990;1996;1992), Finkelstein (2004) and other more materialist proponents of the social model of disability. There is a growing recognition, particularly within the feminist perspective on disability that human

structure, function and physical ability do not conform to a universal norm, that they are socially relative. This reflects the contention of Shakespeare and Watson (2001,17) that,

‘people are disabled both by social barriers and by their bodies. This is straightforward and uncontroversial. The British social model approach, because it ‘over-eggs the pudding’, risks discrediting the entire dish’.

Wendell (1996, 35) refers to her analysis of disability as social constructionist, recognising that disability has biological, social and experiential components, ‘I call the interaction of the biological and social to create (or prevent) disability the social construction of disability’. There is an increasing awareness that the structural organisation of societies based upon idealised body types of ‘young, non-disabled’, ‘ideally shaped’ healthy adult male paradigm of citizens, leads to ‘the failure or unwillingness to create ability among citizens who do not fit the paradigm’ (Wendell 1996). Morris (1992, 89) draws attention to the fact that non disabled writers detailing the perceived ‘double oppression’ experienced by disabled women may individualise disability and allow that ‘attention shifts away from non-disabled people and social institutions as being the problem and onto the disabled women as passive victims of oppression’. Simon de Beauvoir (1953), stated

‘...the relation of the two sexes is not quite like that of two electricity poles for man represents both the positive and the neutral ...whereas woman represents only the negative, defined by limiting criteria, without reciprocity’

(Simon de Beauvoir in Morris 1992,158)

In a patriarchal culture, the male or masculine is set up as the norm and female or feminine is the aberration or other (Sheldon, 1999), disabled people are similarly ‘defined by their difference from the norm’ (Ferri and Gregg 1998, 437). Wider societal hierarchies are often reflected in the priorities pursued by the disabled person’s movement, a white male, middle class agenda is too often generalised to represent the experiences of disabled people, in this way women’s experiences are invisible or only make a faint impression on the overall debate. This point is highlighted by Myers et al., (1998, 94) noting when undertaking a review of research literature relating to community integration for

people with learning difficulties ‘the generally uncritical approach to the selection of people for inclusion in the studies suggests assumptions about the homogeneity of the experience of people defined as learning disabled’. There is an argument that the feminist movement and feminist researchers have, to an extent, colluded in this approach by focussing on the ability of women to be equal to men, with the emphasis upon parity and not on a celebration of diversity thereby not drawing attention to the experiences of disabled women, let alone women with learning disabilities (Shakespeare et al.1996).

Section 3.3.1, earlier in this chapter, detailed the historical development of the concept of normalisation and its influence on the evolution of learning disability policy and practice. Normalisation has had a disproportionate influence within the field of learning disability. The same influence has not been experienced in the wider field of disability policy, research and practice where the social model of disability has had a far greater impact. The following section provides a critique of the influence of normalisation on the social model of disability detailing the areas of commonality and differences between the two approaches.

Proponents of the social model of disability have challenged the veracity of normalisation as a social theory of disability. It should be noted that Wolfensberger’s (1972, 1980) articulation of normalisation, in the form of social role valorisation, was the version that exerted greatest influence on learning disability policy and practice development in Britain in the late 20th century. It is this formulation of normalisation which is most keenly contested by social model theorists.

Oliver (1990) contends that normalisation fails to deliver the three essential components required of a social theory in that it does not provide an adequate language for describing experience, a suitable framework for explaining experience or the scope to influence or transform experience. It is contested that proponents of normalisation perpetuate a discourse based upon distinctions of normal and abnormal, with the assumption that these distinctions are real rather than socially constructed. Reference can be made to Chapter 2 Section, 2.6.3 which details a Foucauldian social constructionist analysis of the way human beings are made into subjects. Expanding on this argument it is

suggested that any social theory that explores subjectivity separate from and a priori to the systems of power and knowledge that generate it is naively over simplistic.

‘The ‘truth of learning disabilities is not (or never was) simply lying in wait’ (Foucault 1972) outside realms of discourse and systems of knowledge, awaiting its discovery by the biological and psychological sciences’

(Yates et al 2008, 252).

Chappell (1992) cites the 1913 Mental Deficiency Act as an example of the social construction of learning disability. This legislation provided the authority that ‘defective women’ who gave birth to an illegitimate child while in receipt of poor relief could be sent to an institution. Chappell suggests that the legislation was applied to many women with or without learning difficulties who contravened the patriarchal social and sexual mores of the time. This contravention of perceived social ‘norms’ was sufficient for women to be defined as having a learning disability and to be incarcerated on those grounds.

In this respect practices based upon normalising people and services both construct and maintain the normal/abnormal dichotomy. In addition, it could be argued that adherence to existing social norms may reproduce other discriminatory practices such as ageism, sexism and racism as ‘social norms are not neutral, but are products of the society which constructs them’ (Chappell 1997, 47). In this respect it can be argued that normalisation does not provide an adequate explanation of societies characterised by difference because of its reductionist views of humanity and society.

‘The focus of implementers and interpreters of normalisation has been to enhance the lives of devalued individuals, rather than change the processes of valuation and devaluation. We try to fit people into existing structures, rather than evaluate what is wrong with a social system that does not accept someone as he or she is’

(Novak Amado 1988, 303).

Normalisation theory fails to take account of the organisation of society that places a premium on certain activities, largely related to economic productivity such as speed of decision making, literacy and numeracy that alienate people

with learning difficulties and result in their being 'largely excluded from the rewards and status of paid work and parenthood, and rendered marginal in society' (Williams 1989, 257).

Significantly, the focus of normalisation theory on service transformation rather than social transformation as the key to improvement in the lives of disabled people fails to take in to account the power dynamic between professionals and people with learning difficulties. It has been argued that the normalisation theory preoccupation with services, results in a professionally centred view of the lived experience of people with learning difficulties,

'Normalisation fails to locate the experience of people with learning difficulties within a political framework. It offers a theory of services, but not a theory of disability'

(Chappell 1992, 40).

In response to Wolfensberger's (1980) assertion that normalisation was instrumental in dismantling the institutional movement, Cohen (1985) suggests that the key issue of the balance of power between disabled people and professionals remains unaddressed,

"....much the same group of experts are doing much the same business as usual. The basic rituals incorporated into the move to the mind - taking case histories, writing social enquiry reports, constructing files, organising case conferences - are still being enacted"

(Cohen 1985, 152).

Crucially, the social model of disability proposes that social, and individual, transformations are inextricably linked. Individuals can transform themselves through collective action; they cannot be transformed by others through social engineering based upon what is perceived to be best for them or for society at large. Normalisation, in the form of social role valorisation, promotes the idea that people with learning difficulties should mix with socially valued people and avoid those who have stigmatised identities. In this formulation the scope for 'collective political action, based on commonality of experience' (Chappell 1997, 49), a prerequisite for social transformation, is seriously curtailed.

Williams and Nind (1999) explore the impact of normalisation from a feminist perspective. This, they suggest, breaks away from the traditional approach in which learning difficulties are discussed without reference to gender but where there is an implicit assumption that the men and women have the same life experiences. The American model of normalisation based upon 'social role valorisation' relies upon 'the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people' (Wolfensberger and Tullman 1989, 211). Within this approach access to normal living activities, housing, relationships, recreation and education are less a right than a means to gain status for the individual with a learning difficulty, in their own community. Corbett and Barton (1992) contend that this places an unreasonable expectation upon people with learning difficulties to be more normal than the norm.

Chappell (1992) contests the assumption that respect is not a right, but is conditional upon adherence to certain perceived societal norms, that appear to be inherent within this approach. In this formulation social acceptance, it could be argued, is 'possible but conditional' (Brown, 1994). Williams and Nind (1999, 661) propose that the concept of normalisation is fundamentally at odds with the inclusion movement and the self-advocacy movement on the basis that 'Normalisation is not about self-empowerment because rights that are 'given' can be taken away'. Normalisation in this respect fails to challenge the underlying societal processes upon which disability is founded and does not appear to recognise that 'groups unequal in power are correspondingly unequal in their ability to make their standpoint known to themselves and others' (Hill Collins 1990, 26).

Some theorists, particularly feminist and post modern theorists within Disability Studies have highlighted the different dimensions to disability which they suggest have been overlooked or down played by the 'materialist' prioritisation of the economic roots of disability (Corker 1999; Thomas 1999). By drawing on a social constructionist framework but focussing on the role of culture and cultural processes such theorists utilise the concept of difference, connected to gender, sexuality, ethnicity and impairment to inform ideas of societal formation and disabled peoples experience within it (Terzi 2004). Similarly theorist have noted the common exclusion of people with learning difficulties from literature on the social model of disability and have argued that the emancipatory research

paradigm, again drawn from the materialist articulation of the social model, has made little impact on research with and for people with learning difficulties (Chappell 1998; Walmsley 2001). Growing frustration over the problem of the 'disappearing individual' in sociological theorising (Whitmore 1994) and a reaction against the 'over-determined' view of reality brought about by methods that impose order on a messy world (Faraday and Plummer 1979) have led to challenges to the assumption that one 'model' of research or another needs to be adopted. One expression of these concerns is the 'excluded voice thesis' developed primarily from feminist research and critical race theory (Farber and Sherry 1997). The 'excluded voice thesis' proposes that narrative methods provide access to the perspectives and experiences of oppressed groups who lack the power to make their voices heard through traditional modes of academic discourse' (Booth and Booth 1996, 55).

Building upon the recognition that traditional research can be regarded as 'alienated knowledge', feminist research takes a different approach which,

'at the outset of inquiry, creates the space for an absent subject, and an absent experience, that is to be filled with the presence and spoken experience of actual women speaking of and in the actualities of their everyday worlds'

(Smith 1988, 107).

It could be argued that in the same way women during the 1970's recognised the legitimacy of their voice (eloquently stated in the following quotation) so could people with learning difficulties. We,

'asserted that our lives, as well as men's lives, were worthy of contemplation; that what we suffered in our lives was not always natural, but was instead the consequences of a political distribution of power. And finally, by these words, we said that the feelings we had of discomfort, dissatisfaction, grief, anger and rage were not madness, but sanity'

(Griffin 1982 in Morris 1992, 163).

Disabled people can argue that their experience needs to be reconsidered in the same light, particularly perhaps people with learning difficulties whose struggle leads to a consequent label of 'challenging behaviour'. Turner (1980 in

Goodley 1996, 333) contends that the absence of insider stories of people with learning difficulties is a reflection of the general assumption that people who have had this label assigned to them are unable to articulate their life experiences. Goodley (1996) suggests that the 'insider stories' research approach has encouraged a move away from a generalised and pathological concept of learning difficulty and as a consequence has broadened the understanding of the range of experiences of learning difficulty.

Davis (2000, 196) references the work of researchers from within the field of anthropology when proposing that people may hold different or even conflicting perspectives on the same phenomena and as a result multiple and competing ideas of what constitutes the truth or reality exist. This would suggest that as a consequence no one model of disability can or should be adopted.

‘In other words those of us who have an interest in discourse are not waging war on the social model. We are encouraging its reflexive use, but more importantly, we are engaged in a different kind of production - liberation and acceptance of silent ‘voices’, new knowledges, and therefore a greater range of positions from which disabled people can subvert hegemony and act in social and political arenas’

(Corker 1999, 209).

Challenges to the social model of disability have not gone uncontested. Stone and Priestley (1996, 713) question the effectiveness of the social relational approach on two counts; that by concentrating on difference, disability studies could be reduced to 'culturally relative story telling' and that by focussing upon diversity, the political power of the collective may be diminished thereby undermining the disabled movement's scope to improve the lives of disabled people. This argument echoes the concerns expressed by Douglas (1992) detailed in the previous chapter in relation to the implications of the individualisation agenda of post modern industrial societies on the 'disappearance' of marginalised groups. Although Davis (2000, 198) suggests that,

‘the problems of essentialism and universalism can be overcome by balancing explanations of people's everyday experiences with

accounts of how those experiences are linked to wider societal influences’.

The approach suggested by Davis might allow for investigation of identity, culture and structure and equally as importantly how people respond to these aspects when they interact with them on a daily basis. An important component of this approach is the study of those in power. For people with learning difficulties the study of people who have influence over their daily lives such as family, friends, psychiatrists, psychologists and social care professionals including support workers should reveal a great deal about the barriers that inhibit self emancipation (Davis 2000, 199).

There has been considerable progress in the field of learning disability research particularly the fact that it is no longer deemed appropriate for individuals to be treated as ‘objects of scientific interest or even of voyeuristic curiosity’ (Stalker 1998, 5). Increasingly it is recognised that individuals with learning difficulties are the best authority on their own lives, perceptions and experiences. However, Walmsley (1994) argues that the projection of the social model of disability (Finkelstein, 1980; Abberley, 1987; Oliver, 1990) which envisages people with learning difficulties self organising and taking control of the research process and thereby overcoming disabling barriers fails to consider the implications of certain physical and sensory impairments. Stalker (1998, 15) cites Chappell (1996) when commenting that the failure to examine the implications of impairment may be due to the fact that the ‘explanatory potential of the social model in relation to this group has been relatively little explored’. A consequence of the failure to address these shortcomings has been an increasing number of researchers adopting an inclusive research approach.

This term inclusive research refers to a range of approaches termed ‘participatory’ or ‘emancipatory’ but covers any research in which people with learning difficulties are involved as more than ‘objects of scientific interest’ or passive respondents. Many influences have stimulated the increasing interest in and development of ‘inclusive research’ in the field of learning disability including; the development of normalisation; the social model of disability; feminist emphasis upon qualitative methods in social science; critiques of self advocates (Aspis 2000) and the encouragement of funders such as the Joseph

Rountree Foundation (Walmsley 2001). Inclusive research is strongly influenced by the emancipatory research ideals, however, drawing on a feminist perspective it challenges some of the core assumptions which the more 'materialist' social model advocates; it also calls into question some of the ideas underpinning the 'normalisation' model prevalent in the field of learning disability in the 1980's and 1990's. A greater emphasis is placed upon the experiential perspective and as a consequence this has influenced the development of narrative approaches to learning disability research in keeping with the rise of the self advocacy movement.

As a direct result of the impact of the social model of disability and development in the disability movement the role of the researcher has changed significantly, although there is still an issue about the control of the power to decide what is researched and with whom and how. For the most part, informants with learning difficulties have been regarded as sources of data for researchers rather than the people who might define the research agenda and design and implement the research. The challenge for researchers interested in learning disability is to undertake research that is relevant to many different audiences such as 'practitioners, policy-makers, people with learning difficulties, their advocates and of course , their own interests', (Ramcharan and Grant 2001, 356). There is also an argument against developing a reductionist approach to learning disability research, as Giddens succinctly states, 'disability studies is an academic investigation of the social world and as such is more than simply common sense' (Giddens 1989 in Shakespeare 1996,117).

The scope of the challenge has been highlighted by a number of researchers in the field. Shakespeare (1996) notes the importance of using techniques which do not obscure the voice of the participants, for example formal structured interviews or questionnaires but instead choosing techniques which enable participants to have control over their words and their participation. Supporting this position Booth and Booth (1996, 56) examining the difference between interview research and narrative research suggest that in the latter, the subject 'determines the frame of reference of the narrative' and contend that there is more to hearing and recording stories of people lives and their perceptions and experiences than simply providing the space and the time. Atkinson (1997, 30)

emphasises that the researcher's role is central and that the skills of the researcher determine how individuals' stories unfold.

3.7 Conclusion

Undertaking a literature review of the historical and theoretical development of the concept of learning disability raised a number of profound questions about the research I was undertaking. Having recognised the 'missing voices' of adults with learning difficulties in the original research design I had to reflect upon the challenges of undertaking meaningful research with potential participants who had not been involved at the genesis of the research project. A further 'lighthouse moment' was experienced when I realised that at no point during the inception of this research study had I consulted with adults with learning difficulties or self advocacy organisations about the areas of research they would like to see conducted. Up until this point the research had been a student centred endeavour. This realisation raised the spectre of a challenge: was it possible for this research to evolve into a participatory research process? This was the next step in the evolution of the research design. Writing myself into the research and adopting a standpoint epistemology I also had to reflect on my own role(s) as a researcher and as a practitioner; a situation further complicated by the fact that I had a professional relationship with a number of the research participants. Ethical consideration developed an increasing prominence in this research project. Chapter 4 charts the evolution of the research design as a journey through ethics.

Chapter 4: Research design- a journey through ethics

4.1 Introduction

The focus of this research changed over the course of the study. To make sense of the distance travelled and the deviations from the original itinerary it is necessary to go back to the starting point for the research design and to chart the influences that affected the direction of travel. All aspects of the journey informed the final destination of this research, the false starts, the blind alleys and the roads that seemed to lead nowhere. In many ways it would have been simpler to write this thesis ignoring all the winding roads and deviations and to chart the research journey as a linear route, as ‘the exclusive and gendered culture of academia’ encourages (Brown and Thomson 1997, 696). It has been suggested by some scholars that academic researchers are socialised,

‘to believe that their published research accurately describes the existence of a neat and sequential pattern of research procedures, each step presupposing the completion of the preceding one. They [academics] learn not to question this model of reporting which creates an oversimplified and dishonest picture of research activity’.

(Ward and Flynn 1994, 35)

In an effort to provide an honest ‘picture of research activity’ Chapter 4 details some of the practical aspects of the research process that informed the research design, particularly the issue of securing Ethics Committee approval. This chapter also describes aspects of the research that were undertaken but were latterly set aside, namely the risk scenario vignette based research. The theoretical ethical considerations relevant to undertaking research with adults with learning difficulties are detailed.

4.2 Overview

Chapter 3 detailed the importance of the long stay institution closure programs in the development of learning disability policy and practice. Building upon the information provided in Chapter 3, Section 4.3 of this chapter provides a

localised portrait of the policy and practice landscape that informed the genesis of this research. Section 4.3.1 turns a more detailed focus on the Robust Services Project, the service framework within which the research participant's support arrangements were organised. Section 4.4 outlines the original research design which was based upon a study of professional perceptions of risk as related to adults with learning difficulties who have been assigned reputations for challenging services. A significant factor that impacted upon the development of this research was the process of securing Ethics Committee approval for the research, the practical aspects of which are discussed in Section 4.5. Starting the field work aspect of the research involved gaining access to professionals within Glasgow Learning Disability Partnership and asking them to score risk scenario based vignettes, this process is detailed in Section 4.6.1. The rather more complex arrangements for recruiting adults with learning difficulties, who had been assigned reputations for challenging services, to participate in the research is outlined in Section 4.6.2. The research reached a crossroads, a point where options needed to be considered and a decision needed to be made about the ongoing research design and methodology, this is detailed in Section 4.7. The field research had followed two paths up until this point and the progress made in these areas is detailed in Section 4.7.1 and Section 4.7.2. The theoretical and ethical influences that informed the critical decision making process are detailed in Section 4.8. Ethical considerations relevant to the new focus of this research endeavour are detailed in Section 4.9 and Section 4.10 summarises the unfolding nature of journey to date and signposts the methodological way forward.

4.3 Background

The policy landscape for the inception of this research was governed by the decision to close long stay learning disability institutions as detailed in Chapter 3. At the outset of the Greater Glasgow Health Board closure programme in 1995, Lennox Castle Hospital was the largest learning disability hospital in Scotland (Dalrymple 1999). Based on the outskirts of Glasgow, Lennox Castle Hospital opened in 1936 and was initially called 'Lennox Castle Certified Institution for Mental Defectives'. It housed six hundred males and six hundred females in segregated sixty bedded dormitory blocks (Open University n.d.).

By 2001 there were less than two hundred people living in Lennox Castle Hospital and other Greater Glasgow funded learning disability long stay institutions. However, consistent with English institutional closure programmes, those remaining at the end of the hospital closure programme had been assessed as having the highest and most complex support needs (Mansell and Beasley 1993). Glasgow Learning Disability Partnership (GLDP) was created by Greater Glasgow Health Board and Glasgow City Council social work department to facilitate the strategic planning and commissioning of learning disability services in the Glasgow area. There was recognition within the GLDP that the majority of people labelled as having challenging behaviour and who lived in segregated settings could live in the community were they to receive the right support. It was also acknowledged that organisations supporting those individuals would need additional support themselves in order to manage risks creatively and to ensure that support services did not become risk averse and prohibitively expensive (Duffy and Smith 2008). To meet the challenge of commissioning and providing support services for those individuals Glasgow Learning Disability Partnership established the Robust Services Project in 2001.

4.3.1 ***Robust services project***

The development of peripatetic specialist teams to provide additional support to adults with learning difficulties who had reputations for challenging services in order to facilitate support in ordinary living environments was recognised as a successful strategy (Emerson 1990; Department of Health 1993; Department of Health 2007). In the Greater Glasgow area the peripatetic specialist function was undertaken by the Complex Needs Support Team. This team consisted of a small number of professionals, including a Psychiatrist, Psychologist, Speech and Language Therapist and Behaviour Nurse Therapist, whose main remit was to provide additional support to individuals and their families and/or their support teams in order to prevent 'placement breakdowns' and to support individuals through periods of difficulty or crisis (Duffy and Smith 2008).

GLDP's Commissioning Team, the Complex Needs Team and three support provider organisations, C-Change for Inclusion, Community Integrated Care and Turning Point worked together to develop the Robust Services Project. The aim

of the project was to foster true partnership working between organisations supporting individuals who had been assessed as having the most significant reputations for challenging the services that supported them.

‘The Robust Services Project is an attempt to discharge a significantly larger number of people with challenging behaviour from hospital. The project will at the same time target the development of the community infrastructure to enable individuals with challenging behaviour to be successfully supported in the community.’

The Robust Services Project (discussion paper 2001)

Glasgow Learning Disability Partnership

It was envisaged that there would be opportunities for joint learning between professionals and organisations and that this learning would be disseminated as best practice guidance within the GLDP. The Robust Services Project established a Robust Services Management Group attended by the senior managers from the care provider organisations, Commissioning Managers, the head of profession for psychology and the manager of the Complex Needs Team. A Practice Development Group was also created and was attended by mid level managers from the various provider organisations, social work and health including those responsible for the Assessment and Treatment Units run by the GLDP. Both forums were established to provide an opportunity for professionals working within different contexts and cultures to share their knowledge and experience.

On a practical level the Robust Services Project developed a programme of shared training, agreed risk management strategies, established approved strategies for inter agency communication around accident/incident reporting and agreed the core components of good working policies or care plans. A less tangible but equally important benefit was the opportunity for individuals and organisations to be honest about the difficulties encountered when supporting people who were complex to support and who challenged the services they were receiving. In this respect as much attention was paid to developing the right culture, one of mutual support and assistance between organisations and within the Robust Services Project, as some of the more practical aspects of the work (Duffy and Smith 2008). Practical exercises and transparent processes were used to facilitate the development of a no blame culture of mutual accountability.

Individuals with learning difficulties supported under the auspices of the Robust Services Project had the advantage of direct referrals to additional professional support by-passing the normal referral procedures for input from Psychology, Speech and Language Therapy and Behaviour Nurse Therapy. The additional support was provided by the Complex Needs Team. Adults with learning difficulties, whose support was part of the Robust Services Project, also accessed support through the mainstream Social Work and Health structures. The interface with mainstream social work and health structures added to the complexity of the field work aspect of this research as learning disability services in Glasgow were restructured a number of times during the data gathering stage of this research.

Glasgow Learning Disability Partnership was established to oversee the strategic planning and operational delivery of learning disability services in Glasgow. The first restructuring during the course of this research was the establishment of nine Area Learning Disability Teams (ALDTs) bringing together health and social work professionals to manage the delivery of operational services across Glasgow. ALDTs were initially headed up by a Co-ordinator from either a health or social care background. These teams underwent a further restructuring with the creation of new professional roles replacing Co-ordinators, Senior Social Workers, and senior nursing positions with Operational Managers, Practice Team Leaders and Clinical Team Leaders. ALDTs moved physical location taking up residence within Adults Learning Disability Resource Centres. Operational Managers took responsibility for all Adults Learning Disability Services in their area, doing away with the artificial split between Commissioning and Operational Teams. In April 2006 there was a further restructuring when Glasgow City Council and Greater Glasgow Health Board replaced Area teams and ALDTs with five Community Health and Social Care Partnerships (CHCPs) responsible for both health and social care service provision in a locality.

A consequence for this research of the numerous restructurings was that front line and management level staff moved jobs and locations on a number of occasions making it more difficult to track their whereabouts.

4.4 Original research design

The focus of this research changed over time and in order to chart the evolutionary nature of this journey it is important to detail the starting point. My original interest in the area of risk and adults with learning difficulties was instigated by professional observation of the chameleon like nature of the concept of risk when used to inform practice decisions. It was also the recognition of the significant impact that the concept of risk had upon the lives of adults with learning difficulties that informed the decision to research risk in theory and in practice.

The first incarnation of the research proposal, as detailed in the paragraph below, focused upon an investigation of the perceptions of risk held by a range of professionals working with adults with learning difficulties; social workers, community nurses, psychologists, psychiatrists, speech and language therapists and commissioners. The proposal was based upon an adaptation of a study conducted by Giovannoni and Becerra (1979) which used vignettes to explore professional perceptions of risk relating to child abuse and neglect. Fox and Dingwall (1985) undertook a partial replication study using vignettes to explore the extent to which differences existed in the perception of child abuse between health visitors and social workers in one English town.

Drafting the initial research proposal took place at the same time as a preliminary literature review which was undertaken in an effort to locate the research within an academic and political landscape. Wider reading of available literature, particularly that relating to the development of the disability movement and the role of the social model of disability and feminist perspectives provoked a critical review of the research design and a recognition that, despite the original intention, the voices of adults with learning difficulties had been omitted.

The second incarnation of the research proposal remedied this omission by adding two sets of interviews with a small number of adults with learning difficulties who had reputations for challenging services. It was proposed that the interviews would take place before and after the individuals moved from

long stay learning disability institutions in order to allow a comparative analysis of the perceptions of risk pre and post discharge. The study at this point was intended to investigate the perceptions of risk held by a range of different professionals and individuals with learning difficulties. The aim was to consider the impact of the range of perceptions on the decision making processes affecting the lives of adults with learning disabilities who had reputations for challenging services.

In furtherance of this aim a number of areas of investigation were identified:

1. The variables affecting professional decision making in relation to risk perception for example, professional qualifications, training, length of service, location of service (demographic data)
2. An analysis of theoretical decision and practice based decision making of professionals (vignettes).
3. Consideration of the balance between risks and rights, responsibility and authority (vignettes).
4. The perceptions of risk of adults with learning difficulties who have reputations for challenging services and whether these correlated with the perceptions of professionals (case studies).

At this stage the research project was to progress on two fronts; vignettes and case studies. The vignette based research required the collection of demographic information and data from the rating of risk scenario based vignettes by approximately eighty professionals employed in the provision of services for adults with learning disabilities in GLDP. The case study research was to include two interviews with between ten and twelve adults with learning difficulties. The interviews were to take place pre discharge and post discharge from long stay learning disability institutions, approximately one year apart.

4.5 Ethics in practice

An application to the Greater Glasgow Primary Care NHS Trust Research Ethics Committee was submitted on the basis of this second research design. At this point the application was submitted by completing a paper pro forma and attaching the relevant documentation. Unfortunately the Ethics Committee deferred the application. Among the reasons cited was the fact that I referred to the potential participants as having ‘reputations for challenging the services that supported them’ and it was deemed inappropriate by the committee to approach participants on the basis of their reputation. As detailed in Chapter 1 the use of this terminology was an attempt to challenge the uncontested nature of labels such as ‘challenging behaviour’ assigned to individuals. The Ethics Committee also noted that I had made reference to the number of people who had been assessed as requiring their support to be co-ordinated under the auspices of the Robust Services Project. This was regarded as privileged information and a stipulation was made that an ‘honorary contract’ was required. It was suggested that I respond to the points and resubmit the application.

A second ethics committee application containing all the suggested amendments was submitted. This second application was again deferred by the Ethics Committee on the basis of concerns about the ability of potential participants with a learning difficulty to give consent to engage with the research and additional concerns recorded as ‘an issue about service user’s views and carer’s views’. Concern was also expressed about the fact that I had suggested that I would meet participants in their home, in my office or in a social setting of their choosing such as a café. It was suggested that participants may exhibit self harming behaviour and concern was expressed about the dangers to other customers and the suggestion was made that permission be sought from café owners. At this point the protracted difficulties gaining Ethics committee approval necessitated a further revision of the research design as the proposed ‘case study subjects’ had moved from the long stay learning disability institutions in which they had been residing into their new homes in the community. It was therefore no longer possible to undertake the pre and post discharge interviews as planned.

The third incarnation of the research proposal retained the risk scenarios based vignette research with professionals and included two sets of interviews with between ten and twelve adults with learning disabilities who had been assessed as 'exhibiting challenging' or 'high risk behaviour'. At this point it was envisaged that the 'case study subjects' would be living in the community in a range of different settings such as individual supported living arrangements and group homes. It was proposed that the case study individuals would be selected from a cohort identified by the Complex Needs Team and GLDP's Commissioning Team as requiring their support to be co-ordinated under the auspices of the Robust Service Project. Additional inclusion criteria were based upon capacity to consent to participate in the research, operationally defined as individuals who did not have a legal guardian (Becker et al. 2004) and the ability to communicate verbally. With the focus upon a specifically identified population i.e. those whose support was co-ordinated under the Robust Services project, purposive sampling strategies were used to recruit potential participants who were willing to share their expertise given the 'richness and diversity of information that informants are able to give, rather than the representativeness of informants of a wider population' (Knox et al 2000, pg 50).

A revised third ethics committee application was submitted. By this time the Greater Glasgow Primary Care NHS Trust Research Ethics Committee was using a lengthy and complicated on line application procedure that required the support of a telephone help desk to complete. Following submission this application was again deferred by the Ethics Committee, this time the grounds for deferment were based upon concerns about the procedures detailed for obtaining consent; the suggestion that a 'power calculation' was required for the vignette based research; clarification about the clinical support available to the case study subjects; clarification of the definition of risk being used with 'case study subjects' and concerns about the ethical considerations of undertaking research into personal areas with adults with learning difficulties.

At this point a delay of a year and a half had been incurred as a consequence of not being able to secure ethical approval. A sense of powerlessness was exacerbated by the fact that the Ethics Committee meetings took place behind closed doors. Although the letter detailing the date and time of the Committee meeting extended an invitation to attend and speak to your application, on the

two occasions I attended the meeting over ran, my application was not considered and I was not called. There seemed to be limited opportunities to put a case forward other than through the electronic application process.

In light of the committee's comments I made a further, fourth revision to the Ethics Committee application. However before submitting it I sought a face to face meeting with the Chair of Greater Glasgow Primary Care NHS Trust Research Ethics Committee. Although it took some time to arrange, the meeting was fruitful. Each area of concern registered by the Committee was discussed, some points it was recognised were already covered in the existing submission and minor amendments were made to other areas of the application.

In addition to submitting the fourth application (the second in electronic form) I sent a hard copy with a covering letter detailing the meeting with the Chair of the Ethics Committee and the agreements reached. My application was heard at the next Greater Glasgow Primary Care NHS Trust Research Ethics Committee and finally, almost two years after the original submission, I gained Ethics Committee approval and was able to start the research field work.

4.6 **Obtaining Consent**

In planning and conducting this research careful thought was given to the ethical issues, particularly as the 'case study' field work involved discussion of sensitive subjects with potentially vulnerable individuals. Ethical considerations were further complicated in relation to this aspect of the research by my dual role as a researcher and a practitioner; a consequence of which was pre existing professional relationships with a significant number of potential participants whose support was co-ordinated under the auspices of the Robust Services Project. The processes for obtaining consent from research participants in the two phases of the research are detailed below.

4.6.1 ***Vignettes***

Obtaining Ethics Committee approval enabled the data gathering aspect of the research proceed. Gaining access to Senior Management professionals working in learning disability services in GLDP was relatively easy. Access may have been

facilitated by existing professional relationships with Senior Managers within the GLDP established during my time working as a Commissioner in Glasgow. I contacted the Joint General Manager of GLDP, who was aware of the research and invited me to attend the next Senior Management Team meeting (SMT), a forum attended by senior managers in learning disability services across Glasgow including Operational Managers, Commissioning Managers and Heads of Professions such as Nursing, Psychiatry and Psychology.

Copies of the Professional Participant Information Sheet and Consent forms were circulated to all those who would be attending prior to the meeting. Time was taken at the beginning of the meeting to explain the purpose of the research and information sheets, consent forms and vignette packs were distributed. Participants were asked to complete the demographic data section and score the risk scenario based vignettes. Completing the packs took between ten and twenty minutes depending upon the amount of time individuals took to consider the risk scenarios and the number of comments they noted. All but one of the twelve Senior Managers present participated in the research and completed a vignette pack.

To facilitate the roll out of the research the Joint General Manager asked the Operational Managers to provide dates for their upcoming Area Learning Disability Team (ALDT), such meetings generally took place monthly. As a consequence of the level of Senior Management endorsement and support, provisional dates for ALDT team meetings were arranged with very little difficulty, although a significant number of appointments subsequently changed as a result of meetings being cancelled due to poor attendance or concerns about competing priorities. Over the course of the following seven months eight ALDT team meetings were attended. I was unable to secure a date to attend one of the ALDT team's meetings due to a lack of co-operation from the Operational Manager in that area.

On two occasions ALDT team members chose not to complete the vignette packs during the meeting, on both occasions the stated reason was pressure of time and competing priorities, and instead agreed to complete the packs after the meeting and return them. Both teams that took this approach nominated one colleague to co-ordinate the return of the packs. The return rate for teams that

chose the latter approach was lower than those that completed the packs during the meeting. In busy teams this may have been as a consequence of the priority given to this task among other competing pressures.

4.6.2 ***‘Case studies’***

The process of obtaining consent to participate in the research from adults with learning disabilities whose support service was delivered under the auspices of the Robust Services Project was complicated by my dual role as a researcher and a practitioner. I was professionally aware of the names and reputations of a significant number of adults with learning difficulties who were considered to challenge services in the Glasgow area as a consequence of my previous role as a Commissioner with GLDP. C-Change for Inclusion, the organisation I founded and worked for as Executive Director originally supported twenty four of the thirty six people who received their support as part of the Robust Services Project. In addition as a member of the Robust Services Management Group, a forum in which the support needs of the individuals supported by the project were discussed, I had access to information pertaining to other individuals supported by the project. As a consequence of these three factors, as a practitioner I either knew personally or knew of the individuals receiving their support as part of the Robust Services Project.

McGill and Emerson (1992) highlighted the susceptibility of people with learning difficulties to influence particularly from Service Providers, it has also been suggested that the predominant mode of relationship between staff and users of services is one of control and the exercise of power (Brown and Thomson 1997). Other scholars have noted that some people with a learning difficulty have a tendency towards acquiescence but suggest that this is not intrinsically related to their disability but as a consequence of so many aspects of their lives being controlled by others (Simons, Booth and Booth 1989). Within this context it was particularly important to establish a confidential process for obtaining consent facilitated by an independent third party. Fortunately the Manager of GLDP's Complex Needs Team agreed that his team would facilitate the process of securing consent from potential participants.

Two nurses from the Complex Needs Team who were actively involved in the Robust Services Project undertook an assessment of the thirty six individuals involved in the project to determine who met the criteria for inclusion in the research. The criteria had been defined as adults with learning difficulties whose support was co-ordinated under the Robust Service Project, who could communicate verbally and who had capacity to consent to participate, operationally defined as individuals who did not have a legal guardian. Accessing case file information and using their own working knowledge of individuals the two nurses identified twenty two of the thirty six individuals as meeting the research inclusion criteria.

I drafted a letter in the name of the Manager of the Complex Needs Team asking potential participants if they would be willing to take part in the research. The letter was signed by the Manager of the Complex Needs Team and sent by his administrative support to the twenty two people identified. The letter included a Participant Information Sheet, a Participant Consent Form (Appendix 1) and a stamped addressed envelope. Completed consent forms were returned to the Manager of the Complex Needs Team.

Nine responses to the initial letter were received, eight people agreed to participate in the research and one declined. A follow up letter was sent eight weeks after the initial letter to those who had not responded. Following the second letter a further six responses were received, three consenting to participate and three declining. In total fifteen of the possible twenty two participants responded to the letters and of those twelve agreed to participate in the research project. Five of the twelve who agreed to participate were female, the remaining seven were male.

4.7 At a crossroads

The field work research continued down two routes; the risk scenario based vignettes exploring the perceptions of risk of professionals and the individual face to face interactions with adults with learning difficulties who had been assigned a reputation for challenging services. I latterly decided to set aside the vignette based research in order to focus upon and adapt the approach taken to

the one to one interactions with the adults with learning difficulties who had agreed to participate in the research. This decision was not an easy one to make, having invested a great deal of time and effort in the vignette based field work and also recognising the considerable contribution of time on the part of the professional participants. However, increasingly I began to realise the value of the contributions of the adults with learning difficulties who had been assigned reputations for challenging services, whose voices were seldom heard and whose perspectives on risk I was unable to find represented in any research or literature. The rationale for this decision is discussed later in this chapter in Section 4.9. However recognising that all aspects of the field work informed and contributed not only to the research journey but the destination, the following paragraphs detail the work that was undertaken and latterly set aside.

4.7.1 *Initial field work: vignettes*

The risk scenario vignette based field work was undertaken with the GLDP's Senior Management Team (SMT) and eight of the nine Area Learning Disability Teams. In total sixty seven vignette packs were completed. The research proposal had estimated a return rate of approximately eighty packs. A number of factors contributed to the lower than expected return rate although it is worth noting that I would now consider the return rate sixty seven as really positive and the proposed return rate of eighty to be an overly ambitious target.

There was no consistency between ALDTs as to the composition of the team. In some areas the team included personnel from the Learning Disability Resource Centre within which they were located, other teams it was strictly health professionals and qualified social work staff. This lack of consistency and the frequent changes of personnel and location, as a consequence of the almost consistent restructuring that took place, made it extremely difficult to get an accurate figure for the potential total sample population. Anecdotal evidence gathered through the process of attending the ALDT meeting where the packs were completed indicated a high level of co-operation and participation. There was a poorer completion rate of packs that were left for team members to complete who had been absent from the meeting either as a result of a competing pressure on their time, sick leave or annual leave. As previously

stated the restructuring processes undertaken by Glasgow social work department and Greater Glasgow Health Board during the field work phase of the research made it more difficult to follow up those who had agreed to participate but who had not completed and returned a pack. The non-participation of one whole ALDT also had an adverse impact upon the return rate.

4.7.2 *Initial fieldwork: 'case studies'*

Before meeting with the twelve individuals who had agreed to participate in the research, two members of the Complex Needs Team used the individual's case files to complete the AAMD Adaptive Behaviour Scale Part 11 (Nihira, K., Foster, R., Shellhaas, M. and Leland, H., 1974) to quantify the level and range of challenging behaviours presented by each of the individuals within this group. The rationale for the psychometric test was to provide quantitative data to ensure that the research was replicable and therefore achieve some level of external validity. This aspect of the research was latterly set aside in favour of the research participants eloquently providing their own more holistic self description as detailed in Chapter 6 Section 6.4.1.

The delays in securing ethical approval to pursue the research although frustrating provided the opportunity to reflect and reconsider the research design. It also allowed time to read more widely in the field of disability research literature and to critically review the standpoint from which I was approaching the research. The decision to withhold the information obtained from the AAMD Adaptive Behaviour Scale was undertaken as a result of ethical deliberation about where I saw this research located within the political and theoretical landscape of learning disability research.

Upon reflection I abdicated responsibility for selecting the 'appropriate' psychometric assessment, relying upon advice from a Psychologist colleague, in no small part due to misgivings about the nature and use of such instruments, particularly in the field of learning disability and challenging behaviour. The intellectual justification for including a psychometric test was that outlining the pros and cons of the use of such assessments would provide a useful focus for discussion. In retrospect this was a deeply disrespectful rationale as it failed to

take into account the impact upon the individuals concerned or the fact that any intellectual debate would be conducted at the expense of the adults with learning difficulties who agreed to participate in this research project. The very people who agreed to give of their time and assist with the research would continue be quantified and qualified by professional perceptions of their behaviour without any redress.

The theoretical considerations that informed the development of the research design and the ongoing emergent research process are detailed in the following chapter. However it is important to note at this point that the decision to set aside the information obtained from the application of the psychometric test was transformative. It marked a determined move from a positivist approach within a bio medical paradigm towards a participatory approach located within a social constructionist framework with an unambiguous focus on validating the 'experiential knowledge' of adults with learning difficulties who use services.

4.8 Ethics and Theory

It is important to set the concept of ethics within a theoretical framework. The practical challenges experienced while trying to obtain ethics committee approval to undertake this research had a profound influence upon the consequent development of the research design as detailed in the previous section. The difficulties trying to gain ethical approval appeared to be located in a clash of research cultures (Tew et al., 2006). The ethical approval process of Greater Glasgow Primary Care NHS Trusts Research Ethics committee was located in a bio medical tradition with an emphasis on quantitative research. The application form and approval process was designed to review 'control trials' and did not readily accommodate research from other research traditions. Ramcharan (2006) asserts that ethics committees review research from the standpoint of the worst case scenario and consider research as intrinsically unethical until proven otherwise. This approach appears most keenly applied when the research involves participants perceived to be vulnerable,

‘the more vulnerable research participants are perceived to be, the greater potential for exploitation and, hence, the greater the regulation required’

(Ramcharan 2006, 183).

It is not only researchers from a bio-medical tradition that propose the need for alternate safeguards to protect vulnerable ‘service users’. McGill and Emerson (1992) suggest that ‘counter controls’ such as advocates, or ethics committees are needed to scrutinise research practice from an independent position. This standpoint is informed by the notion that ‘informed consent’ on the part of potentially vulnerable ‘service users’ does not provide enough protection, particularly given the susceptibility of people with learning disabilities to influence particularly from Service Providers (Brown and Thomson 1997). The issue of consent is particularly important in this context. Murphy and Clare (1995) identify two approaches to the assessment of ‘capacity’ to consent, a diagnostic approach which identifies an individual as one of a group who are considered to have a shared lack of capacity and a functional approach which involves an assessment of particular skills and knowledge needed in any specific context. The latter approach to the issue of ‘capacity’ to consent is more in keeping with the law in Scotland that generally presumes that adults are capable of making decisions for themselves and of managing their own affairs unless assessed otherwise, as exemplified by the Adults with Incapacity (Scotland) Act (2000).

Concerns about capacity to consent were expressed by the Greater Glasgow Primary Care NHS Trust Research Ethics Committee in relation to this research and in particular worries about undertaking research with adults with learning difficulties who challenged the service that supported them. Interestingly, by meeting the Chair of the Committee as detailed earlier in this chapter, the latter concerns expressed by the Committee were assuaged largely on the basis that I knew all of the potential participants. This could be viewed as a person centred approach to an ethical approval process or could be seen as symptomatic of the fact that ‘conflict between autonomy and paternalism/duty of care is commonplace’ in learning disability services (Brown and Thomson 1997, 702).

The ‘gate keeping’ role of ethics committees may be seen to stifle the development of innovative research and some researchers argue that, ‘it seems just as unethical, by virtue of the weight of ethical regulation, to prevent potentially useful research from proceeding , as it is to allow ethically unsound research to go ahead’ (Ramcahran and Cutcliffe 2001, Pg no). It has been noted that the majority of Ethics Committees do not have members who are users of social care and health services (Tew et al. 2006), and Greater Glasgow Primary Care NHS Trust Research Ethics Committee was no exception. It is not unreasonable to suggest that in discharging their duties, Ethics Committees, particularly those working within a bio -medical tradition, could be charged with adopting a,

‘presumed ownership of sole access rights to a group of people (which) exemplifies disempowerment and infringement of individual rights in the extreme. Doubtless this occurs in many other contexts where the medical model presides and non-disabled professionals permit themselves to believe that they are the experts and the rightful managers of the lives of disabled service users and their families’.

(Moore, Beazley and Maelzer 1998, 67)

To meet the requirements of the academy, and in the case of this research the requirements of the ethics committee, researchers can be encouraged to adopt an approach that assumes that consent is a one off “sign the form” event despite literature that contends that consent should be seen as a continuous and interactive process (Wiles, Heath and Crow 2005). It could be argued that the process of prior review, presenting a protocol for the research prior to the research commencing, not only potentially disadvantages research with an emergent design (Ramcahran and Cutcliffe 2001) but also increases the potential for exploitation of vulnerable research participants. Swain, et al. (1998, 34) question any reliance upon ‘Codes, Ethics Committees, retrospective evaluations to the control of ethical decision making by participants’ as they believe this ‘fulfils the researchers’ obligations in principle while leaving the practice of fieldwork open to manipulation and the pursuit of the researchers’ vested interests’.

It has been suggested that many people participate in research knowing that it will not benefit them directly, although it may benefit others (Iacono 2006) and that there is no reason why potentially vulnerable individuals, including adults with learning difficulties, should be excluded from participation (Ramcharan 2006). Dworkin (1988) suggests that 'decent respect' for autonomy may at times involve supporting people to make choices which may not be seen, initially, to be in their best interests. A similar position was taken by John Stuart Mill in the 19th century, cited by Atkinson (1991, 108),

'The only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant'.

It could be argued that in addition to respecting the autonomy of others it is also important to respect their welfare, liberty and rationality (Dworkin 1988). This approach is particularly pertinent for adults with learning difficulties whose voices have historically been excluded from research on the basis of concerns about 'capacity' and 'consent'. Ramcharan (2006) proposes the use of Circles of Support (Kennedy, Poll and Sanderson 2008) which he suggests may be regarded as readymade ethics committees that are better positioned to make balanced judgments about the potential effects of research on potentially vulnerable individuals.

It does appear that more considered efforts to overcome bureaucratic hurdles and develop creative solutions such as those suggested by Ramcharan (2006) are necessary if, as academics and as a society, we value the contributions and standpoint knowledge of marginalised citizens in our community.

4.9 The road less travelled

Changing the aim of this research to focus on the views of marginalised adults with learning difficulties reflected more than a symbolic change in priority. Exploring the perceptions of risk of adults with learning difficulties became the sole focus of this research, not as is often the case, merely a counterpoint to those expressed by professionals or carers (Mitchell and Glendinning 2007). This change reflects not only a growing call for the involvement and participation of

users in research (Ramcharan and Grant 2001) but also an explicit recognition that the standpoint knowledge of adults with learning difficulties, who have reputations for challenging services, has been missing from risk research .

As the focus changed the role of ethics gained prominence. Moving from a bio-medical paradigm to a participatory research approach necessitated a review of potential ethical dilemmas and a more explicit rendering of the ethical standpoint taken. Several aspects of the research highlighted a need to prioritise the role of ethics;

- undertaking research with potentially vulnerable adults with learning difficulties
- researching potentially private and contentious subjects
- my dual role as a researcher and practitioner
- the existence of an ongoing professional relationship with potential participants
- a participatory approach

Developing the research design to fit within a participatory research approach raised ethical concerns in relation to the issue of informed consent. The desire to empower research participants and encourage their active involvement in the development of the research process may be seen to be in conflict with the principle of informed consent based upon capacity, information and voluntariness (Freeman 2001). How can an individual give informed consent to participate in research that will develop as the process unfolds? It could be argued that informed consent and emergent methodologies are inherently contradictory. The approach adopted in this research was what has been defined by some researchers as a 'process driven' model of consent,

‘one in which we seek continually to renew our mandate, as it were, for the conduct of our research with those who are lending themselves to our research endeavour’

(Gregory 2003, 43).

Adopting a participatory research approach required an ethical obligation not only to ‘do no harm’ (Rinpoche 1999) but to aim for a higher research standard that, ‘Moves away from the production of ‘expert’ knowledge that can only be placed in the hands of professionals’ and instead seeks to, ‘provide research findings which can empower practitioners in new ways in assisting service users and carers claim greater control over their lives’ (Tew et al. 2006, 16).

The paradigm shift that took place within this research from a positivist bio-medical model to a participatory approach based upon social constructionist theory required a fundamental reconsideration of the ethical stance adopted. It no longer felt appropriate to rely upon the professional codes and modes of ethics that serve as moral principles in ‘value-free science’. Having gone through the protracted process of gaining Ethics Committee approval it was important that the research remained within the boundaries stipulated within the accepted proposal; bureaucratically that was what was required. However this framework did not provide for the reality of ethical decision making that reaches far beyond these simple procedural aspects and entails questions of ‘knowing and thinking as well as of choosing and everyday action’ (Scott 1990, 5). For insights into a broader realm of ethics I turned to a ‘Foucauldian’ (Koro-Ljungberg et al. 2007, 1078) ethical analysis that suggests that,

‘Ethical responsibilities cannot be separated from the concrete socio-political circumstances, but scholars need to practice “care of self” that anticipates and emphasises the researchers’ care of others without giving up their own ethical agency, freedom and contextualised moral decision making’

(Koro-Ljungberg et al. 2007, 1077).

It is suggested that through a process of critical self reflection researchers retain their ethical agency. It is this approach that I chose to adopt in this research project. In addition to the predictable areas of ethical deliberation detailed

above, a number of unforeseen ethical dilemmas arose during the field work aspect of this research; these issues are discussed in detail in Chapter 7.

It is possible that the unexpected ethical dilemmas that arose were identified as a result of an increased sensitivity to the power relations within the research relationship; itself a direct consequence of adopting a participatory methodological approach, as Roets and Goedgeluck (2007, 92) note,

‘Research on sensitive topics, like exposing hegemonic power arrangements inherent in someone’s everyday life, provides a number of honest ethical, political and methodological challenges’

4.10 Conclusion

It is not easy to recount this research journey in a linear fashion. At a point far nearer the end of the journey than would be indicated by inclusion in this chapter I chose to set aside the risk scenario vignette based research with professionals and also the use of a quantitative measure of challenging behaviour for the adults with learning difficulties who participated in the research. The process of trying to obtain ethics committee approval was a time consuming and frustrating endeavour. It appears that this is not an uncommon experience when trying to obtain approval for social research through Health Research Ethics Committees (Lewis, et al. 2003). Securing ethical approval profoundly influenced the development of this research in terms of the immediate impact upon the research design due to the time delays incurred. However it also provided time for reflection on the appropriateness of the research design and raised some interesting questions about ethics and learning disability research and the role of ethics committees.

As a consequence of the practical consideration detailed in this chapter, such as the difficulties experienced in obtaining ethical approval for the research project, and equally as a consequence of adopting a reflective and evolving approach to the research process, the focus of the research changed. Chapter 5 details the theoretical influences that informed the development of the emergent approach to the research design and supported a participatory research methodology firmly based within a social constructionist paradigm. It

also details how the ethical stance required of such a participatory approach was instantiated.

Chapter 5: Exploring methods - intentions, experience, reflections and revisions.

‘Academic debate often separates itself off from everyday practices’

(Goodley and Moore 2000, 877).

5.1 Introduction

Journeys embarked upon with certainty can often head in unexpected directions, as was the case for this research. Chapter 4 detailed some of the practical aspects that influenced the development of this research journey. Chapter 5 details the sinuous process of data collection and analysis, reflection and revision. It also outlines the theoretical influences that informed the development of this research endeavour. Through a process of critical reflection assumptions that were inherent within the research design were questioned, notions of researcher neutrality challenged and standpoints established.

As detailed in the preceding chapters the original aim of this research was to explore professional perceptions of risk as relate to adults with learning difficulties who had been assigned reputations for challenging services. Over the course of the research project the focus changed. A number of practical considerations acted as a catalyst for developments and these have been detailed in Chapter 4: Ethics; particularly the process of gaining ethical approval. Other developments in the research design occurred as a natural consequence of adopting an evolutionary or emergent approach to the research process - embracing the idea of research as exploration.

5.2 Overview

The theoretical influences supporting the adoption of an emergent approach to the research methodology are detailed in Section 5.3 of this chapter. Section 5.4 begins to outline the evolution of the methodology and leads on to Section 5.4.1 and Section 5.4.2 which describe the theoretical and practical approaches to communication and data gathering that were adopted. Section 5.5 details the

process of undertaking the pilot conversations and Section 5.5.4 highlights what was learnt from this experience. Section 5.6 details the adapted process for undertaking research conversations and explains the conversation guide approach and the use of graphic facilitation. Section 5.7 outlines the significant ‘lighthouse moment’ of learning that influenced the emergent development of the research design at that stage in the process. Section 5.8 explains the process undertaken for the second set of conversations and Section 5.9 introduces the research participants through the use of self descriptions. Section 5.10.1 discusses the different approaches adopted by individuals who chose to withdraw from the research. The data analysis techniques utilised in this research project are outlined in Section 5.11 and the chapter culminates with a brief conclusion that highlights some of the key methodological issues signposting further discussion of these issues in Chapter 7.

5.3 A theoretical guide

‘I’m interested in the politics of mess. I’m interested in the process of knowing mess. My intuition, to say it quickly, is that the world is largely messy. It is also that contemporary social science methods are hopelessly bad at knowing that mess. Indeed it is that dominant approaches to method work with some success to repress the very possibility of mess. They cannot know mess, except in their aporias, as they try to make the world clean and neat. So it is my concern to broaden method. To imagine it more imaginatively. To imagine what method - and its politics - might be if it were not caught in an obsession with clarity, with specificity, and with the definite’.

(Law 2003, 3)

On occasions during this research journey I left the safety of dry land, the predictability of the trodden path, finding myself on the water’s edge I immersed myself in the unknown; sometimes without a clear sense of where the current would take me. There were times when I was despairing of the purpose of the journey or the likelihood that I would ever feel confident or on firm ground again. Reading through academic literature frequently compounded this sense of disorientation; the linear direction and unwavering purpose detailed within the pages of journal articles and books seemed to offer mocking contrast to the confusion and dislocation I was experiencing. Certainty and definitiveness appeared to be what was required when greater opportunity for learning and

intellectual excitement seemed to lie in the illusive shadows and liminal territories of the unknown. A number of texts and articles offered buoyant solace when I felt methodologically all at sea. They provided the confidence to eschew the safety of certainty and to resist the temptation to adjust reality to fit process and to tidy up what seemed too messy to fit method (Law 2003). The following section of this chapter traverses the theoretical evolution of this research project and the literature that influenced developments.

As previously detailed in Chapter 2 the genesis of this research project lay in practice based recognition of the importance of the concept of risk; in particular the impact of perceptions of risk upon the life course of adults with learning difficulties assigned reputations for challenging services. A review of the literature uncovered a relative absence of research exploring risk and learning difficulties, as detailed in Chapter 2. Faced with a paucity of relevant research material the initial response was to opt for the methodological safety of a partial replication study. Pursuing this original option inadvertently subscribed the research to a positivist biomedical paradigm with values based upon the assumption that:

- 'People are passive objects that are done to by the technologies and practices of expert professionals.
- In order for research to be rigorous, it is better if people are ignorant of what is being done to them and why.
- Questions of meaning, categorisation and significance are to be determined by the researchers and not the researched.
- It is the individual, rather than their social/economic/political context that is problematic and needing to change' (Tew and Gould 2006, 3).

A number of questions arise from reflection on this stage of the research process; questions of presence and absence. Why did it take so long to recognise what was absent and assign to it the same level of academic curiosity as was focussed on that which was present, for example the available academic

material that informed the original service design? Why when my interest in risk was initiated by the perceived impact of this concept upon the lives of people with learning difficulties did it take so long to recognise the absence of their voices and in particular the voices of adults with reputations for challenging services? It is relevant to consider the influences that contributed to this intellectual myopia. Was it academic timidity and the need for the reassurance provided by other researchers' methodological credibility? Was it the pressure to meet the academic requirement for a research proposal or map detailing the starting point, way markers and an estimated time of arrival (ETA) so early in the research journey? Was it the influence of working professionally within a medical environment, closing long stay learning disability institutions; an environment where pragmatism was the order of the day? Whatever combination of influences, it is clear that the initial stages of this research project were approached wearing academic blinkers, limiting the paths available. The research journey was initially embarked upon in the form of intellectual orienteering; route outlined, map in hand, stop watch at the ready, all that was needed was to complete the task and get the prize.

Fortunately all did not go to plan. There were unforeseen consequences when pragmatism met passion, when an academic lack of confidence met an inquiring questioning mind, when there were more questions than answers and being certain was more disconcerting than being curious.

'Topics that ignite your passion lead you to do research that can go beyond fulfilling academic requirements and professional credits. You'll enter the studied phenomenon with enthusiasm and open yourself to the research experience and follow where it takes you. The path may present inevitable ambiguities that hurl you in to the existential dislocation of bewilderment. Still, when you bring passion, curiosity, openness, and care to your work, novel experiences will ensue and your ideas will emerge'.

(Charmaz 2006, 185)

The 'novel experience' that 'ensued' during this research was a distinct paradigm shift, a conscious move from the determinism of the positivist, empiricist school towards a social constructionist theoretical framework. The paradigm shift resulted in a fundamental change in approach to the key areas of

study; a move from the quantification of risk as phenomenon to the interpretation of risk as a concept; a shift from the medical model of disability (and definitions of challenging behaviour) to a social model understanding. Chapter 2 details the influence of the social constructionist approach to the concept of risk and Chapter 3 details the formative influence of social constructionist theory on the development of the social model of disability and its implications in relation to the concept of challenging behaviour. The conscious adoption of a social constructionist framework for the methodological approach to this research project marked a turning point in the research journey. It made explicit what had been implicit and quietened the academic dissonance that had been resounding like thunder in the background of this research project.

Adopting a social constructionist approach to the concepts of risk and challenging behaviour changed the focus for this research project, from explanation and prediction to understanding and exploring the possibilities of emergent multiple realities (Foucault, 1972). It offered the opportunity to consider truth as provisional and the inextricability of facts and values (Foucault 1980). Recognising that knowledge and theories are situated and located in particular positions, perspectives and experiences (Foucault 1973; Charmaz 2006) brought the role of the practitioner as researcher in to presence. Adopting a social constructionist approach promoted the exploration of other realities, the realities of a silenced people, adults with learning difficulties who have reputations for challenging others. Within this paradigm the voices of people traditionally silenced and excluded from society, on the basis of the risks they pose, have a valuable contribution to make to the definition and understanding of the subject of risk.

The concepts of risk and learning disability and challenging behaviour can be seen to be social constructs, assigned a variety of definitions in research literature and in practice as outlined in Chapter 2 and Chapter 3. Researchers need to be cognisant of the fact that these are contested domains. However this is not reflected in the research literature where generalised assumptions exist that the range of definitions used in research and practice are recognised, understood and accepted by people with learning difficulties to whom they are applied. These assumptions do not appear to be borne out by the findings of this

research project as detailed in the following Chapters 6: Findings and Chapter 7: Discussion. One of the difficulties experienced studying the concepts of risk and challenging behaviour was that they appeared to have ‘shape-shifting properties’ (Law 2003, 5) and trying to pin them down and make them ‘unambiguous and clear’ (Law 2003, 5), particularly during the stage when I was trying to conduct social research within bio-medical paradigm, was a disconcerting and sometimes frustrating experience. These difficulties may have been exacerbated by the tension induced by the clash of research cultures however it was with no small measure of relief that I read the following paragraph and recognised in it my own intellectual struggles.

‘But maybe, we slowly came to believe, it wasn’t actually like that in reality. Maybe we were dealing with a slippery phenomenon, one that changed its shape, and was fuzzy around the edges. Maybe we were dealing with something that wasn’t definite. That didn’t have single form. A fluid object. Or even one that was ephemeral in any given form, flipping from one configuration to another, dancing like a flame’

(Law 2003, 5).

The realisation that the difficulties I experienced were a normal, though not oft spoken of, aspect of the research process lifted a huge metaphorical weight and opened up panoply of opportunities for exploring the concept of risk from the perspective of people with learning difficulties. With the weight of determinism lifted and the pre ordained route map discarded the challenges of researching the abstract concept of risk from the perspective of adults with learning difficulties became an opportunity for creative endeavour.

One consequence of the theoretical realignment of this research project was that many of the assumptions built in to the original research design came to the fore. Loosening methodological strictures provided opportunities for these assumptions to be explored and on occasions challenged. Methodological and theoretical development was ongoing during the process of engaging with research participants and throughout the analysis of the data. A consequence of the evolutionary approach to the research methodology adopted in this research project was that there was no easy synthesis with established research methodologies, although there were considerable areas of overlap. With a

strong emphasis upon the emergent nature of the research process the most obvious methodological reference point for this research project was grounded theory (Glaser and Strauss 1967). The following brief summary of grounded theory acts a counterpoint to facilitate discussion of the methodological similarities and differences between this approach and the research undertaken.

The key components of grounded theory as proposed by Glaser and Strauss (1967; Glaser, 1978; Strauss, 1987) are detailed in Figure 1: Key components of classic grounded theory.

1. 'Simultaneous involvement in data collection and analysis
2. Constructing analytical codes and categories from data, not from preconceived logically deduced hypotheses
3. Using constant comparative method, which involves making comparisons during each stage of the analysis
4. Advancing theory development during each step of data collection and analysis
5. Memo-writing to elaborate categories, specify properties, define relationships between categories, and identify gaps
6. Sampling aimed towards theory construction, not for population representativeness
7. Conducting the literature review after developing independent analysis'

(Charmaz 2006, 6)

Figure 1: Key components of classic grounded theory

The information detailed above appears to indicate that predetermined procedural steps need to be adhered to in order to locate research within a grounded theory methodology. When first considering a change of focus for this research project a grounded theory approach had been considered and discounted for a number of reasons. As a consequence of the dual roles of being a researcher and a practitioner it was difficult to support the idea that theory emerges separate from the researcher as a scientific observer as suggested in some classic grounded theory works (Glaser and Strauss 1967; Glaser, 1978; Strauss, 1987). Secondly the prescriptive process as detailed above appeared to rule out adopting the grounded theory approach on the basis that a literature review had been undertaken prior to data gathering and had informed the development of the research project.

I now believe that the original decision to discount a grounded theory approach was based on a misplaced assumption for the need to adopt a formulaic approach to research methods. Some social constructionist proponents of grounded theory such as Charmaz (2006) advocate a non linear approach to research, based upon the explicit recognition that theoretical propositions offer an interpretive portrayal of the studied world not an exact reflection of it. Constructivist grounded theory emphasises a process of deconstruction and reconstruction, a process that was an intrinsic component of this research. The theoretical approach adopted in this research project draws on the influence of social constructivist grounded theory, similarities and areas of divergence are detailed in the following paragraphs.

The practical 'data gathering' aspect of this research project involved one to one conversations with adults with learning difficulties who had been assigned reputations for challenging services. Two conversations were planned with each participant, to take place approximately a year apart. However it became apparent, through the process of conversing with participants, that fundamental issues were not being addressed and that the research had not gone back to definitional source, and that therefore further clarification was required.

‘The logic of grounded theory entails going back to data and forward into analysis. Subsequently you return to the field to gather further data and to refine the emerging theoretical framework’

(Charmaz 2006, 23).

The fundamental issues that were being overlooked were questions of power and definition, for example whose definition of risk was informing the research project? Whose definition of challenging behaviour was informing the nature and content of the research conversations? Did the research participants recognise and understand the terminology, the concepts and their application and, fundamentally, did they agree with them? Raising these questions challenged a number of the implicit assumptions within the research design and prompted a review and revision of the research focus and the methodological approach. The core concepts at the heart of the research became problematic, definitions of risk and challenging behaviour could no longer be regarded as ‘natural’ or given. As a consequence issues of power and control emerged from the analysis and subsequently informed the second set of research conversations. This process of active reflection and revision appears to conform to the theoretical sampling process detailed as key activity within a grounded theory approach (as detailed in Figure 1: Point 4).

‘Theoretical sampling - going back in - involves starting with data, constructing tentative ideas about the data, and then examining these ideas through further empirical inquiry’

(Charmaz 2006, 102).

The research progressed, risk themes emerged and data was analysed on an ongoing basis as theories developed. To facilitate the recording of this emergent data a research journal was kept throughout the research process. Notes were taken after each encounter with a research participant either in the office or in the car if the meeting had been in the participant’s home. The journal was used to record practical observations, questions, ruminations and concerns. It also included some other practical information such as notes taken during meetings with study supervisors. The use of a contemporaneous research journal fulfilled some practical aspects of memo writing, a key component of a grounded theory approach (as detailed in Figure 1: Point 5), recording

preliminary analytical notes, codes, comparisons and ideas about the data. The research journal performed an important function and informed ongoing analysis of the data. At other times the journal was used as a cathartic mechanism to record unformed thoughts in a stream of consciousness that aided the process of maintaining theoretical distance. The journal included graphic illustrations when words could not articulate what needed to be recorded.

Viewed from a classic purest approach to grounded theory (Glaser and Strauss 1967; Glaser, 1978; Strauss, 1987) it could be argued that this particular research project did not start out with the data (as detailed in Figure 1: Point 7) as a literature review had been undertaken prior to embarking upon data collection in the field. A counter argument could be made using the idea of sensitising concepts (Blumer 1969), described as the factors that provide a researcher with the initial idea to pursue and sensitises them to ask particular questions about the topic. As a consequence of the dual roles of researcher and practitioner adopted in this research, it could be argued that initial data took the form of practice based observations. For this research project, observing the significant influence of the concept of risk upon the lives of adults with learning difficulties, was data or information that provided a starting point for the research journey. The methodological disorientation that followed was a consequence of the sublimation of the original research focus. Direction was regained with the explicit rendering of the implicit origins of this research project i.e. engaging with those whose lives had prompted the initial interest in this area of study, adults with learning difficulties who had been assigned reputations for challenging services.

Further reference to grounded theory is made later in this Chapter in Section 5.11 Data analysis. It is important to note here that no attempt has been made to force the research methodology undertaken for this research project into a grounded theory technical overlay, merely to note areas of overlap. The research undertaken was more of a bricolage than a technical set piece model but as Law (2003, 11) states,

‘We need new philosophies, new disciplines of research. We need to understand that our methods are always more or less unruly assemblages’.

I drew comfort that I was not alone in adopting ‘the road less travelled’ approach having found that existing research maps traced routes that did not satisfy the quest for knowledge.

5.4 Case studies or conversations

The following sections of this chapter detail the methodological approach that developed during the process of researching the perceptions of risk of adults with learning difficulties who had been assigned reputations for challenging services. The logistical aspects of interaction with the research participants, such as gaining access, undertaking pilot conversations and the number of meetings did not change significantly from that which was agreed by Greater Glasgow Primary Care NHS Trust Research Ethics Committee (as detailed in Chapter 4). However, the practical application of these logistical processes was profoundly influenced by the adoption of a social constructionist theoretical framework and standpoint epistemology (Tew and Gould 2006). Scholars argue that power relations manifest in particular culturally situated research encounters must be examined because they shape the research relationship, ethics and the politics of knowledge construction (Elmwood and Martin 2000). The conscious shift from a bio medical paradigm to a social constructionist approach brought about an awareness of the implications of power relations, and a subsequent transformation in language used to describe the research. Recognising that ‘implicit in the process of classifying of persons as ‘normal’ or ‘abnormal’ is the power dynamic whereby those who have the power to define the norm have control over those who must be measured against it’ (Peter 2000, 354) a significant shift took place within the research. In an effort to reframe the research and assert the new standpoint epistemology and to make explicit the movement away from the objectification of the ‘other’ the vocabulary of the research process changed. A commitment was made to,

‘articulate the lived experiences of oppression and resistance’ in order to ‘re-value disqualified knowledge and to restore lives of disabled people who are cast-off from society for decades’

(Roets et al. 2008, 91)

The service to this revised aim the anonymity of case studies was replaced by the textured nuance of real people with the ability to define and describe themselves (refer to Section 6.4.1). Passive research subjects were transformed into active research participants regarded as contributors to the research process with expertise, knowledge and valuable insights that could be drawn upon to inform our understanding of disability and risk perception. A practical implication of this transformation was that the research method based upon an interview schedule evolved in to more participatory research conversation (refer Section 5.4.2 Learning to Converse, for more the more practical details of this development). Possibly most significantly the balance of power changed, the researcher's role became that of an inquisitive student listening and learning as participants offered their unique perspective on risk, learning disability and challenging behaviour a move reflected in the Roets et al (2008, 100)

‘The traditional objectivity of the social sciences, in pursuit of which a rigid detachment is maintained between researcher and subject, has been replaced in much contemporary feminist research by an ethic of involvement’

5.4.1 *Learning to listen*

The language of research contains assumptions of power and knowledge that the process of undertaking this research brought to the fore. Linguists Sperber and Wilson (1986) challenge traditional theories of communication that place the onus of successful communication upon the individual imparting the message. Gladwell (2008) citing Sohn (1993) locates the challenge to traditional theories within a cultural context suggesting that Asian societies place the onus for successful communication on the listener. Exploration of these cultural differences was beyond the scope of this research; however the debate informed the development of the research project. Using the concept of ‘ostending’ Sperber and Wilson (1986) suggest that human beings radiate information all the time in the form of words, gestures, body postures, movements etc and that communication takes place when the ‘listener’ attends to and interprets these ‘ostentions’. They also contend that these interpretations are informed by the listeners ‘encyclopaedic knowledge’ based upon their knowledge of the individual and their situation and as a consequence it is the listener who bears the responsibility for successful communication. The approach proposed by

Sperber and Wilson (1986) informed this research in two key ways, firstly by engendering an explicit recognition that the responsibility for understanding communication with the research participants lay with the researcher. This placed the focus on utilising developing data gathering methods that suited individual participants. The second implication was the overt recognition of the potential benefits of being both a practitioner and a researcher in terms of the 'encyclopaedic knowledge' brought to the interpretations of the 'ostentions' of research participants, with a possible benefit of enhancing the richness and depth of the data gathered.

It could be argued that the criteria used to identify potential research participants based upon their ability to communicate verbally was exclusionary and rooted within a deficit model of disability. Rather than confront the limitations of the research methods the criteria used located the 'problem' within the personal capabilities of the disabled person.

'..a 'deficit model' of informant response is rooted in a view of disability as a problem of the individual. It serves to legitimate the exclusion of people with learning disabilities.....in a way that mirrors their exclusion from wider society'.

(Booth and Booth 1994, 66)

The fact that some individuals were excluded from participation in this research project on the basis that they were unable to communicate verbally somewhat limits the application of the approach proposed by Sperber and Wilson (1986). However the principle of the responsibility resting with the listener (researcher), was adopted within the research conversations that took place.

5.4.2 ***Learning to converse***

The original research design described a process of data gathering that involved conducting two 'semi structured interviews' of approximately one hour duration, with each case study 'subject', one year apart. An interview may be regarded as a directed conversation (Lofland and Lofland 1995) where the interviewer seeks to gain greater understanding of a subject through information gleaned from a 'research subject'. Focussing upon the definitional difference between an interview and a conversation may appear semantic hair splitting; however as

power dynamics are particularly important in terms of the evolution of this research project, the matter is worthy of further consideration. It could be argued that the dynamics of an interview tend to place power, control and expertise in the hands of the researcher, whereas a conversation involves a different power balance, one that involves 'no struggle, no domination', (Ephraim 1998, 212). This subtle but important distinction explicitly recognises the role of the research participants as experts and provides a greater focus on eliciting their 'definitions of terms, situations and events,' and tries to tap their 'assumptions, implicit meanings and tacit rules' (Charmaz 2006, 32).

Within the framework of an emergent research approach the data collection method detailed was aimed at increasing participants' agency and empowerment and privileging the individual experience and personal interpretations of participants. The methodological approach adopted was informed by the experience of other scholars in the field of learning disability research detailed in Chapter 3 and practitioners from the wider field of qualitative research. 'Exploitation, invasion of privacy, manipulation, deceit and abuse of power' (Swain et al, 1998,35) have all been highlighted as potential risks when using open ended research interviews with people with learning difficulties. Practical steps to ameliorate these potential risks and manage the power differentials existing in research encounters are detailed in following sections of this chapter outlining the practical application of the research methodology.

Drawing upon the role of graphic facilitation in Person Centred Planning (Sanderson 2002) as detailed in Chapter 3, one strategy adopted was the use of hand drawn graphics to provide a contemporaneous visual record of the research conversations. Research participants were offered the opportunity to participate in a graphic recording of the conversation that took place using flip chart paper and multi coloured art pens/chalks/acrylics. If the individual participant chose not to actively engage with the graphic recording of the conversation a graphic record was still taken and referred to throughout the conversation.

All social interactions, including research interactions are conducted through a process of developing shared meaning systems (Denzin 1994; Dixon and Duck

1993). A number of researchers have highlighted the potential difficulties of undertaking research with people with learning difficulties based upon abstract concepts such as time (Booth and Booth 1996; Flynn 1986; Biklen and Moseley 1988). It was important to establish a shared meaning system around the abstract concept of risk by initially establishing what the term risk meant to each participant. With this in mind the first area to explore with research participants was whether they had ever heard of the term risk, and if they had, what the term meant to them. This elicited a range of responses that informed the course of the subsequent conversation. It was important to reflect back to participants that their views were valued and that their comments were being listened to. In addition to the use of graphics another approach adopted was to mirror back to participants the language they used, for example Mr. Purple referred to risk as 'danger', the word 'danger' was then used to explore the concept of risk further by asking the question 'danger to who?' to which he responded

'..to me, to support staff, to anyone who is with me'

Having established participants understanding of the abstract concept of risk it was important to locate this understanding within a concrete frame of reference. This was achieved by establishing a list of topics or domains prior to the research conversations taking place. Kitchin (2000) describes this as an 'interview guide approach' where the potential areas of discussion are detailed in advance and act as an aide memoire for the researcher,

'..as a result the interviewer has much more freedom to explore specific avenues of enquiry, the logical gaps within the data can be anticipated and closed. The interview also takes on a more conversational feel while ensuring all the topics of interest are explored'

(Kitchin 2000, 28)

I adopted this approach, referring to the aide memoire as a 'conversation guide'. The domains selected for the conversation guide reflected the specific aim of this research; an exploration the perceptions of risk of adults with learning difficulties who had been assigned reputations for challenging services. Efforts were made to select risk domains that provided a focus for the

conversation without limiting the nature and extent of the discussion. The domains selected for the first set of conversations were informed by existing choice categories (Conroy and Feinstein 1986), quality of life measures (Emerson and Hatton 1994; Emerson and Hatton 1996) and social inclusion indicators (Raynes, Sumpton and Pettipher 1989) drawn from learning disability research literature. The broad risk domains selected were relationships, home environment, community and social inclusion and finally physical and emotional health. Conversation Guide 1 (see Appendix 2) was used to facilitate discussion with participants about their perception of risk in everyday life. A conversational style of interaction was envisaged and although the guide provided a list supplementary questions that acted as a researcher prompt, the direction of the conversation was determined by the participant's responses and not by the order or nature in which the questions appeared in the Conversation Guide.

5.5 Pilot conversations: help me learn

In the interests of anonymity each person was identified by a pseudonym based upon a colour (Tarantino 1992). A contemporaneous graphic record, using hand drawn symbols and picture, was taken during the research conversations. As part of this process participants were asked what colour they wanted the symbol that represented them to be. Some (male) participants chose colours that reflected their football team affiliations. Where possible the colour chosen by the participant was used, where two people chose the same colour another colour pseudonym was assigned.

The conversational approach to data gathering was piloted with two of the twelve individuals who had agreed to participate in the research, one man Mr. Purple and one woman Ms. Gold. These individuals were selected for the pilot conversations on the basis that as a practitioner I knew them both well and considered that they would give me honest feedback on whether the process made sense for them.

Pilot conversations were only conducted using Conversation Guide 1 as Conversation Guide 2 evolved out of the first set of conversations and the data analysis that took place.

5.5.1 *Rules of engagement*

The Conversation Guide also included a protocol on page one for introducing the research process to participants. In the interests of illustrating the process of trying to facilitate participant's agency and involvement, the following section outlines the areas of the protocol and information imparted. The protocol detailed the ethical and administrative information that participants required before starting the research discussion.

1. Thank individual for agreeing to participate in the research

I was very much aware that individuals were giving of their time and were often welcoming me as a guest in their homes. It was important that participants were aware that in this relationship I was in their debt and that I was there to learn from them.

2. Go over the purpose of the meeting - refer to research information sheet.

I identified myself as a student undertaking some research by referring to my photograph on the Participant Information Sheet that had been sent out along with the Consent Form. I also reiterated the purpose of the meeting using the Participant Information Sheet and asked participants if they needed any clarification about the purpose of the research.

3. Clarify consent - refer to consent form

I read through the details on the Consent Form that they had signed and returned and asked participants if they were still willing to participate in the research. Adhering to the principles of process consent, I also informed participants that they could stop the conversation at any point.

4. Detail confidentiality agreement.

Participants were informed that anything they said during the conversation would be confidential. There was one stipulation added to this, as detailed

below, that if information was disclosed which put the participant or others at risk I reserved the right to inform an appropriate individual/agency. I did however reassure participants that should this situation arise I would inform them of my intention to share the information disclosed. I also informed participants that I would not use their name in any documentation in relation to the research

5. Ask permission to audio record the conversation.

I did not have access to Dictaphone equipment so used a mini disc recorder and micro phone. At the beginning of each conversation I asked participants if I had permission to record our conversation. I informed them that our conversation would be recorded on a single mini disc and that this would be kept safely in a locked drawer when we finished. In all cases participants agreed to the session being recorded.

6. Set up and test equipment.

Upon securing agreement to record the session I explained to participants how the equipment worked.

I asked individuals whether they would prefer the micro phone to be placed on the table or clipped on to their clothes. Interestingly all participants' opted to have the micro phone clipped on to their clothes, this and other implications of the mechanics of the interview process are discussed in Chapter 7: Discussion.

I asked each individual to speak in to the micro phone to test the equipment and then played back their recording, again seeking an assurance that they knew the implications of the conversation being recorded.

7. Ask permission to draw a graphic record, ask participant if they want to assist.

I brought flip chart paper and art box containing multi coloured felt pens and marker pens and tape to each meeting and asked for permission to draw pictures of the conversation. I also asked each individual if they wanted to participate in this activity. Individuals chose to participate in this activity in different and illuminating ways see Chapter 7: Discussion.

8. Clarify role as a researcher/practitioner - 'I may ask question that you think I know the answers to'.

The dual roles as researcher and practitioner could have caused confusion particularly as all but one research participant knew me as a practitioner. It was therefore important that I clarified my role at the outset.

'Today I am here as a researcher not as the person you know from the office'

'I might ask you questions you think I know the answers to'.

9. Confirm that we will be having a conversation, I might ask some questions but there are no right or wrong answers, I want their ideas/views and thoughts.

It was important that participants felt at their ease and did not feel constrained by thinking that there were certain things that I as a researcher wanted to hear.

10. Check that individual has understood the above and obtain permission to start.

Again adhering to the principles of informed and process consent I checked that participants had understood the information discussed before seeking agreement to proceed with the research conversation.

5.5.2 Mr Purple

Mr. Purple chose to hold the first conversation in his own home. The conversation lasted slightly more than an hour and Mr. Purple chose to meet me alone, with no support worker or family member present. I tried to introduce a conversational approach but Mr. Purple stated that he would feel happier if I asked him questions and this resulted in more of an interview style encounter. I sensed from our discussion that Mr. Purple felt that he was being tested and that there were right or wrong answers to the questions I was asking him. This led to a raised level of anxiety throughout the discussion and Mr Purple getting quite loud and animated on occasions.

Mr. Purple did not want the conversation to be graphically recorded and expressed some anxiety about what would happen to the audio recording of our conversation, stating in particular that,

Mr. Purple: I do not want my social worker to know what I am saying

Mr. Purple expressed some surprise and concern at questions that were asked particularly in relation to his understanding of risks relating to sexual health and wellbeing stating,

Mr. Purple: I might have to speak to your university, asking me questions like that!

I asked Mr. Purple if he thought I should ask other people these questions and he replied,

Mr. Purple: Yes, it's up to other people if they answer them or not.

Towards the end of the conversation I developed a troubling concern that I was somehow contributing to Mr. Purple's sense that he was assessed and judged by the people, and in particular the professionals, involved in his life. This led to an anxiety that the conversation had become more of an interview and that Mr. Purple felt he would either pass or fail. I asked him if he wanted to stop the conversation and whether he wanted to withdraw from the research. His response was both emphatic and generous,

Mr Purple: No, no, no, it's difficult, if it helps you, if it helps other people, go on, go on.

5.5.3 **Ms Gold.**

I met Ms. Gold in the office in which I worked. I had prepared a meeting room by setting out water, tea, coffee and biscuits on the table and by taping flip chart paper to the walls in the event that Ms Gold agreed to the graphic facilitation of the conversation. Ms Gold arrived with her support worker but chose to meet me on her own. Her support worker waited in another room for her. Our meeting lasted just under one hour. Ms. Gold was very clear and emphatic in her responses to the questions asked. She agreed to a graphic record to be taken of the meeting. She sat at the table while I stood up and drew the graphics on the flip chart paper. The nature of the verbal interaction was conversational however the layout of the room and the fact that I stood up whilst Ms Gold sat led to a power imbalance and added a note of unnecessary formality. There were no areas covered by Conversation Guide 1 that Ms. Gold was unwilling to discuss.

I was struck by Ms. Gold's ability to respect the different roles that I occupied. I had a long standing professional relationship with Ms. Gold however she was able to respond to me as a researcher in the context of our conversation. I was also made aware during the process of our conversation of the tremendous privilege afforded me in the twin roles of researcher and practitioner. I had known Ms Gold in a professional capacity for approximately eight years at the time of the first conversation and in the space of one hour had learnt a lot of information about her that I did not know, information about her thoughts and feelings about issues, what she valued and what her motivations were around certain aspects of her life.

The conversation with Ms Gold raised some ethical research questions that are discussed in Chapter 7: Discussions but also raised some personal questions for me about the nature of my professional relationships with the people I worked with.

5.5.4 *The learning*

A number of practical adaptations to the conversational approach were adopted as a consequence of the pilot conversations. In light of Mr. Purples discomfort I decided to be far more explicit about participants' ability to opt out of answering questions relating to the area of sexual health and well being, prefacing these questions with statements such as,

Sam: Remember, it's a personal question so you don't have to answer.

In light of the potential power imbalance within the research interaction, particularly given my role as a professional practitioner as well as a researcher, I decided to adapt the use of the graphic facilitation. Instead of preparing the meeting rooms by taping flip chart paper to the wall, as one would if undertaking person centred planning, it was more important that the graphic facilitation was either a collaborative process or was directed by the participant in the research process. Flip chart paper was taken along to meetings and was made use of in a way that suited the individual participant. In this respect an effort was made to use person centred planning techniques to facilitate person

centred research. So, for example, as Mr. Blue had a physical impairment so the graphic facilitation of our conversations involved me sitting on the floor in front of his arm chair in his living room, while he directed the graphic recording of our conversation.

5.6 Our first conversation

5.6.1 *Conversation Guide*

The following extract demonstrates how the direction of the conversation was determined by the participant's responses and not by the order or nature in which the questions appeared in the *Conversation Guide*.

Ms White: *like the other day when I went in to Glasgow, there was this track suit that I liked, it was in JB Sports and it was really nice, it was like a black adidas one, but ** (Team Leader) didn't like and said she wouldn't pay £40 for it, I would. I liked it so some days if I like it, I don't get it because the carer doesn't like it, so rather than stand there arguing I just leave it.*

Sam: *And do you think that's right?*

Ms. White: *No I don't think that's right.*

Sam: *Is there anything you can do about that, anyone you can speak to?*

Ms. White: *Just got to get on with it, just accept what they are saying. They are only trying to help me and advise me.*

Sam: *Are they always right?*

Ms. White: *Not always.*

Sam: *So if you are right sometimes what do you think you could do about that?*

Ms. White: *Nothing.*

Later in the conversation Ms. White is able to put the situation she described into context when she discussing how she manages her money. Ms White recognises that budgeting is an area of her life that she has some difficulty and

does not see this as a personal failing but as a consequence of not having spent as much time as her Team Leader in the community.

Sam: So do you manage to budget.

Ms. White: No I don't manage to budget, I'm not good at that.

Sam: Like lots of people then.

Ms. White: Yes

Sam: How do you do that then?

*Ms. White: ** (Team Leader)'s helping me to do that. She is trying to help me manage my money because see come the end of the week, I would have no money, ** (Team Leader)'s helping me with that, to budget. She has more experience with the community then I have and knows how to budget.*

Sam: And see the money that you do get, what do you spend it on?

Ms. White: Food, sometimes CDs, sometimes stuff for my garden or just birthday presents or sometimes I give money to my family for their birthday.

Sam: was just wondering about the track suit that you liked did you have enough money to buy it?

Ms. White: No I never.

Sam: So you liked it but you didn't have enough money to buy it? I just wondered, cause that sometimes happens to me, you know you go to the shops and you like to have a look, window shopping.

The extract detailed above also provides an example of how the conversational approach to data gathering offers the opportunity to revisit subjects that have previously been discussed to uncover additional layers of meaning and develop greater levels of understanding, in this instance in relation Ms. White's understanding of how she budgets her money.

5.6.2 **Graphics Facilitation**

The application of the graphic facilitation of the research conversations evolved over the course of the research. It was utilised by research participants in very

different ways, for example Ms. Scarlett and Mr. Yellow chose not to graphically record the conversation we had but instead both individuals chose to draw abstract pictures whilst conversing. Ms. Scarlett's artwork, drawn during conversation¹ is illustrated in Figure 2.



Figure 2: Ms Scarlett picture conversation 1

For Ms. Scarlett the process of drawing whilst talking appeared to reduce the intensity of the conversational experience.

Ms. White chose to graphic some of the conversation herself and also directed the graphic representation of the conversation by specifying the size, colour and shape of the illustrations. The process was very interactive even although the conversation discussed very sensitive issues such as self harm and emotional upset as detailed in Figure 3: Ms. White graphics conversation 2.

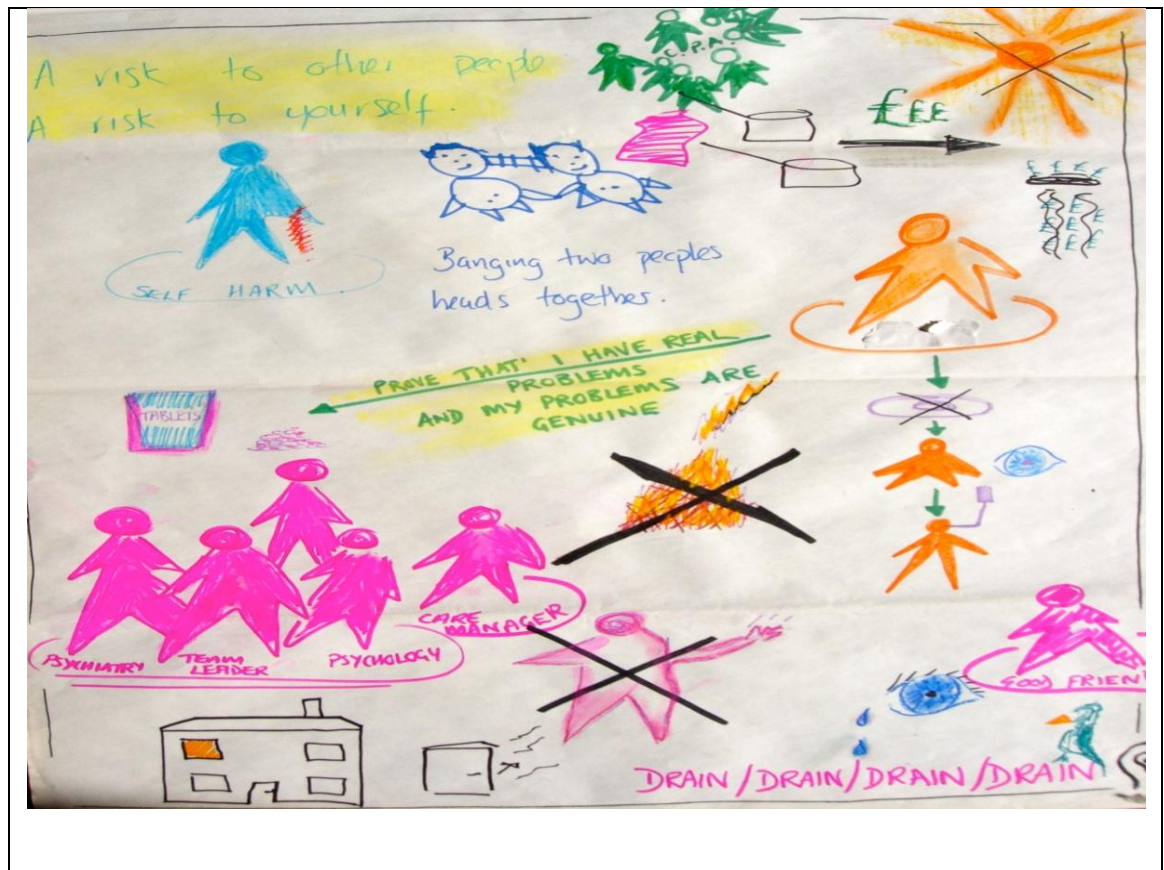


Figure 3: Ms. White graphics conversation 2

A contemporaneous graphic recording was also a useful way of checking that the information recorded was accurate. On more than one occasion the misunderstandings/misinterpretations on my part that could have misled the research process, were clarified using the graphic recordings. For example the following excerpt from my first conversation with Mr Green,

Mr. Green: I like ma bird.

Sam: Can I draw that?

Mr. Green: Yes I like my bird, beautiful - nice.

Sam: Are you any good at drawing? Can you draw your bird?

Mr. Green: No. I can't draw.

Sam: You can't draw a bird, I will have to try. What does your bird look like?

Mr. Green: It's nice, a sexy bird.

Sam: *Oh, a woman bird! Oh my apologies, I was thinking of a bird on a branch. Oh a woman.*

Mr. Green: *A woman*

Mr. Green was aware that I had misunderstood him when I drew a feathered bird and was then able to clarify the situation by stating that it was a ‘sexy bird’ that he was referring to. The graphic representation helped to resolve this misunderstanding quickly and ensured that Mr Green was able to maintain control of the information he was imparting.



Figure 4: Mr. Green graphics conversation 1

Further discussion about the use and effectiveness of graphic facilitation within this research project is detailed in Chapter 7: Discussion.

5.6.3 *Have I heard you correctly?*

It was important that research conversations with participants were concluded in a manner that ensured that the interaction was as far as possible both an interesting and empowering experience. Swain et al (1998, 33) suggest that ‘at the end of the research ask the participant how they are feeling, how did it feel

talking, being asked questions about different areas in their life?’ It was important that participants felt that they had control over the information they had imparted. At the end of each conversation I reiterated the key aspects of the conversation using the graphic recording and, on occasion, the audio recording as a guide. As an example of how this worked at the end of the first conversation Ms Lilac took the opportunity to listen to the complete audio recording of our conversation whilst simultaneously running her hand down the graphic recording turning the pages of flip chart pages at what appeared to be the appropriate juncture. I recorded the comments detailed in Figure 5. in the car following the first research conversation with Ms. Lilac.

The use of graphics seemed to help Ms. Lilac follow the course of the conversation. It seemed to anchor the conversation and when we did go off on a tangent it was a useful aid to bring the conversation back to the topic we had been discussing.

Figure 5: Journal entry 1 - Ms. Lilac

At the end of this process I asked Ms. Lilac if there was any information she wanted me to change, she declined to make any changes. Other participants chose not to listen to the audio recording but instead reviewed the graphic recording. At the end of the first conversation I asked participants if they would be willing to meet up with me again and on each occasion they gave their agreement.

5.7 A lighthouse moment – am I speaking a foreign language?

‘The main function of data collections and analysis is to make one’s own underlying premises as visible as possible and to challenge and develop the initial framework’

(Alasuutari 1996, 373).

In between the first set of conversations and the second I experienced a ‘lighthouse’ moment, a blinding flash of realisation that again had me questioning the direction of travel of the research journey. I read an article “‘Like the Secret Service Isn’t It”. People with Learning Difficulties, Perceptions of Staff and Services: mystification and disempowerment’ by Colin Goble (1999) that questioned the level of understanding that people with learning difficulties have about the architecture and functioning of ‘service land’. Reflecting upon the implications of this journal article I began to question assumptions that until that point I had not realised were inherent within the research such as:

- I had assumed that participants were aware of the term challenging behaviour and shared the professional and academic definition of this concept.
- I had assumed that participants knew that the label ‘challenging behaviour’ was applied to them by professionals.
- I had assumed that participants knew that their support services had been designed around their reputations for challenging services.
- I had also assumed or did not question that participants were aware of the Robust Services project and that their support was co-ordinated under the auspices of this project.

These assumptions had been written through the research design. I referred to ‘challenging behaviour’ in the Participant Information Sheets and Participant Consent Forms that had been sent out to those whose support was co-ordinated by the Robust Services project and who were assessed as meeting the eligibility criteria for the research. I had to question whether the language I had used had made sense to the research participants. What if, among the research participants, there was no shared understanding of the definition of challenging behaviour or an acknowledgement or ownership of the label applied to them by professionals? There were a number of ethical and methodological issues to consider; these are discussed in greater detail in Chapter 7: Discussion.

The practical implications of this reflective process involved redrafting the Conversation Guide 2 (Appendix 3) for the second set of conversations. It was important to peel back the methodological assumptions again and go back to definitional source. This necessitated exploration of participants' understanding of the concepts of learning difficulties, challenging behaviour and support services and how they related to them; a further discussion was required about the risks associated with these areas.

5.8 Our second conversation

The second conversations were planned to take place one year after the first conversations in line with the original research design which had been based upon a longitudinal study of adults with learning difficulties pre and post discharge from long stay institutions. Given the difficulties obtaining Ethics Committee approval, as detailed in the previous chapter, a pragmatic decision was taken to maintain the time frame for conversations rather than seek an approval for an adaptation to the research design.

The same protocol that was used for the first conversation was used to introduce the research and discuss issues such as roles and confidentiality. In addition the opportunity was taken to recap the first conversation using the graphic recording from the first session. This process was aimed at providing a sense of continuity to the research even although the meetings took place one year apart. It was also a further check that the information recorded was consistent with the participants' views, this process describe as 'member validation' Knox et al (2000).

A commitment was given to participants at the end of the second session that the results of the research would be produced in an accessible format in order to address the concerns raised by Kitchin (2000, 31) that 'as is well reported few disabled people reach university, as such, inaccessible academic texts are exclusionary and deny the disabled community the opportunity to act on the findings in a positive way'.

5.9 An introduction: who are you?

Throughout conversations with participants regular checks were made to ensure that participants understood the purpose of the meeting and the fact that the information they were providing was informing the research project. At the end of the second conversation (year two) research participants were asked if they would provide a self description (in some cases with the assistance of the support worker(s) working with them (see Appendix 4). It was envisaged that participants' self descriptions would provide a balance for the reputations assigned to this group of individuals in relation to their perceived challenging behaviour. As previously detailed in this chapter quantitative data based upon the AAMD Adaptive Behaviour Scale Part 11 (Nihira, K., Foster, R., Shellhaas, M. and Leland, H., 1974) measure of perceived challenging behaviour of participants in this research was undertaken and then intentionally excluded from this thesis. The general professional perception of this group of individuals is sufficiently conveyed by the fact that a specific project, the Robust Services Project, was established to co-ordinate the support of these individuals due to the level of challenge they were considered to pose services working with them.

Participants' self descriptions were graphically recorded using accessible hand drawn representations, for example Figure 6: Mr. Orange graphic self description.



Figure 6: Mr. Orange graphic self description

5.10 Learning together

Two directed conversations with research participants took place approximately one year apart. However, Table 1 details the fact that there were a number of instances when conversations took place over a number of face to face meetings.

Table 1: Number and location of meetings

Name	Conversation1 No. Meetings	Location	Conversation2 No. Meetings	Location
Mr. Pink	2	Office/House	1	House
Mr. Orange	2	Office	1	Office
Ms. Gold	1	Office	1	House
Mr. Blue	1	House	2	House/House
Mr. Yellow	1	House	2	House
Ms White	1	Office	2	Office/Office
Ms. Lilac	1	House	1	House
Mr. Green	2	Office/House	1	House
Mr. Purple	1	House	1	House
Ms. Scarlett	1	House	1	House
Mr. Grey	0	0	0	0
Ms. Silver	1	House	0	0

There were three main reasons why multiple meetings took place. On a number of occasions the research participants requested that the meetings were adjourned, for example, during our first conversation both Mr. Green and Mr. Pink individually requested a cigarette break and then chose not to resume the conversation upon their return. They were both willing to reconvene the meeting at another time and location. Both Mr. Green and Mr. Pink requested that the subsequent meeting take place in their own homes. Another example of individuals exercising their agency involved Mr. Yellow. In seeking to assist Mr Yellow to his seat I inadvertently touched his elbow. Mr. Yellow is very sensitive to physical contact and my intrusion caused him considerable upset and distress. The meeting was adjourned. On one occasion a research participant experienced ill health during our conversation; our meeting was reconvened at a later date. On two occasions technical malfunctions occurred, despite checks, the mini disc audio recording equipment used failed to record the full conversation. On both occasions Mr. Blue and Ms. White agreed to meet again and re-record our conversation. In both instances the graphic recording of the original conversation provided a useful prompt when re -recording the conversation.

5.10.1 *How to say no?*

Two individuals Mr. Grey and Ms. Silver initially agreed to participate in the research, they then both subsequently chose to withdraw from their involvement. Working from the principle that 'all is data' (Glaser 2002) I have chosen to detail the different ways they chose to indicate their withdrawal from the research process. Within research relationships researchers and research participants use power (Thapar- Bjorkert and Henry 2004) however occupying the dual roles of researcher and practitioner may have introduced additional pressure to participate in the research. There are obvious ethical issues that arise from this situation and these are discussed further in Chapter 7.

It is important to note that neither Mr. Grey nor Ms. Silver were passive in their response to the research. They may have used unconventional methods of withdrawing from the research process but both individuals exercised power to achieve the ends they sought, which was their non participation. In this respect neither Mr. Grey nor Ms. Silver fit the stereotypical picture of the vulnerable research participant open to exploitation.

5.10.2 *Mr. Grey*

Mr. Grey did not turn up to any of the pre-arranged meetings. A total of four meetings were scheduled at locations of his choosing: the first two meetings were scheduled to take place at his house, the second two at the offices of the Supported Living organisation that supports him and for whom I work. On the first three occasions I contacted Mr. Grey and on each occasion he was extremely apologetic and appeared to have a reasonable reason for not meeting with me; either having forgotten the appointment, having a conflicting diary appointment that had arisen at short notice and on the third occasion a misunderstanding over the proposed location. On each occasion Mr. Grey appeared to be keen to reorganise another date and time when we could talk. After the fourth attempt it seemed appropriate not to try to reschedule the meeting again in the belief that if Mr. Grey really wanted to participate he knew how to contact me. In the course of my professional involvement with Mr. Grey I had recourse to meet with him on a number of occasions about other matters,

on each occasion we met up as arranged. At no point did Mr Grey initiate discussion regarding the research and the missed appointments with me. For reasons I have, as yet, been unable to discuss with Mr. Grey, he found it difficult to articulate verbally that he did not want to participate in the research; his behaviour however said it all (Goodley and Moore 2000).

Acquiescence on the part of people with learning difficulties in the research process has been highlighted as a potential area of concern within academic literature (Biklen and Moseley 1998). It is conceivable that the dual roles of researcher and practitioner may have added to the pressure that Mr. Grey felt to acquiesce despite his reservations.

5.10.3 *Ms. Silver*

Ms. Silver agreed to participate in the research and arranged for the first conversation to take place in her own home. The meeting took place and Ms. Silver agreed to the conversation being audio recorded and for a graphic record to be taken. Ms Silver was extremely candid during the conversation about her perception of the risks in her life and in the community. Rich and thought provoking data was gathered.

One week after the initial conversation Ms. Silver contacted me by phone and informed me that she no longer wanted to participate in the research. She asked me to meet her again at her house and to bring with me the mini disc on which we had recorded our conversation. When I met with her she again confirmed her intention to withdraw from the research and asked me to destroy the mini disc in her presence. I had also brought along the graphic recording of our conversation although Ms. Silver had not mentioned it; this was also ripped up in her presence.

The reason Ms. Silver cited for withdrawing from the research was that she felt that she had 'said too much'. Unlike Mr. Grey, Ms. Silver was able to verbally articulate her desire to withdraw from the research project. She was also emphatic about the destruction of the physical manifestation of the conversation, the breaking in half of the mini disc. Koro-Ljunberg, et al., (2008, 334) considered the relationship between research participants and 'tangible

objects of research(e.g. protocols, digital devices)’ during their work with young people with a diagnosis of ADHD, recognising the influence these interactions had on the construction of data they obtained. It would appear that Ms Silver was aware of and affected by the process of recording the conversation and that erasing the recording was an important symbolic gesture of her withdrawal.

Initially I experienced a degree of frustration at the withdrawal of consent by two participants, particularly in the case of Ms. Silver whose initial conversation had provided such rich and informative data, ‘stories that are ‘messy’ are considered both troubled and troubling, and more than representing an alternative, they represent a disappointment’ Noy (2003, 11). However from this initial disappointment a number of key issues for consideration emerged which are highlighted briefly here and discussed in more depth in Chapter 7: Discussions. Hoffmann (2007) suggests that shifts in power and emotion are important and should be considered as significant data. The different ways Mr. Grey and Ms. Silver chose to withdraw from the research may be regarded as evidence that they felt able to exert a measure of power and control over their own agency, that neither individual felt obliged to adopt the role of a ‘passive prisoner of the research process’ (Stanfield 1994, 168). As previously highlighted in Chapter 3 scholars have noted that the level of rapport between researcher and research participant can engender a different level of sharing (Walmsley 2001, Koro-Ljungberg 2008). Knox et al (2000, 55) state that ‘it is often the personal characteristics of the inquirer rather than his or her research skills, that expedite the inquirers’ entry into the informants world’. Although an independent process for obtaining consent to participate was in place, it is possible that the dual role of researcher and practitioner made it more difficult for potential participants to withhold their consent.

It is also worth noting the possibility that Ms. Silvers’ desire to withdraw from the research may have been as a direct consequence of the nature of our relationship out with the research arena. Ms Silver and I have a particularly strong and trusting relationship based upon a shared historical experience during particularly difficult times in her life. It is possible that Ms. Silver may have found herself being more open, and as a consequence disclosing more than she intended, as a result of our relationship. Ms. Silver was able to resolve this

situation by withdrawing from the research, however this in itself raises additional ethical dimensions in relation to the role of the practitioner as a researcher; these are discussed in greater depth Chapter 7.

5.11 **Data analysis**

The data collected took a number of different forms including transcripts of the audio recorded conversations; observations and reflections noted in the research journal and the graphic recordings of the conversations. The combination of all three forms of collection techniques added to the depth and contours of the data available. I will deal with each of these in turn. Analysis of the data required a number of different approaches to capture the nuances of the data available.

5.11.1 ***Audio recordings***

During the course of the data collection, the conversations with research participants' words and phrases began to emerge and themes began to bubble to the surface of my consciousness. These themes were captured and detailed in the research journal. It was these overarching themes that I thought would form the basis of the findings of this research; informed as they were by my knowledge and experience as a practitioner. However the process of manually analysing the data, utilising the principles of grounded theory, totally transformed my understanding of the data. I will go on to explain the process that was undertaken and the influences that were brought to bear.

Conversations with participants were recorded on to mini disc audio recorder. The mini disc recordings were then manually transcribed into a Microsoft word document. This information was then formatted into a landscape document that enabled manual three level coding to taken place, a sample of three level coding of Ms. Lilacs' transcript can be found in Appendix 5. The initial first level coding was undertaken line by line, a microanalysis scale of detailed questioning and analysis (Strauss and Corbin 1998). The aim of this process was to self consciously bring discipline to the analysis (Strauss and Corbin 1998). Total immersion in the data increased the sensitivity to its properties and dimensions.

By deconstructing the conversations into individual words, lines and phrases new levels of meaning were uncovered.

This process of line by line coding bridged a distance that I was unaware had been created between what I heard and what I listened to. As a practitioner I had heard the words of a number of the participants, even their expressions of hurt and distress; coding the same statements line by line removed the professional distance and provided new ears to listen to their voice. The intensity of the coding enabled me to look anew at processes and patterns that had faded in to the background of my consciousness, like metaphorical wallpaper. This new perspective allowed me to focus on the detail of what was not said in addition to what was; the absence in addition to the present. Analysing the data on a line by line basis uncovered unacknowledged assumptions that had muffled my hearing during the conversations with participants. New patterns of words and undercurrents of meaning began to emerge and inform the analysis.

This process of unknowing in order to know was only achieved by attaining a physical distance from the subjects of this research. As a practitioner I had a professional relationship with all but one of the participants. During the initial stages of the coding process I found it difficult to separate the two roles and initially this affected the data analysis. Taking some time away from work and all that was familiar freed up the space view the data from a different perspective. Line by line coding of each conversation was a time consuming but cathartic process.

Concepts and themes emerged from the data unforced by preconceptions. These concepts were collated into an intermediary level coding that I assigned as level 2 coding. The embryonic clustering of concepts initiated the process of conceptualising the codes analytically. I used hand drawn graphics as a non linear, visual and accessible format for organising the material I had gleaned from conversations. Key words and phrases (in vivo codes) were highlighted as anchors for the analysis of particular themes, for example 'being not well' was a phrase that recurred throughout the conversations. It was used by participants to describe and explain behaviours that others found challenging. This phrase provided an anchor for analysis on bringing in the concepts of emotions,

language, health discourse, internalised reputations. Through this process of identifying relationships and connections between emerging concepts the core categories began to develop.

5.11.2 ***Research diary***

The data in this form recorded observations and thoughts about the process of undertaking the research. This included encounters with research participants and also observation on my research conduct. The written transcripts recorded the spoken words of research participants; the research journal attempted to capture the context within which the conversations took place, the scenes, the actions and observations of what was and was not present. This included observations on the interaction with research participants and others who were present during the research conversations. Data from the research journal provided additional information that informed analysis of the transcripts.

5.11.3 ***Graphic facilitation***

Using some of the processes of person centred planning was an attempt to improve the accessibility of the research process to participants. The graphic facilitation of the conversations appeared to encourage a level of participation and engagement. It provided immediate feedback to participants that they were not only being listened to but that their comments were being recorded, before their eyes. The graphics collected were not the subject of analysis but did provide a useful function, providing an immediate check on the accuracy of the data gathered.

5.12 **Conclusion**

The methodology for this research developed through an emergent and reflexive process. New knowledge was obtained through the process of undertaking the research, in addition to that explicitly rendered from the data collected and coded. There were limitations to the process that evolved, the research conversations in the form that they took place did not give voice to all participants equally and there is learning to be gathered from this. The process

did appear to be a positive experience for most of the participants. The data gathered provides a fascinating glimpse of the concept of risk from the perspective of adults with learning difficulties in keeping with the aspirations of Roets and Goedgeluck (2007, 91) when stating,

‘Qualitative researchers do not research or write to capture the totality of social life but to interpret reflectively slices and glimpses of localized interactions to understand more fully both others and ourselves’

The key findings of this research are detailed in the following Chapter 6.

Chapter 6: Findings - traversing terra incognita

‘The whole point in social research is to come up with new viewpoints to the mundane reality organised by the natural attitude, and in doing so to find out new things about it’.

(Alasuutari 1996, 372)

6.1 Introduction

Freed from the methodological constraints of the original research design and the unconscious adherence to a medical paradigm, the research evolved. Setting aside perceived academic constraints enabled the research to refocus on an exploration of the perception of risk held by adults with learning difficulties. Adopting a post modern social constructionist approach the research was aimed at celebrating difference and giving voice (Woods 1999) to adults with learning difficulties who had been assigned reputations for challenging services. Additional research questions grew from this new direction, not in the form of restrictive parameters on the research journey but as expressions of interest in potential new areas worthy of exploration. The questions that arose were;

- In what ways do adults with a label of learning difficulties perceive the concept of risk and to what extent does it inform their life choices and decision making?
- Does being assigned a reputation for ‘challenging services’ influence perceptions of risk?
- To what extent are the perceptions of risk of adults with learning difficulties reflected in current learning disability theory, policy and practice?

The aim was to use research conversations, to give voice to the research participants (Roets and Van Hove 2003). Challenging behaviour has been the subject of much research and academic literature in the field of learning disability. Adults with learning difficulties assigned the label have been researched, quantified and discussed at great length and such deliberations have

informed the development of policy and practice. There is, however, a dearth of literature exploring the concept of challenging behaviour from the perspective of adults with learning difficulties, as discussed in Chapter 3 Section 3.3.2. Similarly risk as a concept has developed an increased prominence and influence in society in general, including in the arena of social care as detailed in Chapter 2; there are, however, very few research studies exploring the concept of risk from the perspective of adults with learning difficulties. There are even fewer studies exploring this concept from the perspective of those who would be regarded as ‘risky individuals’, adults with learning difficulties who have been assigned reputations for challenging services.

‘Disability is about stories, having the space to tell them, and an audience which will listen. It is also about recognising differences, and isolating the significant attributes and experiences which constitute disability....But (metaphorically, if not physiologically), it all starts with having a voice’

(Shakespeare 1996, 111).

6.2 Overview

This chapter outlines the findings from the research conversations undertaken with participants in the research process. It attempts to combine a cogent representation of the voices of the adults with learning difficulties who supported this research endeavour by giving of their time and knowledge, with analysis borne of the situated knowledge of a practitioner as researcher. An effort was made to represent multiple subjectivities in relation to the terms risk, learning difficulty and challenging behaviour in order to deconstruct taken for granted ‘truths’ and reconstruct plural understandings of these concepts (Roets and Van Hove 2003).

Research participants spoke with power and insight, voicing previously unheard perspectives on the concept of risk. The dialogue offered insights into the social worlds of participants and their relationships to it (Yates et al. 2008). Extracts from conversations with participants are interspersed throughout the following discussion of the findings of this research. Some of the dialogue takes the form of soliloquy that offer grounded insights into the lived experience of

participants. These tracts are used to landmarks around and through which analysis was interwoven. Conversing with participants offered an opportunity to glimpse new insights into their lived experience and the influence of the concept of risk in their lives. These insights were gleaned from what was absent in the conversations in addition to what was present, from what was not spoken about as well as what was and from actions and processes as well as words.

‘The identity of something is given by that which it is not, that which it is absent from - for example, darkness is ‘the absence of light’...Meaning and therefore knowledge is never stable... Knowledge is a consequence, not a representation, of action in a dynamically open field of play’

(Derrida, 1976 cited in Corker 1999, 638).

The role of the practitioner as researcher afforded the opportunity to delineate the context, scenes, and situations of action and carefully uncover the layers of additional nuanced meaning in the everyday situations encountered. These insights offered potential inroads into an understanding of the underlying processes and intentions affecting the lives of adults with learning difficulties and informed the analysis. The particular use of language, words, and phrases was an important lens through which to critically analyse, interpret and ascertain attributed meaning in an effort to uncover, ‘taken for granted and hidden assumptions of ...participants; showing how they are revealed through affects and actions (Charmaz 2006, 21).

The first set of research conversations was loosely structured around the risk domains of relationships, home, community and physical and emotional well being. Following the first set of conversations additional risk themes emerged from the data, through the practical process of data gathering, ongoing data analysis and as a result of reflections upon the research process. These reflections were stimulated and informed by the academic literature review that was undertaken at the same time as work in the field. Risks associated with the concept of learning difficulties, challenging behaviour and support services were additional domains explored during the second set of research conversations.

The introduction of these additional domains was both a consequence of the emergent nature of the research process and was also an overt attempt to

overcome some of the unconscious methodological assumptions that had been inherent within the original research design. These original assumptions were founded upon the naïve belief that individual research participants were aware that they had been assigned the labels of ‘learning difficulties’ and ‘challenging behaviour’ by the professionals involved in their support. Recognising that this might not be the case, it became important that these assumptions were tested and refuted as necessary. This process also provided an opportunity for issues of language, definition and labelling to be brought in to the research process and for participants to offer their perspective. The findings from this area of the research are detailed in this chapter.

In addition to the themes relating to ‘learning difficulties’, ‘challenging behaviour’ and ‘services’ a number of other core themes emerged as the research process unfolded. These were identified through the process of data analysis including the coding of transcripts and also ongoing reflection on the practical aspects of the research process. These emergent themes were labelled voice and harm; a discussion of each of these emergent themes forms the structure for the main body of this chapter. Although these themes or categories have been identified separately for ease of discussion, there were considerable areas of overlap.

The two core themes identified consisted of a number of sub themes that emerged from the data, for example, within the category voice, the sub themes of reputation, becoming ‘other’ and communication intertwine and coalesce. A brief summary of the key findings for the core theme is provided at the end of each section.

Before exploring the emergent themes it is necessary to provide a definitional context for the discussion by exploring the participant’s perception of risk as a concept.

6.3 Risk and Danger

Discussion of abstract concepts such as time, have been highlighted by a number of researchers as an area of difficulty when undertaking research with adults with learning difficulties (Stalker 1998; Booth and Booth 1996). This was

reflected, to an extent, within the findings of this research. Risk, as an abstract concept, was difficult for a number of participants to define; for example Mr. Orange and Mr. Yellow were unable to describe what the term risk meant to them and Mr. Green stated that it was not a word that he had heard before. For other participants it was a concept that they were aware of and in most cases risk was synonymous with danger.

‘Heyman and Huckle (1993) interviewed people with learning difficulties and their family carers. Their overwhelming impression at the end of this interview process was of a ‘strong sense of danger which most conveyed’. Although they stated that there was a range of attitudes,

‘a majority of adults with learning difficulties, and their family carers worried about the adult wandering around their local ‘community’, fearing, variously that they might be verbally abused, run-over, kidnapped, mugged, raped or killed’

(Heyman 1993, 4)

The perception of risk conveyed by participants in this research was of risk as danger. There appeared to be a wide range of perceived risks involved in everyday life, Ms. Scarlett defined risk as,

Ms. Scarlett: *‘Things you’ve got to watch out for so you don’t get hurt, you’ve got to watch when you cross the road in case you get knocked down. It’s better if you cross at the lights.’*

Sam: *Are there any other things that you think involve risk, other than crossing the road?*

Ms. Scarlett: *Getting burnt.*

Sam: *How would that happen?*

Ms. Scarlett: *You could burn yourself at a cooker or something like that. You could be in a house and it could be on fire, the building in flames or something like that.*

Asked to give a concrete example of what he thought was a risk Mr. Pink also mentioned ‘fire’. Asked whether he thought there was such a thing as risky people Mr Pink indicated that he felt that there was and gave the following enigmatic description,

Mr Pink: bad people with evil on their minds, evil in their hearts.

Mr. Purple stated that he recognised the term risk but indicated that that no one had ever talked to him specifically about it. Mr. Purple's response was interesting as an assessment of risk, of which he appeared to be unaware, would have informed the fact that his support arrangements were co-ordinated under the auspices of the Robust Services Project. Mr Purple's response appears to indicate that risk discourse forms part of the architecture of 'service land'; informing significant decisions affecting the lives of adults with learning difficulties, but is not part of the dialogue with those who access services.

Mr. Purple was consistent in his understanding of the concept of risk equating it to 'danger'. Asked the question 'danger to whom?' Mr Purple responded '*to me, to support staff, to anyone who is with me*'. However asked what risks he experienced Mr. Purple minimised the idea of risks in his day to day life, initially stating that he did not think there were any. Mr Purple subsequently indicated that his notion of risk was informed by the health and safety practice of his support provider. Asked where he had heard the word risk mentioned he stated,

Mr. Purple: in the office, hearing people go on about health and safety

Sam: do you know of any risks that other people might see in relation to you?

Mr. Purple: no, there's not a risk here?

However later in conversation Mr. Purple indicates that he believed attitudes to risk affect the lives of people with disabilities leading to restrictions being placed upon them that are not experienced by non disabled people. Interestingly Mr. Purple intimated that he had personally challenged risk based restrictions imposed upon him.

Mr. Purple: well we all have to take risks, we can't be wrapped in cotton wool, I don't agree in being wrapped in cotton wool.

Sam: and why is that?

Mr. Purple: *because it's just people with disabilities always seem to be wrapped in cotton wool and I don't agree with it; never agreed with it.*

Sam: *and do you feel you're wrapped in cotton wool.*

Mr. Purple: *no, I destroyed the cotton wool.*

Two participants expressed markedly different responses to other participants when asked the question about what the word risk meant to them. Mr. Blue and Ms. White described risk as the risks they posed to themselves. Asked what he thought risk was Mr. Blue stated,

Mr. Blue: *Yes, I am risk. I was a risk to myself, because I self harm but I don't do it much. I have not done it for a couple of months. The last time I did was New Year and nearly Christmas but that was all.*

He later went on to discuss risk in a wider context relating to it in more neutral terms as,

Mr. Blue: *Just that there's a risk. There is something that is going to happen.*

He then went on to give an example of risk being the chance of getting a ticket when going through a red light at a traffic junction. However, Mr. Blue's initial response appeared to reflect an internalised perception of risk and seemed to relate to his experience of self harm. A similar experience was shared by Ms. White who conveyed a very strong sense of the risks she felt that she posed to herself and others, eloquently illustrated by the following excerpt from our second conversation,

Ms. White: *You can be a risk to other people or a risk to yourself, especially including self harm behaviour.*

Sam: *Can you think of any risks in your life?*

Ms. White: *Overdose.*

Sam: *The risk of an overdose?*

Ms. White: *Cutting yourself, swallowing things, eh, cutting yourself, swallowing things, overdose, banging your head on the floor, bursting*

blood clots in your head when you're banging your head, just basically all I can think of.

Sam: *And that's the risks to you. Are there any risks to others?*

Ms. White: *You can maybe class the risks as maybe biting people or injuring people, let's just say hitting them, physically abusing them, being really violent towards them like injuring the other person like means breaking their jaw or cutting them or breaking their leg or arm or that, you know what I mean?*

Sam: *Ok. I think when we talked before...*

Ms. White: *And also there's a risk of fire as well. If you're setting a fire you're putting the other person in danger you're not thinking about your actions. You're just going ahead you know rather than taking a step back and saying look, what have I done here, and before you know it the damage is already done. And then you've got lots of, eh, reports to do and the on-call and that and the police to be phoned so it takes a lot of work.*

Sam: *Okay. Because the last time we talked you spoke about self harm didn't you? There's a picture we drew of, I think that must have been you cutting yourself and...*

Ms. White: *And there are other things like self-harm can mean swallowing screws and swallowing watches batteries, anything.*

Sam: *Really, so swallowing things that aren't meant to be swallowed?*

Ms. White: *Yeah, that's right.*

Ms. White's soliloquy raises a number of interesting points. She uses the concept of risk to describe behaviours that would be categorised as 'challenging behaviour' in learning disability literature. She also makes use of the language of mental health services and literature when describing the self inflicted damage to her body as 'self-harm', rather than 'self injurious behaviour' the term generally used in learning disability services and literature. Ms. White's description of risk highlights a dichotomy in the language used in 'service land', an issue discussed in greater length in Chapter 7.

Ms. White was able to detail risky or challenging behaviour and when referring to the setting fires, was also able to articulate other possible courses of action available to her. She was clearly aware of the negative consequences of fire

setting in terms of organisational procedures, referring to ‘on-call’ systems and ‘reports’ and the possibility of the involvement of other agencies such as the police. Ms. White does not appear to lack an understanding of the ‘risky’ behaviour she engages in, if ‘challenging behaviour can be viewed as a form of communication Ms. White appears to have something very important that she wants others to hear.

6.3.1 ***Key finding- concept of risk***

- Participants perceived risk to be synonymous with danger
- Risk appeared to be part of the architecture of social care but was not the subject of discourse between professionals and those labelled as ‘risky’ or ‘challenging’.
- A number of participants had internalised the label of ‘challenging behaviour’. This was particularly noticeable for participants who talked about self-harming.
- The research methodology was not inclusive enough to elicit the views of participants who experienced difficulty verbally articulating meaning for abstract concepts.

6.4 Risk and Voice

The first key theme that emerged from the data was that of voice, this theme was composed of a number of sub themes, reputation, becoming 'other', communication [see Figure 8. Voice-sub themes]. The sub themes are discussed in turn in the following sections of this chapter.



Figure 7 Voice - sub themes

6.4.1 *Reputation*

The participants who assisted with this research were unique and interesting individuals. However they had a number of key life experiences in common, having been assigned the label learning difficulty and in addition a reputation for challenging the services that supported them. They also all had experience of living in secure institutional settings as a service response to their perceived 'challenging behaviour'.

Aull Davies and Jenkins (1997, 96) suggest that there are two forms of identity, the collective defined identity of people with learning difficulties articulated through public meanings and discourses and the self-identity developed through experience. Historically professionals working within the medical paradigm have dominated the public discourse in relation to learning difficulties and particularly the discourse in relation to those whose behaviour was considered to challenge services. Until recently the voices of those assigned the labels have been silent. In an effort to facilitate a dialogue, giving ‘voice’ to adults with learning difficulties, that challenged the monologue about ‘madness’ that has been established on the basis of silence (Foucault 1967), research participants were asked to provide an alternative representation of themselves through a self description. Two examples of self descriptions can be found below, in Figure 8 : Mr. Pink self description and Figure 9: Mr. Purple self description. The self descriptions of other participants can be found in Appendix 4

‘I’m fair’	‘I want a 49 th birthday party’
I’m a fast thinker and a slow worker’	‘I’m a smoothie’
‘I was born in B....hill’	‘I have got a nice personality’
‘My family is important to me’	‘I remember birthdays’
‘I’m kind’	‘I’m good’
‘I’m an Elvis fan’	‘I’m a good thinker’
‘I like a beer/lager but I cannae get it’	‘I was reared with the Jews’
‘I lived in the G.....s’	‘I am unique’
‘I am honest’	‘I smoke’
<i>“People take a liking to him”</i>	‘I am such a nice guy’
‘I have got a decent streak’	

Figure 8 : Mr. Pink self description

'I am very easy going'	'I am a 28 year old Scottish man'
'I am quite nice all the same'	'I believe in freedom for all, everyone has a right to have their voice heard'
'I am a loyal supporter of the Celtic'	'I believe that all team members should do a six month probation when they join a team'
'I believe that all team members should be given a chance'	'I am better now for taking things on the chin. I don't mean literally, now if I think someone is being unreasonable I will say'.
'I do like to treat everybody the same'	'I believe in consequences for action, reasonable consequences'
'I am the most challenging person you support - Researcher " <i>Do you want me to write that?</i> " - Mr. Purple 'No, No, No!' ***	'I don't believe in holding a grudge'
'I don't believe in sacking your support worker if they make a mistake'	
'I am a peer consultant'	

Figure 9: Mr. Purple self description

*** Mr Purple agreed that to this statement being included when I suggested that it would be useful for the research. His original comment was made with humour which is why I had checked whether he wanted it to be included.

Goodley (2001) suggested that people with learning difficulties are often subjugated under the system but their life stories can highlight other sides to life. The same could be said for providing an opportunity for individuals to challenge their reputations as 'risky individuals' defined in a reductionist manner on the basis of perceived behaviour and diagnosis. Given the opportunity, participants chose to represent themselves with humour, generosity, humility and activism. The self descriptions are brief, however, I would contest that they provide an insight into the characters of the individuals who gave of their time to be involved in this research project. They convey the humour, self reflection and sense of self that I had the privilege of experiencing, as a researcher, spending time in the company of these individuals. Common to each of the self descriptions was a sense of activity, of individuals participating

and engaging with those around them. Each person appeared to be an identifiable individual with something to offer to others, countering the notion of passivity often conveyed in learning disability literature. A strong sense of decency, justice and fairness was also common to the self descriptions and particularly noted in that provided by Mr Purple, detailed in Figure 9.

The self descriptions challenge the notion that the label learning disability is an all encompassing identity. Instead, they support the sense that identity is a social construct that is both fluid and dynamic and open to negotiation through interaction (Rapley, Kiernan and Antaki 1999). There is a potential concern that through disabling interactions the formation of a self identity may be stifled and adults with learning disabilities internalise the negative identities assigned to them through labels such as 'challenging behaviour'. The self descriptions not only act as a strong counterpoint to a great deal of learning disability academic literature about adults who are perceived to challenge services, they also provide a context from which to explore the risks associated with being assigned the labels 'learning difficulties' and 'challenging behaviour'.

6.4.1.1 The concept of 'learning difficulties'

There were a number of different responses from participants when asked if they had heard the term 'learning difficulties'. Ten of the twelve participants responded that they had heard the term; two participants Mr. Orange and Mr. Yellow found the concept difficult to relate to and were unable, during the course of our conversation, to articulate a meaning for it. The ten participants who had heard of the term were able to describe what it meant to them.

Ms. Scarlett talked about the stigma attached to being labelled as having learning difficulties. Asked why she saw a Psychiatrist Ms. Scarlett responded that her mother had spoken to somebody and had got her treatment at the local psychiatric hospital.

*Ms Scarlett: Because my mammy explained it to somebody head (by this I think she means someone senior). I wasn't right in the head. I was. I was. I wasn't right in the head. But I know I'm all right. I know I'm not daft. My mammy used to push me in front of boys in G**** (the local area in which she lived) and she said "don't bother with her, she's under L*****" (name of a local psychiatric hospital). She pushed me in front of them.*

Ms. Scarlett's mother's attempts to explain her daughter to the local youth left a lasting impact on Ms. Scarlett, in ways that still affect her to this day, some forty years later. Asked what her understanding of the term learning difficulties was Ms Scarlett gives a broad and considered definition,

Ms Scarlett: Aye. Some are backwards with their lessons. Same with me and some can't look after themselves properly and some have got to get fed and that and taken care of. It doesn't mean to say that you're daft just because you've got a learning difficulty.

With this definition Ms. Scarlett appears to challenge some of the stigmatising aspects associated with the label learning difficulties.

With the exception of the Mr. Orange and Mr. Yellow participants appeared to recognise the label learning difficulties and were aware that the label was applied to them by professionals. There was a more disparate range of responses from participants when I asked whether they had heard the term 'challenging behaviour'.

6.4.1.2 The concept of 'challenging behaviour'

There was a spectrum of resistance from participants to the label 'challenging behaviour', ranging from Mr. Purple's assertions that he was 'not challenging enough' through disagreement with some aspects of the term, to a whole sale rebuttal and contesting of the legitimacy of the label. Again Mr. Orange and Mr. Yellow found discussion of this abstract concept difficult, which further underlined some of the limitations of the research approach, a factor discussed later in this chapter in Section 7.

Mr. Pink stated that he did not know what the words 'challenging behaviour' meant and had never heard anyone talk about him using the words. Other research participants appeared to have internalised the dominant discourse of

medical environments in which they had lived, for example when Ms. White was asked whether she had ever heard the words challenging behaviour she described it in terms of her diagnosis as she knew it.

Ms. White: *I have, yes. Challenging behaviour means you display a number of ways... challenging behaviour's not just one issue... challenging behaviour can mean you can behave inappropriate. You don't think before you react so you do, you do things without thinking. It can also mean your actions towards other people. It can mean huffiness, moodiness, you can throw a temper tantrum or you can bang doors or scream and shout so you can be heard. That involves basically everything.*

Sam: *That's all challenging behaviour?*

Ms. White: *Yes. It means you also... challenging behaviour can also mean you can do things without thinking, cause that's the same as malagrade coping strategies you can do something and you don't regret it.*

Sam: *Say that again, what were the words you were using?*

Ms. White: *Malagrade coping strategies.*

Sam: *Maladaptive coping strategies?*

Ms. White: *No malagrade coping strategies.*

Sam: *'Malgrade' coping strategies?*

Ms. White: *Yes. It means you do stuff without thinking. You don't realise the consequences that you're putting yourself in and putting the other person in.*

Sam: *Who used those words?*

Ms. White: *That's what I, that's what I got told that's the problem I've got.*

Sam: *Who told you that?*

Ms White: *My doctor at my last place.*

Sam: *Oh right.*

Ms. White: *Saying I've got malagrade coping strategies because I do a lot of things without thinking. I maybe say stuff... that I don't mean.*

So I say things without knowing what they mean, or without the damages that other people are in.

Sam: *Without knowing what damage you might do?*

Ms. White: *Yeah, to others. So I don't think about the consequences so before I know it the damage is already done. Before it's too late.*

Ms White's response appeared to indicate that she had internalised the definition of 'challenging behaviour' and the diagnosis that she was assigned by the Psychiatrist in the institution in which she previously lived, 'that's the problem I've got'. The terms Ms. White used to describe her 'condition' sounded like a conflation of two terms used in learning disability services. 'High', 'medium' and 'low grade' was the diagnostic stratification system historically used by the medical profession within long stay learning disability hospitals and the term 'maladaptive behaviour' is still used in learning disability research and practice emanating from the medical paradigm.

At the beginning of the statement Ms. White appeared to indicate the purposefulness of her behaviour when stating 'you can bang doors or scream and shout so you can be heard'. The link between behaviour and communication and the risks of misinterpretation are discussed in more detail in Section 6.4.3 of this chapter. Later in the conversation Ms. White discussed a further diagnosis she understood she had been assigned by her Psychiatrist.

Ms White: *He says there's a thing I've been diagnosed with is misunderstanding people in conversations 'cause like when I'm having, say I'm having a conversation with you, I could pick it up in the wrong way and get the wrong end of the stick.*

There is a risk that by internalising perceived negative behavioural characteristics in the form of a diagnosis, adults with learning difficulties lose control over the definition (and the rationale) for their behaviour, ceding it to medical professionals.

The responses of a number of participants in this research appeared to reinforce this finding. Ms. Scarlett, Ms. Lilac and Mr. Blue described themselves as being 'not well' when speaking about behaviours they engaged in that others found challenging. This could be interpreted as a way of absolving themselves from

personal responsibility for behaviours that other people find difficult. However all three individuals also talked about the positive developments that have taken place in their lives since they left institutional care and appear to draw a link between their social and emotional wellbeing, their physical environment and the support they receive. Although Ms. White appears to have internalised the medical diagnosis of her 'behaviour', when asked whether she has experienced the same difficulties since she left the institution she responded by saying,

Ms. White: Yeah. A wee bit but I'm a lot better because I'm three years in my house on the 18th of March.

This statement appears to indicate that Ms. White was aware of the social and environmental aspects that contributed to behaviours that she described as challenging. Asked why she thought she found some things difficult she articulated a connection with the support she received and the way she responded. Ms. White reflected upon occasions when she had hurt people when she was angry and was able to give a clear rationale for what would be defined as 'maladaptive behaviour' in much available academic learning disability literature.

Sam: Have you ever hurt other people when you have been angry?

Ms. White: Yes. Yes.

Sam: And why was that?

Ms. White: Because they were hurting me so it was like self defence. If someone does me harm, I will do them harm.

Ms. White's response calls into question the interpretation of her behaviour as 'maladaptive'. Whilst not condoning violence of any kind, it would seem plausible to reinterpret her past behaviours as adaptive survival strategies developed in an unsafe environment. Certainly Ms. White seemed clear that she would not need to resort to these strategies in her new home.

Sam: Has this happened in your new house?

Ms. White: No and it never will because I am getting the right help in my house.

For someone with ‘maladaptive coping strategies’ Ms. White was able to articulate sophisticated and considered ways of coping with situations that she found difficult and in which she may previously have resorted to physical aggression. Discussing the risks associated with aggression and violence she stated,

Ms. White: I used to do it but not now but the temper can still be there, sometimes if I’m angry with my carers it can bring on the thoughts and feelings, but I tend to take myself away from the situation; to avoid the situation and avoid other people. So rather than going into a conflict I’ll just take myself up to my room and just take myself away from it and just do what a grown up would do.

Ms. White spent all but the last three years of her life (at the time of this conversation) in institutional care, her opportunities for witnessing everyday ‘grown up’ behaviour, would have been seriously curtailed. With the exception of family members, the only adults she would have spent time with would have been other patients in the alienating environment of a secure ward and health staff undertaking their professional duties. The range of options of how to respond when under pressure would have been informed by this limited and limiting environment. It is important to recognise the impact of the physical, social and emotional environment when considering Ms. White’s behaviour. Before judging and labelling her it would seem reasonable to consider what recourse she had to express her unhappiness, distress or dissatisfaction in more constructive ways and importantly what positive role models she had to illustrate that these strategies would be effective?

If the detrimental impact on social and emotional development of living in secure institutional care is overlooked, the ‘adaptive survival strategies’ developed in one environment may be defined as ‘maladaptive’ in another and may even contribute to an individual being assigned a reputation for ‘challenging behaviour’. Support based upon the deficit model of the medical paradigm favours the control and management of behaviours that are regarded as undesirable, an approach that fails to take into account the capacities and strengths of adults with learning difficulties. Asked how she managed to bring about the positive changes in her life and how she coped with difficult situations now Ms. White detailed strategies that, I would suggest, are similar to those adopted by people with less traumatic and difficult histories than Ms. White’s.

Ms. White: *I try to focus on the good things rather than the negative things and the thing that's made me change the most is because I've moved into my house and I know that there's good things to come yet. I know there's better to come, it's still progressing. The thing is, one day at a time and I'm still taking my baby steps but it's made a big difference with my life 'cause I've been in my house for almost three years in March.*

Sam: *That's amazing. It seems like yesterday.*

Ms White: *It does. So I'm going to go out for a meal to celebrate. I think also the reason I've changed as well because of other people's input and because of other peoples help getting me to the stage where I am now. ...I want to change for the better and show people I can do it. Know what I mean? Show people I can do it and I'm the person who I want to be.*

Ms White spent 37 years of her life in institutions, most of them in secure settings and challenging behaviour wards. She regards her life as having started the day she moved out of institutional care and treats it as an anniversary to be celebrated. Her healing appears to have started with her move to her own home, for her hospital was not a healthy place to live. The positive changes in her life have come about on the basis of her investment in the knowledge that she has the chance of a better future ahead of her. These findings supports the concerns expressed by Beadle-Brown et al., (2006) when detailing the curtailed life experiences of adults with reputations for challenging services who are referred to out of area placements.

Both Ms. White and Mr Blue used language drawn from the medical paradigm to describe their understanding of the word 'challenging behaviour'. Asked whether he had ever heard the words 'challenging behaviour' Mr. Blue turned the tables and by asking me a question,

Mr. Blue: *I am going to put you on the spot. Have you ever heard of behaviour modification so that is just slightly the same thing as challenging behaviour?*

Mr Blue performs a wonderful play on words as behaviour modification was a particular form of behaviourist intervention favoured by the practitioners working within the medical professional. His response implies that behaviour modification is 'challenging behaviour' which when taken with his description of

his actual experience of these intervention programmes, discussed later in this chapter in Section 6.5.1, does not seem to be an unreasonable description.

Interestingly Ms. Gold's response to the question of whether she had heard the term challenging behaviour provided a different perspective to that related by Mr. Blue. She stated that she only heard the term challenging behaviour when she began to be supported by a provider organisation after she moved out of the institution, stating that, 'you never heard of it in the Castle'. Ms. Gold was aware that the provider support staff had to attend certain courses in order to support people who had been assigned the label. When asked whether anyone had ever spoken about her in those terms she replied,

Ms Gold: No, I don't think my behaviour is that bad... don't think I was violent maybe a bit hyper at times but not now life's changed about, got to grow up now.

Ms Gold's words echo those of Ms. White, the sense of growing up, maturing, realising that one's life can be different. There is a risk that without the right support, opportunities for growth and development can be limited. The findings from this research have implications for the design of support services for people who are perceived to challenge services. Many specialist services, particularly congregate services, are designed to control and manage people whose behaviours are perceived to challenge services; they are designed on the basis of what people do rather than for who they are (Lovett 1996). Unless services are designed to provide opportunities for personal growth and development and are configured to allow and support such changes, people with reputations for challenging services will be contained in services with no hope of an alternative future. Ms Gold speaks eloquently about the experience of living with other people, who had a reputation for challenging service,

Ms. Gold: 'their behaviour was really bad and could be quite violent with their behaviour, people that were out of control and could not cope with life.

Ms Gold considers 'challenging behaviour' part of her history, although she recognised that she still had the potential to get upset about things but believed that she dealt with these issues differently. She spoke of aspirations of living without support in the future.

Sam: What do you do when you get angry?

Ms. Gold: Calm myself down...yes I would shout.... I used to hurt myself but I've not done that for years now....I used to hurt people but I don't do it now.

Sam: Who would you hurt?

Ms. Gold: Staff, old ones not the ones I have now... In the future I want to live on my own.

Mr Blue similarly regarded 'challenging behaviour' to be a part of his history and not something with any relevance to his life, in his own home, in the community.

Sam: Okay. Do people ever talk to you about challenging behaviour now?

Mr. Blue: No.

Sam: When did that stop, when did people stop talking about it?

Mr. Blue: When I left the castle. There has been nobody said anything. I don't know if you know but you are the first one that has brought it up in a wee while.

Mr Blue's comments raise ethical issues in relation to the potential risks associated with exploring a subject like challenging behaviour with adults with learning difficulties who no longer considered the concept relevant to their lived experience. The converse of this position is that as there appears to be very little academic research that explores the opportunities for people to redefine themselves, 'challenging behaviour' seems to be a label that sticks. The situation as represented by current research literature could be considered to be indicative of service inadequacies rather than anything inherent within the individuals assigned the label challenging behaviour. A legitimate question to consider may be, at what point does it become possible for a person with learning difficulties who has been assigned a reputation for challenging services to set that reputation aside? It was important having received the response from Mr. Blue that I check with him that raising this subject was not causing him upset, he indicated that it wasn't.

For Ms. Scarlett her recollection of challenging behaviour goes back to her school days,

Ms. Scarlett: In school. If you don't do what you're telt (told) you get called disobedient if you don't do as you're telt. You just get called disobedient.

Sam: Has anyone ever talked to you in that way, Ms Scarlett?

Ms. Scarlett: Aye, but it was because I was a wee bit cheeky but then everyone's a wee bit cheeky. I've always had my answers for people and they don't like it.

There is a real sense from this description that for Ms Scarlett 'challenging behaviour' was about behaving differently and not internalising the normative values of the institutions and environments in which she found herself. Ms. Scarlett went on to describe the fact that people perceived her as a risky person and that this is not a label she agreed with. In fact, as can be ascertained from the following statement, Ms. Scarlett believed that she was at greater risk.

Ms Scarlett: People used to say I was a danger to the public years ago. A year or two ago. That I shouldn't be out in the community. But I know I wasn't a danger to the public. I was just scared myself. I wouldn't harm children and I wouldn't harm animals. I might raise my voice occasionally, aye, but I wouldnae harm anybody. Injure naebody.

Sam: And why do you think they would say that?

Ms Scarlett: I don't know. It was just because I was walking the streets. They said I was a danger to the public and a danger to the community but I said I'm in more danger than what they are. I'm in more danger of getting stabbed and having someone take my life than anybody else. I don't know what they said it for. I'm not dangerous to the public. I've never harmed anybody in my life.

Asked whether things have changed, Ms. Scarlett spoke about her life being better as a result of her managing to cope with her emotions in ways that are less destructive. Ms. White talked about learning new ways of communicating with people, this was another recurrent theme that emerged from the research and is discussed later in this chapter in Section 6.4.3. Ms. Scarlett appeared to reject the reputation that has been assigned to her.

A different perspective on challenging behaviour was offered by Mr. Green who stated that he had never heard of the term challenging behaviour. However when I asked him about behaviour that was wrong, Mr Green went on to describe the behaviour of the other adults with learning difficulties with whom he shared his house.

Sam: Have you ever heard anyone talk about behaviour that is wrong?

Mr Green: Yes, in here.

Sam: in here, okay. What kind of things is that?

*Mr. Green: ** (housemates name) going mad.*

Sam: (Housemate) going mad? Okay. Why does he go mad?

Mr Green: Hitting his head and his face.

Sam: Hitting himself.

*Mr Green: Shouting and screaming. That's the way ** (Housemate) is, all the time...Hitting yourself, I don't know, hitting me...hitting me, grabbing me!*

Mr. Green talks of challenging behaviour in terms of the risks to him, the risks of viewing this level of upset in others, the disturbance of the peace and quiet in his own home due to screaming and being the victim of physical aggression. It is a sobering thought that this is Mr. Green's experience of living with his housemates, particularly as it appears he had no choice over the people he lives with.

*Sam: Did you choose to live with ** (housemate) and ** (housemate)?*

Mr. Green: I don't know. The choice was made for me probably.

A review of academic literature undertaken for this research project revealed a lack of research exploring the impact of sharing living environments with other adults who have behaviour that may be considered challenging. This is an area of research worthy of further exploration.

Mr. Purple again offered a different perspective on the term ‘challenging behaviour’ describing it as being about ‘people who are... acting up’. When we discussed whether this term had ever been used in relation to him he gave an interesting response which appeared to counter the notion that being labelled as having ‘challenging behaviour’ is necessarily stigmatising. Mr. Purple appears to echo Ms Scarlett’s sentiments that being labelled as challenging is a consequence of speaking up for yourself.

Sam: do you think people would have ever thought of you as having challenging behaviour?

Mr. Purple: I don’t think I’m challenging enough, I should be more challenging it’s about time I was.

Sam: And why would that be

Mr. Purple: Because I just don’t think I’m that challenging

Sam: Do you think anyone would have ever thought of you as challenging?

Mr. Purple: Yes

Sam: Is that now or would that have been in the past?

Mr. Purple: I’ve not been challenging for quite a while

Sam: Do you think people would have used the words challenging behaviour about you?

Mr. Purple: I don’t think they would have said it directly to me but they would have thought it.

I discussed with Mr. Purple the fact that his support had been organised through the Robust Service Project and asked him whether he was aware that he had been assigned a label for challenging the services that supported him. Mr. Purple recognised that at a different points in his life he would ‘*start world war three every day*’ and interestingly was able to give reasons for his behaviour that resonate the responses of other participants and have their origin in difficulties with communication, a theme discussed in Section 6.4.3

Sam: *I wondered....if you knew that people talked about you in terms of challenging the services that supported you?*

Mr. Purple: *I knew I was challenging, I would start world war three every day*

Sam: *Is that now or was that in the past?*

Mr. Purple: *The past*

Sam: *Can you think back about why you might have challenged people?*

Mr. Purple: *It was that long ago, my own life, my own freedom, sick of being told what to do in ** (Assessment and Treatment Unit) don't do this don't do that.*

Unlike other people who participated in the research Mr. Purple did not seem to have direct experience of people talking with him about challenging behaviour although, as with all the other participants in this research, he was referred to the Robust Services Project on the basis of the perceived challenges. It is interesting that an articulate young man such as Mr. Purple was less aware of the wider service processes that informed his support service than other participants. One reason may have been the particular way that he chose to express his frustration with his support and the challenges experienced by services supporting him at that point in time. Mr. Purple was adamant that this chapter of his life was closed although he was able to recognise that the difficult times he had experienced were a combination of where he lived and how he reacted,

Mr Purple: *That part of my life is gone*

Sam: *So you don't see your life like that at all now*

Mr. Purple: *no*

Sam: *and the things that you did then, do you think they were about you or where you lived and the way people treat you?*

Mr. Purple: *A bit of both*

Although he is unequivocal about the service response that led to his institutionalisation,

Mr. Purple: My issues were just sick and tired of being put away just because it's the easiest thing for them to do, might have been the easiest thing for them but was it easy for me?

Asked about the level of support he received from multi disciplinary professionals Mr Purple appeared to reflect the aspirations of a number of participants to reduce the level of professional intervention in his life. Mr. Purple appeared to be proud of the fact that he no longer had a Psychiatrist or a Community Nurse involved in his support and used humour to explain why he still had a social worker /care manager.

Sam: Do you have a social worker or care manager?

Mr. Purple: That's the one thing we can't get rid of, two outa three aint bad!

The self descriptions and definitions of risk and of 'learning difficulties' and 'challenging behaviour' provided by participants in this research offer a significantly different perspective than that represented in research literature relating to this field of study. The very human and personal accounts of the impact of being assigned the labels and receiving support based upon these assumptions provide a powerful counterpoint to prevailing professional perspectives on risk and challenging behaviour. These findings appear to support Taylor's (1996) assertion that the social construct 'learning difficulties' exists in the mind of those who label other people, not those so labelled, although there is a danger of individuals internalising the dominant discourse.

It has been noted that the label 'learning difficulty' breaks dialogue and leaves people objects of intervention (Goodley 2001). It could be argued that this is exacerbated when the label 'challenging behaviour' is assigned to individuals. Participants in this research imparted a sense of relative powerlessness in the face of what appeared to be summary justice, with reputations being assigned with little or no redress. Within the dynamic of power that exist within the dominant hegemony any expressions of frustration and annoyance at injustice imparted was itself interpreted as confirmation of the appropriateness of the label.

There is a risk that aggregate research studies perpetuate the creation of such alienating knowledge when referring to typologies of behaviour and categorisations such as ‘maladaptive behaviour’. This terminology should be considered to be value laden and, in light of the perception of participants in this research, potentially devoid of meaning when considered in the absence of the social, emotional and physical environment in which the reported behaviours took place. Using terminology such as ‘maladaptive behaviour’ may be seen to contribute to the ‘othering’ of adults with learning difficulties who are perceived by professionals to challenge services. The next set of findings within the wider theme ‘voice’ addresses this issue and is detailed under the sub-headed ‘becoming ‘other’.

6.4.2 ***Becoming ‘other’***

Danforth (1997, 101) drawing on the theories expounded by Foucault (1965) describes the existence of a regime of power running through our social world that creates a ‘truth’ in current social practices. Implicit in the process of classification of persons as ‘normal’ and ‘abnormal’ is the power dynamic whereby those who have power to define the norm have control over those who must be measured against it (Peter 2000); with the consequence that those classified ‘abnormal’ become the ‘other’ - different, inferior and silent (Danforth 2000, 366).

There is a risk that adults with learning difficulties, particularly those who have spent long periods of time in institutional care settings have their expectations and opportunities curtailed by the culture that exists in the service settings within which they reside. It has been argued that discourses in disability related social institutions maintain the power imbalance, ensuring that people are firmly under the control of professionals (Peter 2000, 356). Recognising the existence of an insidious disabling power dynamic, calls into question the validity of quality of life and choice measures as reflections of the aspirations of adults with learning difficulties; for as Roets and Van Hove (2003, 609) suggest,

‘A component of (disability) oppression is its psychological internalisation, a process which creates alienation and isolates people with ‘learning difficulties’....when a person is perceived as deviant he is cast into a role that carries with it powerful expectations’.

A consequence of the disabling dynamic is that disempowered individuals start to believe that they are less normal and capable than others. Swain (1989) uses learned helplessness theory as a way of articulating the powerlessness that results from the internalisation of oppression.

There were a number of notable instances of ‘unconscious’ disabling practices or ‘othering’ observed while undertaking the fieldwork for this research. Two illustrative examples involved Mr. Green. The first instance took place during the initial conversation with Mr. Green; a conversation in two parts. The first half of the meeting took place in the office in which I worked and was adjourned part way through at Mr Green’s request. The meeting was subsequently reconvened at a later date at Mr. Green’s home. Detailed observations and reflections were recorded in my research journal following both meetings.

Mr. Green’s support worker was present during the first conversation that took place in the office. I noted that he did not ask Mr. Green whether he was to remain in the room during our meeting, it just happened. Throughout the conversation the support worker made a number of interjections, often amending or correcting Mr. Green’s responses. This was a source of minor frustration for me as a researcher, as I was attempting to elicit Mr. Green’s views. Mr. Green, however, appeared to accept that this was the way his interactions with the outside world took place, through a process of correction, amendment and censorship. The brief excerpt detailed below relates to a discussion with Mr. Green around the fairly innocuous subject of housework.

Sam: In your house, who does the housework?

Mr. Green: The staff and me as well.

Support Worker: Sometimes, sometimes.

Mr. Green: sometimes I do hoovering and sometimes I do mopping, sometimes I tidy up and everything. Sometimes I do the kitchen.

Support Worker: And sometimes you have a habit of hanging on to things that are broken and you don’t chuck them out.

Mr. Green: I don’t chuck them out.

Sam: *So you will do the hoovering and you will do the mopping?*

Mr. Green: *The staff do it and I do it as well.*

Sam: *So do you get help if you are doing the hoovering and the mopping?*

Mr. Green: *Sometimes. The hoover doesn't work we will have to get a new one. My recorder, that is broken, it's in the bin, it won't record. It still works but the radio and the video.*

Sam: *And whose telly is it?*

Mr. Green: *It's my telly and see my telly it won't get a picture on it. The video bit.*

Support Worker: *Your telly is fine Mr. Green.*

The notes recorded in my research journal immediately after the conversation with Mr. Green are detailed in Figure 10: Journal entry .

What must it be like to constantly have your view no matter how accurate or erroneous constantly qualified by support staff that regards it as their job to present an accurate picture, without realizing that there can be many views and all are legitimate? Self esteem!

Figure 10: Journal entry 2 – Mr. Green

Such interactions must slowly erode one's sense of self, sandpapering away your belief in your own self worth. There is a risk that the product of this slow and steady erosion becomes 'naturalised' into a perception of passivity on the part of people with learning difficulties. Another practical incidence of 'othering' was observed when the meeting with Mr. Green was reconvened, this time at his home. Research observations were again recorded in my research journal, this time in the car immediately after the conversation with Mr. Green and are detailed in Figure. 12 Journal entry 2.

I rang the bell and the support worker answered the door. They were obviously expecting me as I had telephoned earlier to confirm that the arrangements we had made were still suitable for Mr. Green. The support worker invited me in to the house and through to the second living area. He called Mr. Green to let him know I had arrived and then asked me if I wanted a cup of tea. When Mr. Green arrived the support worker asked him if he wanted a cup of tea. Mr. Green and I settled down to talk at a large table.

Mr. Green did not answer his own front door or invite me in to his home, he did not decide which room we were going to sit in. He was not afforded the opportunity to play host in his own home by offering me simple hospitality such as a cup of tea and all of this had seemed completely normal to both him and the support worker - this is how it is.

Figure 11 Journal entry 3 – Mr. Green (b)

It seemed to me at the time that there was a significant risk that Mr. Green could be ‘cared’ into redundancy, out ‘efficient-ed’ in his own home. In this brief encounter, there were numerous missed opportunities for Mr. Green to be active rather than passive in his interaction with others, to reveal his skills and gifts and to give as well as receive support and assistance. The small incremental steps towards greater self direction that appeared to be overlooked in Mr. Green’s situation were highlighted by Mr. Blue as a source of pride and achievement, as exemplified in the following statement.

Mr Blue: *Maybe this has improved since the last time, when I go to the doctors somebody used to go in with me. I go in myself and I speak to the doctor myself and if the doctor or the nurse needs to know anything we call them back in when I have had my time with the doctor.*

In this brief statement Mr. Blue conveys a sense of authority and control over aspects of his life that are important to him. It appears from these findings that the level of support available is not necessarily the primary issue, the risk of not directing or having choice over life decisions, has its foundation in the way that support is delivered and who believes that they have the power to decide.

It would be easy to underestimate the importance of everyday decision making and the detrimental impact that this can have if it is not respected. Mr Blue provides a very clear illustration of how important these everyday decisions and choices are to him.

Mr Blue: There are a lot of things I can do now. I just get on with it, I can watch the telly, I can go to the shop and I can stay here and not go to the shop, but if I want to go to the shop, I can go. I am ok in my house and I have got things done, I sign all the papers myself and if they want to sign them, they can sign them, but they leave it to me and if anything needs to be signed I do it. They don't do it.

The important issue here is choice, not just choice over significant issues such as where you live and who you live with, but the importance of control over what may be considered every day and mundane decisions. The conversations with Mr. Green were permeated with a sense of a life controlled by others and provide a lived example of the 'othering' highlighted by Roets and Van Hove (2003, 610) when they described how 'decisions, even really intrusive ones like moving houses, are taken without consultation of the person at issue'. Both conversations with Mr. Green provided numerous examples of significant life decisions being made in ways that make no sense to him, the following extract is just one such example.

Sam: Why do you live in this house?

Mr. Green: They just put me here.

Sam: Who put you here?

Mr. Green: The staff on the ward.

Sam: The staff on the ward. Why do you think you live in this house?

Mr. Green: I don't know, they just brought me here.

Although Mr. Green appears to accept the decisions that have been made for him, it is worth noting the comments of Roets and Van Hove (2003, 609) that ‘if people are frequently in situations in which they have no control, their expectation and belief that they can do anything to affect or change events wears off’. Another example of reduced expectations is illustrated by the following extract. When asked whether he spent time on his own Mr. Green indicated that he did, however, it was clear from his response that his understanding of this concept was the time that he spent alone in his bedroom,

Sam: do you spend any time on your own?

Mr. Green: Yes I do. I get peace and quiet and just watch television and that.

Peter (2000, 357) argues that the process of ‘othering’ takes place within a dominant discourse based upon a deficit approach to disability, articulated as dependence and incompetence; rather than a potential alternative discourse based upon giftedness, which would result in descriptions based upon competence and responsibility. It could be argued that like most of us, people with learning difficulties will do what they can, within the constraints and circumstances in which they find themselves. However adults with learning difficulties who access support to assist them with everyday living face additional constraints and restrictions as a result of their interface with the bureaucratic processes of support agencies.

Mr Purple highlights another risk of being ‘othered’ when he describes the alienating processes of the organisation that supports him. He expresses a sense of injustice about the bureaucratic activities that result in his behaviour being shared with and judged by others, because he has a disability. He eloquently describes a life in ‘service land’ where his private life is made public and activities in his domestic life are shared.

Mr. Purple: I’ll tell you how the system should work, do away with incident reports, it’s a waste of paper work, how many people have an off day, loads.... it’s reporting on an individual because they have been in an off mood, how many people every day of the year have an off mood and they don’t get incident reports written about them, because we’ve got disabilities why should it be written about us.

Asked to consider whether organisational processes, such as incident reports, might inform support organisations about to support an individual more effectively Mr. Purple responds by saying,

Mr. Purple: yeah but I think a lot of incident reports are exaggerated, it wasn't even an incident but is been written as one, what warrants an incident report.

Mr. Purple's response draws attention to a gulf of understanding between those who provide support services and those who access them. There is an obvious risk articulated by the conversation with Mr. Purple, that if organisational processes are not clear and transparent, the potential for individuals receiving support to feel that things are being done to them is increased. Throughout the course of the conversations research participants highlighted the risks associated with social work intervention and being in receipt of support from provider organisations; risks that are not articulated in academic research literature considered through the process of undertaking the literature review for this research.

An interesting aside to these findings was highlighted in conversation with Ms. Gold when she intimated a sense of liberation from service intervention. Asked when her life had changed for the better, she was able to identify a turning point,

Sam: Does anyone ever talk about challenging behaviour or risk in your life now?

Ms Gold: no I don't see anyone and I am off the register completely I got a letter from them, I'm a lot more happier.

A number of different forms of 'subjectification' of adults with learning difficulties have been illustrated in this section, under the theme of 'voice'. Through the processes highlighted, people with learning difficulties are conceptually separated and made 'other'. Being defined as someone in receipt of support provides a subject position against which individuals manage and govern their own behaviour or risk being judged. Yates et al (2008, 255) referencing Foucault (1982) suggests that,

‘Forms of power that govern people’s lives become complimented by ‘self government’ in which people relate to themselves in an active fashion. When governed in this sense people are not forced or coerced. Rather, it is a matter of their aligning their activity and practices with the ends with which government of their lives is concerned’.

6.4.3 **Communication**

A consistent theme suggesting the importance of communication emerged from the data gathered from conversations with the research participants. Within this theme, a number of recurrent issues came to the fore during conversations; that participants felt that they were not being listened to or heard; that they used behaviour consciously or unconsciously as a form of non verbal communication and that a number of participants experienced difficulties verbally articulating emotions. These areas are discussed in the following section of this chapter.

It was interesting to note that a number of research participants used the pronoun ‘you’ when describing their experience of support, as illustrated in the following excerpt from a conversation in which Mr. Blue describes the ‘token economy’ that existed in the institution in which he had lived.

Mr Blue: and they had like a wee shop and you would get tokens for your behaviour and if I behaved I would get three tokens and that would earn me three things at the shop, like sweeties and crisps and you would get tokens and that would earn you but highest tokens you would get would be ten tokens and who would get two packets of crisps and sweeties. If you have been bad you wouldn’t get tokens, they would be taken away from you.

Sam: did that work for you?

Mr Blue: No it didn’t work for me.

Sam: Why not?

Mr. Blue: It worked a wee bit but I didn’t like it you know.

By using the pronoun ‘you’ Mr. Blue appears to convey not only his own experience of institutional life, but that of the collective ‘other’, who had experienced the same behavioural programmes. The sense of ‘them’ and ‘us’

conveyed by Mr. Blue's statement was reaffirmed by the following statement by Ms. Lilac, when referring to the role of professionals in terms of her relationship with her boyfriend,

Ms Lilac: it's not up to them, it's our life, you know what I mean.

This comment appears to portray the presence of a powerful 'them' that has the potential to control or make decisions in her life, although she seems to indicate her resistance to such imposition.

Mr Purple talked about the 'staff' in the institution where he had lived being a risk to him. He spoke of a culture of '*one strike and you're down*' referring to the physical and pharmacological restraint techniques used and linked this directly with a lack of opportunity to talk through problems and difficulties. Mr Purple articulated his experience of a service model based upon control and restraint, a model of support that appeared to make little sense to him.

Mr Purple: they were just bullies, not them all but most of them anyway, they were just control freaks, they go on about how it's our house and then they treat it like prison

Sam: and what's the difference now?

*Mr. Purple: the difference now is you don't get ** (Team Leader) and ** (Support Worker) ** (Support Worker) restraining me and giving me a jag.*

*Sam: and did that happen in ** (institution)?*

Mr. Purple: yes

Sam: That must have been tough.

Mr. Purple: didn't listen to the problems just ignored them.

Again this statement reiterates the recurring theme of the risks of not being listened to. It appears from these findings that the services that have not worked for people in the past have been ones that have tried to manage and control them rather than work with them. In keeping with this theme there was a recurring sentiment that participants felt that speaking out or speaking up was seen by the professionals as being challenging. This link between

communication and 'challenging behaviour' echoes Mr. Purple and Ms. Scarlett's descriptions of challenging behaviour detailed in the previous Section 6.4.1.2.

Behaviour as a form of communication, used to articulate upset and distress was another theme that emerged through conversation with participants. The language used to describe incidents was, in itself, illuminating conveying a sense of individuals experiencing judgement rather than empathy for the emotional distress and upset they were experiencing. When Mr. Green talked about 'bad behaviour' he had been engaged in historically, he related it in terms of the risks to him of staff aggression. Interestingly the activities that he engaged in when he was angry or upset involved breaking his own most treasured possessions, his radios, against the wall. Asked what he did when he got upset and angry Mr. Green stated,

Mr. Green: Staff were hitting me all the time.

Sam: Staff were hitting you, ok. So when you used to get angry, not now, but when you used to what kind of things did you used to do?

Mr. Green: Punch the radio off the wall.

Sam: Do what off the wall?

Mr. Green: Punch the radio off the wall.

Sam: Punch things off the wall. So you would maybe break things?

Mr. Green: Radios.

This action seems to carry a powerful communicative load, however, there is a risk that although his behaviour and upset may be acknowledged, the message behind it may not be heard, let alone understood. Speaking with Ms. White about whether she ever hurt herself her answer was very matter of fact and appears to clearly illustrate challenging behaviour as form of communication,

Ms. White: I pull out my hair, scratch my arm or bang my head.

Sam: and why do you do that?

Ms. White: *Just because the way I am feeling, I can't control my emotions. It's like crying for pain, you just want to reach for help and you can't get help - you don't know where to start.*

There is a real risk that a service response organised on the basis of managing and controlling Ms. White's behaviour would miss the point of her communication and confirm her sense of not being heard or listened to.

The use of behaviour to articulate upset and distress appeared for some participants to stem, in part, from a difficulty articulating emotions verbally. An example of this may be seen in the explanation Ms. Lilac gave for why she believed she might be a difficult person to support,

Ms. Lilac: *No, I am quite hard 'cause I find it hard to let people know, you know what I mean? I find it hard to mix with people'*

Ephraim (1998, 222) discusses this phenomena suggesting that,

'one of the areas that is most difficult to talk about is feeling. Often the person has learnt that it is only acceptable to be happy. They have been taught that to be angry or sad or whatever is not acceptable'.

This observation is reflected in the findings of this research and is illustrated in the following extract from a conversation with Mr. Blue. Asked to describe what made him unhappy Mr. Blue became visibly anxious, he found this topic of conversation very difficult to talk about and was particularly concerned about me articulating this verbally or even in graphic form.

Sam: *OK things that you said make you unhappy are people saying things that you don't like, and not feeling well. How would you like me to draw that?*

Mr. Blue: *I don't know. No don't draw that, no.*

Sam: *Okay, anything else that makes you unhappy.*

Mr. Blue: *No, no*

Mr. Blue also found it extremely difficult to articulate verbally any issues in his life that made him angry, as highlighted in the following extract

Sam: *Okay, can you think of anything that makes you angry?*

Mr. Blue: *No not really no.*

Sam: *See if you were upset, what would you do if you were upset?*

Mr. Blue: *I sometimes self harm. That's telling you the truth, that, that happens.*

Mr. Blue's statements about emotions left me, as a researcher, with questions about whether Mr. Blue found gaining insight into this area of his life difficult or whether he struggled with language to articulate his emotional response to situations. It is also worth noting that Mr. Blue used service language drawn from the medical paradigm to describe how he dealt with upset in his life, using the phrase, 'I sometimes self harm' rather than, sometimes I hurt myself resonated with Ms White's responses. There is a risk that individuals assigned the label 'challenging behaviour' internalise the dominant hegemony of the institutions from which they access support.

Ms. White recognised that moving out of the institution had not changed all the issues that caused her difficulty and reflected on the fact that communication was still an area of her life with which she struggled,

Ms. White: *Yeah. It still is a big thing. Sometimes I don't see. Like say if somebody says black I'll maybe say white, I'll maybe say the opposite. I've got to get the last word out. It's just me, I just cannae hold it in, I've got to get the last word out. I've got to actually get the better of them by getting the last word out. They say something I'll maybe say something really nasty back so I cannae hold it in. See like if I don't like somebody, I've got to tell them. I've got to say I hate your guts. I cannae hold that in. That's the way I am.*

With the level of insight Ms. White seemed to have into the areas of her life that cause her difficulty it would seem feasible that the right support might ameliorate the effects of these difficulties in the same way that the wrong support could exacerbate the difficulties she experiences. Ephraim (1998, 212) suggested that,

'Exotic communication is the communication of the desperate. Convivial conversation is the pastime of the relaxed and confident'

If that is the case then it provides a clearer mandate for professionals working with Ms. White to improve her life and leave her reputation for challenging services behind. In conversation, Ms Scarlett echoed some similar difficulties to Ms. White in terms of her experiences communicating with people, however she was able to acknowledge that her life had improved as a result of receiving the right support and working hard herself.

Ms Scarlett: I've changed better and my mood's better. I used to say things I didnae need to say. That was the way I was. I'm a lot better than what I've been.

Sam: How do you think that happened?

*Ms Scarlett: Because ** (provider) has helped me along the way and I helped myself.*

6.4.4 **Key findings – risk and voice**

- There is a profound risk of individual's behaviour being misinterpreted and misrepresented if it is considered out with the social, emotional, environmental and cultural context.
- There is a risk that adults with learning difficulties are not aware of the service landscape within which their support is delivered.
- Participants articulated that service interventions may be seen as a risk as a result of disabling support, alienating language and bureaucratising processes.
- There was a clearly stated risk that participants felt that they were not listened to or understood
- Services based upon a deficit model and providing support interventions based upon the management and control of behaviour are a risk to individual's physical and emotional wellbeing.

6.5 Risk and Harm

The second core theme to emerge from the ongoing process of analysis of the conversations with participants and reflections on the research process was entitled risk and harm. This broad theme incorporated the sub themes abuse; resilience and resistance and home, as illustrated in Figure 12 Harm- sub themes, below.



Figure 12 Harm- sub themes

6.5.1 *Abuse*

A strong theme emerging from the data was the pain and abuse experienced by participants who assisted with this research. Their experiences underlined the relevance of the words of Ephraim (1998, 210) when stating,

‘the words ‘the pained, the unheard and the unloved’ represent as simple a framework as possible to help understand the very broad, rich yet tragic range of human experience which is labelled challenging behaviour’.

The range of abuse experienced and disclosed in conversation was disturbingly wide ranging and included verbal abuse, physical abuse, sexual abuse and psychological abuse. This abuse took many different forms and was experienced at the hands of family, professional carers and at the hands of peers and fellow patients. The conversational approach to data gathering facilitated an exploration of the lived experiences of participants who provided a unique perspective on the risk of harm.

When asked about the term challenging behaviour Mr Green stated that he had never heard anyone use the words about him. When asked if he ever lived with anyone who had challenging behaviour he provided a very interesting response, stating the following,

Mr. Green: *Yes, with **, **’s hitting me, punched me in the eye.*

Sam: ***, who is **?*

Mr. Green: *My Dad.... He punched me in the eye, I begged him and next minute bam, punched me in the eye!*

For Mr. Green ‘challenging behaviour’ was not associated with the label ‘learning difficulties’ but appeared to be about the impact of the behaviour upon another person. Mr. Green talked about domestic violence and being the victim of physical abuse in his family home resulting in his removal and placement into the care system. He used the graphics we had drawn to emphasise the points that he is making.

Mr. Green: *Do you know what my Mum and Dad done? Punched me, punched me in the eye for no reason....’ I need a drink, I need a drink’. His dad hit his mum, his mum hit his dad and hit his brother, wee **. That one there, (pointing to the graphic representation of his brother).*

Interestingly the support worker interjected at this point, moving the conversation away from the behaviour of Mr. Green’s family, the subject that

Mr. Green had introduced, and redirected the conversation on to Mr. Green's behaviour saying,

Support Worker: *Mr. Green got into a bit of trouble.*

The support workers intervention appeared to be a less than sympathetic response to Mr. Green's disclosure of his experience of domestic violence. It was clear from Mr. Green's recollections that these incidents took place in his youth. Mr Green was a middle aged adult at the time of our conversation and it appeared from his recounting of events that he was still affected by the experience. The issues in his past appeared to be unresolved and continued to impact upon his daily life. Reframing Mr. Green's experience as that of a survivor and recognising his resilience in the face of abuse may help the professionals involved in his support understand his historic and present actions in a more person centred way. There is a risk that the social and emotional aspects of an individual's well being are neglected in favour of the control responses favoured by the medical paradigm.

Mr Blue discussed his experience of behavioural programmes in the challenging behaviour wards in which he had lived. He spoke of them in terms of the controls that were exercised over him and the abuses of power that took place.

Mr. Blue: *I was a wee boy in Lennox Castle, I had big heavy gloves, right up to here (points to his under arms) to stop me harming myself and actually was making programmes and doing this and that's just like the word that you said, challenging behaviour.*

He goes on to state how unpleasant he found the behavioural programmes,

Mr. Blue: *one of them was actually and I hated it and I told ** (Behaviour Therapist) I hated it but ** didn't have anything to do with that. They would give me my tea cold. They would leave it and I would get my tea cold.*

Although Mr. Blue initially conveyed a sense of powerlessness experienced during his time in the challenging behaviour wards, he later went on to describe the fact that he was able to remove the gloves, more accurately described as gauntlets, surreptitiously and it would appear that this became the site of his resistance.

Mr. Blue: Yes I had big gloves on, up to here (Mr Blue points to his under arms) and my arms were straight like that and dead sore and they took the gloves off and everything is fine but there were times when I did do it (self harm). If I wanted there were times when I could take the gloves off but I didn't but they took the gloves, they scrapped the gloves.

Sam: So you could take the gloves off anyway?

Mr. Blue: Yes I could take them off, but I didn't but I knew how to.

Sam: Did they know you knew how to?

Mr. Blue: No they didn't know but I knew. Yes but they caught me so they knew I knew how to.

Sam: So they caught you?

Mr. Blue: Yes

Sam: and what would happen when you took the gloves off?

Mr. Blue: I would just get into mischief put things into my ears.

There is a serious risk that resistance to these unpleasant and painful practices, such the wearing of restraints, that Mr. Blue experienced would itself be described as 'challenging behaviour'. There is a potentially legitimate and powerful way of reframing Mr. Blue's behaviour in the language of resilience and resistance. A retelling of the story from Mr. Blue's perspective would recast his role as that of a man struggling to retain a sense of self in a brutalising system of arbitrary punishments, engaged in a fight for the care of the self. Mr. Blue's understanding of his active resistance is clearly conveyed in the following statement.

Mr. Blue: they would come and up and they would say he is going to do something but it didn't turn out to be what they were saying because I didn't do it so I was one step before them.

Mr. Blue's experience of 'specialist' challenging behaviour services appears to exemplify a gulf of misunderstanding within the dominant health paradigm. The focus of health intervention programmes was based upon the treatment the symptoms of Mr. Blue's distress, his self harming behaviour, the cause of which was located within Mr Blue's individual pathology. The social and emotional

influences on Mr. Blue's sense of well being and self worth appear to have been ignored. Parallels with the responses of other groups of individuals who have their lives controlled, such as political prisoners, should not go unstated.

Mr. Blue was clear about the rationale for the behavioural programmes he experienced,

Mr. Blue: they were just to stop you; there would be different people on different programmes.

The behavioural interventions located within the medical paradigm appeared to focus on the outcome, a reduction in self harming behaviour; the process and its impact upon the individual's self esteem and dignity were secondary considerations, if considered at all. Mr. Blue was clear about the coercive nature of the programmes he and other patients were placed on.

Sam: Has anyone ever talked to you about challenging behaviour?

*Mr. Blue: Yes ** (Behaviour Nurse Therapist).*

Sam: and can you remember what they said about challenging behaviour?

Mr. Blue: they just said if you didn't behave yourself you are not getting rewarded but you know the patients they were wanting sweeties so they would behave themselves.

Mr. Blue related that the ultimate sanction employed by hospital staff would be to prevent him going out of the hospital with a close family friend, Ms. M., who used to visit him. He was very clear that Ms. M. treated him very differently.

Mr. Blue: Ms M. would take me out but if I didn't behave myself I wouldn't get going out. Ms. M. just treated me the same...It wouldn't be like it was bad last night, so you are not getting out, she just took me out and treated me the same way. Like for instance, I used to break the windows and if I broke a window, I wouldn't get out or I wouldn't get tokens for so many days.

Asked why it was that he used to break windows Mr Blue states, 'I just was fed up' and then goes on to relate how he experienced auditory hallucination and how frightening this can be. It causes one to pause to consider the impact of the reward and punishment regime in the hospital on the opportunities for Mr

Blue to develop coping strategies to assist to manage the difficulties he experiences. He was treated as a passive patient who was judged and reported on and to whom things were done.

Mr. Blue: and she would come in and look at the charts and you would get a red mark and you would go to your chart and if you went out to work it would be marked in your chart.

Again Mr. Blue's experiences are further examples of the risk of subjectification and 'othering' experienced by adults with learning difficulties who have been assigned reputations for challenging services and as previously iterated in Section 6.4.2. Again there is the risk that internalising negative labels reduces individual's expectations about what is reasonable and decent enough care or support. It is clear from the following extract that, for Mr. Blue, verbal abuse at the hands of nursing staff was considered unremarkable.

Sam: Did you used to think you had challenging behaviour?

Mr. Blue: Yes.

Sam: and so you would break windows you said and what other things do you think you might have done that would be challenging behaviour?

Mr. Blue: I would hit and spit at the staff.

Sam: and anything else?

Mr. Blue: No really. No.

Sam: Why did you have the gloves on?

Mr. Blue: because I was self harm and put certain stuff up my ears, up my nose and swallowing stuff but my arms would be like that, straight out.

Sam: Okay.

Mr. Blue: I don't mind telling you as long as that is going to help you.

Sam: It is really interesting, so you say you used to have challenging behaviour and what were you... can you remember why you did it?

Mr. Blue: Between you and me just to get attention.

Sam: *Just to get attention.*

Mr. Blue: *Yes but I don't do it now, I just was like that part of the time that was all, they used to call me the wee attention seeking f-ing you know and they would call me the word and the staff would call me that the word you know, the attention seeking wee f..k*

It is worth noting the incredible generosity of Mr Blue in retelling aspects of his past which must be difficult and unpleasant to have to recall. In addition to the coercive behavioural intervention Mr. Blue also detailed incidents of physical and psychological abuse in the institution in which he lived, such as being made to sit and face a door for hours on end,

Mr. Blue: when I was in gloves...they used to take me up to the door with a chair and they used to sit it at the door facing the door, not anything else just facing the door and nobody could see me and nobody could hear me..... if any other deputy came in they would rush, take the chair away and put me back down.

Mr. Blue's experience of abuse in 'care' was reiterated by a number of participants. Several participants spoke of the use of pharmacological interventions 'the jag' to manage and control them, Ms. Lilac spoke of the use of medication to 'dope me'.

The catalogue of risks of abuse detailed in the conversations with participants included, the risk of physical assault at the hands of care staff, the risk of medication being used as a form of control, the risk of physical harm at the hands of other patients, the risk of social isolation, of sexual abuse, the risk of constant judgment and this list is not exhaustive. However it is clear that according to participants in this research, living in institutional services for adults with learning difficulties who have been assigned a label for challenging services was a very risky experience.

The experiences of abuse disclosed by participants were not limited to experiences in institutional care. A number of participants detailed experiences of sexual and physical abuse within their family and in intimate relationships and verbal abuse at the hands of the community. The participants in this research had been assigned reputations as risky individuals given their perceived challenging behaviour. The conversations with participants revealed a group of

vulnerable individuals who are categorised as being a **risk to** themselves or others, however I experienced individuals who were similarly **at risk of** harm at the hands of a dehumanising service system and who showed tremendous resilience in the face of painful and traumatic experiences.

Ms. Lilac talked about her experience of institutional care, detailing her route through ‘service land’,

*Ms. Lilac: aye, I’ve been everywhere and I’ve never got any help. I’m very different than I was in ** (secure ward). It was the place I was living, it was where I was living that made it difficult.*

Asked what has made the difference and how she has managed to stay in her current home for so long she states,

Ms. Lilac: Well, well, I’ve been made to feel better

The next section of this chapter discusses the resilience and resistance of the research participants.

6.5.2 **Resilience and resistance**

Charlton (1998, 11) cited in (Roets and Van Hove 2003, 605) suggests that an understanding of the lived experience of people with disabilities is critical to the development of a broad thesis of oppression and resistance. Goodley (2000) defined resilience as the capacity of the human spirit to resist oppression. The oppressive experiences of institutionalisation and abuse detailed in previous sections of this chapter suggest that the participants of this research be regarded as survivors. Roets and Goedgeluck (2007, 99) suggest that ‘critical agency and resistance that emerge from the margins of power as political action make a redefinition of oppressive discourse possible’ it could be argued that the activism and hidden resistance of participants; be it Mr. Blue removing his restraint ‘gloves’ or Mr. Green breaking his radios off of the wall; or Mr. Purple, Ms. White and Ms. Scarlett continuing to speak up against perceived injustice or Mr. Orange not liking to be touched all constitute forms of resistance. For as Foucault (1967) intimated, where there is power there is also resistance.

Resilience in the face of adversity may be seen as a way of maintaining a sense of self, a sense of coherence and personal integrity (Goodley 2001). This approach challenges the assumption of the passive role of people with learning difficulties and instead recognises the active roles assumed by adults with learning difficulties and in particular those assigned the label challenging behaviour, whose actions it is suggested can be recast as activism. Bogdan and Taylor (1989) suggest that the fact that these voices have not been heard and recognised to date is not due to lack of effort on the part of people with learning difficulties but is because society has chosen not to listen.

I would contest that research exploring preceptions of risk should consider both active and passive risks and it is with this in mind that an emergent theme of resilience was included in these findings. Goodley (1999) cautions against disability research ignoring a priori resilience and inadvertently contributing to a disability research paradigm that views people with learning difficulties as passive objects rather than active agents in their own lives. He also suggests that it is contingent upon researchers to recognise the subtle (and I would suggest sometimes not so subtle) resistance of the oppressed and assist them to utilise the power of their reactions to inform social change (Goodley, 1999). I would argue that the findings of this research add to the increased awareness of the emergent resilient cultures of people with learning difficulties.

‘Power is not given to people nor is it earned. It happens as a result of a constructive, meaningful activity that leads people to be more knowledgeable, skillful, informed and aware than they were before’

(Roets and Van Hove 2003, 616).

Mr. Green’s experience reveals how difficult it is to engage in meaningful activity with the benefit of all that flows from it when your life is dominated by a service culture based upon a deficit model of support. Mr Green was able to inform me during our conversations that staff members interfering with him and his belongings was something he found very difficult and that he responded to this in ways that his support workers would describe as challenging. It was particularly interesting that Mr Green identified staff interfering as the reason for his behaviour. As previously noted almost all aspects of Mr Green’s support appear to be controlled and determined by others, from when and where he gets

cigarettes, to how is money is spent and by whom, who he lives with and where he spends his time. Using this as a context one can reasonably recast his behaviour as showing remarkable resilience and tolerance despite the occasional outburst of frustration an example of which he describes below.

Sam: Can you tell me some of the things that upset you?

Mr. Green: Sometimes the staff. Staff interfering.

Sam: And what happens if you get annoyed at the staff for interfering.

Mr. Green: I fling stuff at them. That's what I do if they annoy me. I fling stuff at them.

Sam: What kind of things do you fling at them?

Mr. Green: Cups, plates, dishes, radios.

Sam: So it would be cups and plates? Even your radio? You fling your radio?

Mr. Green: Aye. I'd fling my radio. I'd fling my radio if they annoy me.

Ms. Scarlett describes the considerable resourcefulness she deployed escaping a situation involving domestic violence at the hands of her partner, only to find herself stuck in the social work system.

*Ms. Scarlett: I went down to this old lady who had a home-maker in and she phoned the social work but ** (Social Worker) was on holiday at the time and I stayed in ** (residential facility) for seven months - nearly a year - and I was only meant to stay there a week.*

Having experienced an improvement in her own personal situation Ms. White expressed a desire to utilise her activism for the benefit of others, again countering the passive role assigned to people with learning difficulties and underlining the importance of opportunities for people to contribute as active citizens.

Sam: Are there any things you would like to do in the future.

Ms. White: *Chairing conferences, being the representative for other people, sticking up for other people's rights and helping them. Like a spokes person.*

Sam: *Brilliant. So how do you think you would do that?*

Ms. White: *Speak up for other people's rights and see what they need. Take other people's safety into account and say this is what should be happening, this is how it should be treated and this is how it should be dealt with.*

6.5.3 **Home**

A number of issues arose as a consequence of discussing with participants potential risks in the home. A number of participants expressed high levels of anxiety in relation to their own personal vulnerability, risks associated with choice and control in the home and everyday domestic risks were discussed. Each of these will be dealt with in turn.

For a number of research participants routine and predictability afforded them a sense of security. Mr. Blue and Ms. Scarlett both spoke with considerable pride about spending time without support in their own homes, an aspiration also conveyed by Ms Lilac when she stated,

Ms. Lilac: *so you can write this down. I would like to stay on my own next year on every Sunday, next year*

The independence conveyed by spending time alone without support was coupled with high levels of anxiety for both Mr. Blue and Ms. Scarlett and both individuals had devised strategies for managing these feelings. Mr. Blue experienced high levels of anxiety answering the phone or the door due to the unpredictable nature of the potential interaction. He was aware that his fear and anxiety made some aspects of his life more complicated however he balanced this against the potential benefits,

Mr. Blue: *Like last week, every Thursday they come with my meds and I wouldn't even let them in because I didn't know who it was, so my meds had to be left at the chemist and we had to go to the chemist after and get them*

Mr. Blue and his support team have come up with a system of codes for the door and the phone so that he feels confident answering, knowing it will be them.

Mr. Blue: The team have got a thing, you know if they ring the phone twice or knock the door, I know its them so I let them in so we don't do any other thing.

Ms. Scarlett had a profound sense of personal vulnerability that affected her day to day lived experience. When she spent time on her own without support she stated that she generally spent it alone in the house,

Ms. Scarlett: Aye, it's just safer that way..... I cope not bad on my own during the day. Don't get me wrang, I'm still scared but I still do it. As long as I've got someone at night I'm not so bad. I can sleep better in my bed. If I'm on my own in my bed I can't sleep. I'll just sit up and watch the telly. It stops me feeling so scared.

It was really important to both individuals that that their strategies and routines were respected, such as Ms. Scarlett's anxiety that not only did she ensure that she locked the doors at night but also gave her support workers clear instructions,

Ms. Scarlet: I tell them not to put the rubbish outside the door till I get up in the morning.

The prescriptive nature of the support that Ms. Scarlett required in order to feel safe and secure was reflected across the conversations with research participants. A number of participants engaged in activities that would make co-habiting with another person difficult, for example Ms. White, Ms. Scarlett and Ms. Lilac all regularly moved all their furniture around their flats during the night. Ms. White's need to organise aspects of her domestic life in particular ways is achievable as she lives in her own home with support however it would not be too difficult to imagine the potential for conflict were she required to live in a congregate living environment.

Sam: Can I ask you, what kind of things do you like to do?

Ms. White: Listen to music or watch telly, or clean the house the cupboards, that means sterilise the plates the cutlery and the cups.

Sam: why do you sterilise them?

Ms. White: because it's just part of my problem, just to make sure the plates are clean, it's just a problem I have.

Sam: Why is it a problem?

Ms. White: I just don't like eating off plates that others have eaten off of because they stink.

Sam: sorry, say that again.

Ms. White: because they stink.

Sam: so you like things to be clean?

Ms. White: I like things to be my way.

Sam: so you have certain ways you like to do things.

Ms. White: yes, compared to other people.

The risks to individuals of not developing services around their individual needs and preferences are considerable. One also has to consider, given how particular Ms. White is about certain aspects of her domestic life, how difficult and unpleasant it must have been for her living in an institutional setting where she had very little control over the important aspects of her life detailed above. Ms. White was extremely articulate when expressing her particular requirements in terms of her domestic arrangements, other participants in this research also appeared to have very specific domestic arrangements that needed to be respected in order for them to feel safe and happy. Mr. Yellow found it very difficult to tolerate physical changes to his domestic environment, certain items in his house had to be placed in a particular place or he would experience extreme distress and upset, for example coffee mugs needed to be lined up in a certain order in order for him to feel relaxed and happy in his own home. It is possible that the specificity of individual's domestic requirements, when not respected, contributed to individuals being assigned a reputation for challenging services.

Unlike the other research participants Mr. Green lived in a congregate living environment, sharing his home with three other men at the time of our first conversation and two other men when we met for the second conversation.

During the first conversation Mr. Green spoke about the experience of witnessing his housemate harm himself.

Mr. Green: (Referring to his housemate who had just walked into the room) Why you moaning pal? You're moaning all the time. See when he does this, he scratches his face.

Sam: He scratches his face?

Mr. Green: So he does. So he does.

Sam: He's looking a wee bit upset.

Mr. Green: Aye. I know, in there, sitting in there banging his face. Really hard, like this. I know it's terrible isn't it. Bashing your face.

Mr. Green is sympathetic to his housemate however it should be actively acknowledged that he has to live with the implications of his housemate's behaviour which appears to be distressing and difficult to watch. There seems to be an implicit assumption within 'service land' that people with learning difficulties are inured to the emotional impact of witnessing this kind of incident.

In the period between my first conversation with Mr. Green and the second conversation a fatal accident involving one of his housemates occurred in Mr. Green's home. This incident had a profound effect on the second conversation with Mr. Green. In order to maintain confidentiality I will not be using any extracts from the conversation that relate to the incident. Mr. Green seemed deeply affected by the incident that had taken place in his home and had a marked sense of increased personal vulnerability. During the second conversation the subject of the incident was returned to frequently, often when discussing other potentially sensitive subjects. For example when I asked Mr. Green about his behaviour and his medication we had the following discussion that then led back to discussion about the incident of his housemate's death.

Sam: What is the medication for?

Mr Green: To make me sleep.

Sam: To make you sleep?

Mr Green: *Don't sleep well.*

Sam: *So your medication helps you sleep?*

Mr. Green: *I can't cope; I put my radio on and my medication.*

Mr. Green had a heightened sense of risk and concerns about death in all areas of domestic life we discussed not only those activities relating to the circumstance of his housemate's death and sought constant reassurance that the same fate would not befall him. He also needed to be reassured that he had not been at fault,

Mr. Green: *Wasn't my fault wasn't it not. It might happen again, sure it might?*

There are risks that service responses following tragic incidents, such as took place in Mr Green's home, fail to take into account the emotional impact upon adults with learning difficulties; this situation may be exacerbated particularly if the individuals involved have a limited emotional vocabulary with which to express their distress, other than in ways that are considered to challenge their support.

Profound ethical considerations arose as a result of this conversation with Mr. Green; these are discussed in more detail in Chapter 7.

In terms of risks in the domestic sphere most participants appeared to be well versed in household safety in terms of the reasons for locking doors, cooking, pouring a bath and what to do in the event of a fire, Ms Lilac's response to the latter was,

Ms. Lilac: *you run out and phone the fire brigade and the police.*

In conversation Mr. Purple was keen to minimise any potential risks around the house however further discussion revealed that he adopted every day common sense risk management strategies. Asked what he would do if there was a fire, Mr. Purple stated,

Mr. Purple: *no chance not in this house, electricity is off when I'm in my bed, everything is safe as houses, there won't be a fire in here*

unless I do an insurance job which has no chance of happening so no fire.

Ms. Scarlett adopted a very sensible approach to managing the risks associated with smoking stating,

Ms. Scarlett: If I felt a wee bit tired I wouldn't smoke a fag.

Sam: and why's that?

Ms. Scarlett: because I would set myself on fire.

Ms. White was really open to trying all sorts of experiences that had been unavailable to her in the institution in which she had lived. The ordinariness of her pleasures was humbling, asked what she likes spending her time doing now that she couldn't do before she replied,

Ms. White: go for a bath when I feel free. Go to my room when I feel I need time out. Clean the house, relaxation, basically do my own thing without people hounding me at my back looking over my shoulder.

Although not everyone was as eloquent as Ms. White, there was nothing special or different about what participants were looking for in terms of their support or their lifestyle. Achieving these aspirations may just take a bit more effort and thought on the part of the professionals supporting them.

6.5.4 **Key findings – risk and harm**

- The risk of abuse and harm at the hands of others was particularly significant - all of the participants in the research had experienced some form of abuse. This is an area that requires further research.
- Participants reported institutional care as a risk
- There is a risk that resilience and resistance is not recognised as active care of the 'self' and is instead interpreted as challenging behaviour.
- There is a risk that in pursuing 'normalising' principles service do not value and respect difference.

- There is a risk that organisations do not respect the emotional impact of service responses on the individuals in receipt of support.

6.5.5 ***Additional Areas***

A number of other interesting findings did not fit within the themes of voice and harm but are worthy of noting. There was a consistent theme about the importance of continuity in the support individuals received from the organisations that worked with them. On a number of occasions valued support workers were described in terms of the length of time they had been in an individual's team. Consistency of support from long standing and valued support workers was highlighted as a key to an improved lifestyle. In addition all but three of the participants spoke about feeling 'unsafe' when they had strangers supporting them. For some participants, Mr Blue and Ms Scarlett in particular, they indicated that they would rather spend time on their own than have a stranger or 'agency' support worker as they found that easier. These findings have significant implications for organisations providing support to individuals. The message was clear. It was not the amount of support that was the most important issue it was how and by whom it was delivered.

Another area that is worthy of consideration was the level of information and understanding participants had in terms of their sexual health and wellbeing. Although a number of participants articulated that they were sexually active, the level of knowledge would, I suggest, leave all of the participants in this research vulnerable in this aspect of their lives. This factor was all the more disturbing given the levels of sexual and physical abuse reported by participants. Again this is an area that requires further research. There are also practice issues for organisations supporting adults with learning difficulties in terms of the recognition of their status as sexual beings who may need proactive support with this aspect of their lives.

There was a gender difference in the perception of personal vulnerability detailed by the research participants. The women who spoke with me, without exception, had a heightened sense of their personal vulnerability at the hands of men. Ms. Scarlett would not allow men in to her home, with the exception of one long standing male friend. This sense of vulnerability also extended to their

fear of the community, Ms. Lilac for example, stated that she did not carry money in case she got mugged. Ms. Scarlett secreted her money about her person and Ms. White was clear that although she could go out on her own without support, she wouldn't, for fear of something 'bad' happening to her. There appeared to be powerful forces at play reinforcing the female research participant's sense of extreme personal vulnerability. I am not aware, in any of the academic literature I reviewed, of specific research in this area or any practical responses such as inclusive personal safety campaigns organised to address this issue.

There were other areas of risk highlighted that would warrant further exploration but that are beyond the limited scope of this research, some of which are highlighted in Chapter 8.

6.6 Conclusion

As the title of this chapter suggest with the words 'traversing terra incognita', analysing the data and contemplating the findings of this research was akin to exploring a new world. This was for me, as a practitioner and a researcher who thought I shared a world with the research participants, a disconcerting experience. The perceptions of risk of participants elucidated through the research conversations provide another view of the experience of living with the labels of learning difficulties and 'challenging behaviour'. These perspectives offer a valuable contribution to risk and disability theory and practice and are discussed in Chapter 7.

Chapter 7: Discussion - theoretical cartography

‘One takes a one-step distance from members’ perspectives, not by arguing that it is narrower or incorrect, but by studying how it works in constituting social realities. Theories are thus deconstructions of the way in which we construct realities and social conditions and ourselves as subjects in those realities. They cannot compete with lay thinking, because their very objective is to make sense of it in its various forms and in different instances’.

(Alasuutari 1996, 382)

7.1 Introduction

The original impetus for undertaking this course of study was observations of the impact of the use of the concept of risk to curtail the opportunities of adults with learning difficulties, who had been assigned reputations for challenging services. As I have described in the previous chapters, I was blown off this original course, affected and influenced by a number of external and internal factors that prioritised the academy, the bureaucracy and the ethics committee.

The sinuous journey, that this research became, brought some advantages. Having recognised that the original focus had been lost I was able to realign and adapt the research methodology to give ‘voice’ to individuals who had moved out of secure institutional settings but who still carried the label of learning difficulties and ‘challenging behaviour’; individuals who had situated knowledge that had remained unheard. Biklen (2000, 445) stated that ‘we have a responsibility to understand what happens at society’s margins’. This research aimed to use the conceptual category of risk as an analytical tool to explore the dynamics of ‘service land’ and community from the perspective of adults with learning difficulties who had been assigned reputations for challenging services. Goodley (1997, 343) cautioned that,

‘failure to locate stories in social theory of disability may seriously jeopardize informant’s words - leaving them open to interpretations elaborating individual pathology over disabling environments’.

It is with this in mind that this chapter attempts to locate the findings discussed in Chapter 6 within the landscape of risk theory and disability theory.

Consideration of the ethical implications of this research project will also be set within a theoretical context, exploring the implications of the practitioner as researcher and the emergent methodological approach.

7.2 Risk and disability in a social context

Individual's accounts of the personal experience of being an adult with learning difficulties and their perceptions of risk are powerful; 'an individual's experience is best understood from the standpoint of the social world of that individual' (Garrick 2000, 209). One of the fascinating aspects of this research, detailed in Chapter 5, when looking at the development of the research conversations and Chapter 6 the research findings, was the sense of dislocation that the adults with learning difficulties who participated in the research felt from the social structures that influenced many aspects of their lives. Law (2003) explored alcohol services in hospitals and advice centres and remarked upon the lack of a discernable system and of trajectories and movements being badly co-ordinated. This sentiment was reiterated by participants in this research who struggled to understand the larger processes that informed significant issues in their lives; issues as fundamental as where they lived and who they lived with.

There is always a risk, as Thompson and McHugh (1995, 370) put it, that 'phenomena such as power or control, which are expressed through relatively durable structures beyond specific situations and face to face interactions' are overlooked. Simon Aspis (1997) a researcher and self advocate with learning difficulties, raised the issue of adults with learning difficulties being asked to comment on that which society makes available rather than challenging issues such as the lack of power that people with learning difficulties have in their everyday lives. Key themes that emerged from the research were a lack of voice and the process of 'othering' experienced by participants. In the starkness of their raw testimony, participants' words reflected society's treatment of people with learning difficulties. Detailing their experience of institutional care, participants narrated histories of abuse, neglect and harm. These accounts highlight the need to,

‘understand how subjectivities are produced and regulated through historically produced social forms and how these forms carry and embody particular interests. At the core of this position is the need to develop modes of enquiry that not only investigate how experience is shaped, lived and endured within particular social forms....but also how certain apparatuses of power produced forms of knowledge that legitimate a particular kind of truth and way of life’.

(Sherman and Webb 1988, 196)

On a day to day level the lived experience of ‘othering’ for participants in this research involved, not having one’s voice heard or views listened to and not being afforded the opportunity to make every day decisions and undertake the general activities of an active citizen. However these actions are merely symptomatic of wider social processes rooted in ideas of the ‘normal’ and ‘natural’. Sevenhuijsen (1998, 131) in Watson et al (2004) describes the ‘silent logic of the “natural” provision of care within the family and kinship networks where it seems equally self-evident that it will be women rather than men, who care spontaneously for others whenever the needs arises’. Throughout the process of undertaking this research I have come across the fleeting shadows of other silent logics stretching over learning disability research and practice; silent assumptions that the compromises in choice experienced by people with learning difficulties were somehow ‘natural’ and inevitable. There were silent logics that judged and measured people with learning difficulties, concluding that they should develop ‘adaptive behaviour’, conform and behave; that it is their challenge to fit in and conform, not ours as a society to provide welcoming communities and inclusive supports.

In a journal article it was reported that an adult with learning difficulties was asked what was bad about the residential home where he lived, he responded ‘If I am naughty I don’t go out. I stay here, they punish me. If I’m naughty, or loud or walking around in circles, I don’t go out’ (Beadle-Brown, Mansell and Hutchison 2006, 851). There was a silent logic at play here, much more insidious than the ‘problems- mainly relationships with other residents and staff’ as reported in the journal article. There was a silent logic written into the fact that this man’s experience was not written up as a reflection of abusive power relations; that it is not reasonable in our society for an adult’s liberty to enjoy everyday activities to be contingent upon others’ subjective judgement of their

behaviour. The silent logic underlying these situations was sometimes heard as whispers; whispers of an acceptance of a level of manipulation, control and coercion in learning disability 'service land'. These whispers have not been transformed into shouts of outrage across the academic community. Challenging behaviour is routinely reported on in clinical terms, which mask the harm to the individuals who bear the labels.

These dialectics of compromise create and maintain inequalities of choice and opportunities for people with learning difficulties across their life-course. This situation is magnified in the case of people who have been labelled as having behaviour that challenges others. The concept of challenging behaviour is socially constructed rather than 'natural' state. Notions of the 'natural' or 'pathological' construct and colonise the disabled experience and none more so, I would suggest, than people with learning difficulties.

The rhetoric of the social model of disability has guided the promotion of policies based upon equal citizenship and the development of practices based on social inclusion. However, I would contest that when difficulties or significant contentions arise, sanctuary is sought in the purported certainty and 'defensibility' of the discourse of positivism. In terms of risk this involves resorting to 'objective' quantitative assessment tools; and in relation to learning disability and challenging behaviour, the use of quasi scientific labels such as maladaptive behaviour. Much learning disability research, and particularly that with challenging behaviour as its subject matter, appears to reproduce this hegemony. The characteristics of this research betray underlying assumptions that appear to endorse the 'othering' of people with learning difficulties, sometimes appearing to marginalise the negative impact of policies and practices that would not be acceptable in a non 'service land' context.

There is an inherent danger in an approach where compromises are assumed on the part of people with learning difficulties that would not be acceptable to most academics and practitioners. These compromises expected of people with learning difficulties often go unacknowledged, and if unacknowledged, they become the norm from which point more compromises are expected and assumed. When compromises are made on behalf of others and not even tacitly acknowledged as such, there is a danger that those individuals become

marginalised and disappear from the collective consciousness. A case in point it could be argued would be the growth of 'out of area' placements for adults with complex needs.

Normalisation is the key theoretical position underpinning learning disability policy and practice in Britain today (Yates, Dyson and Hiles 2008). Within a social constructionist perspective 'normalisation' is the intrinsic process underpinning the problematization of the way that human beings are made subjects (Foucault 1991). This process of subjectification results in a rejection of difference in a society that creates insiders and outsiders (Taylor and Bogdan 1989,22). Individuals are required to conform to normative standards or be considered 'other'.

The predominance of the medical paradigm in the development of learning disability services has left a legacy of interventions based upon a deficit model of support. The findings of this research pose a challenge to the foundations of this approach to adults with learning difficulties. The participants in this research revealed extraordinary levels of resilience, resistance and resourcefulness in the face of extreme adversity. Individuals were not passive in the face of power and subjectification. Challenging behaviour as a form of communication was another key theme within the finding of this research. Rather than focus on the individual act of behaviour the question, I suggest, ought to be, what is so wrong with the system in which the individual lives that they resort to such forms of communication in order to be heard? From this perspective rather than view challenging behaviour as an individual pathology social theorists and practitioners should consider that,

'Systems of control and the agents that man them are implicated in the process by which others become deviant. The very effort to prevent, intervene arrest, and 'cure persons of their alleged pathologies may precipitate or seriously aggravate the tendency society wishes to guard against'

Matza, D (1969, 80) cited in (Peter 1999, 805).

Matza's analytical standpoint reflects the findings of this research. Despite diagnosis and reputations the prospect of a better tomorrow was enough of an incentive for at least one of the participants in this research to find alternate

ways of communicating her upset and distress. A greater understanding of the influence of the social, emotional, environmental and cultural influences on risk and challenging behaviour is required.

In *Asylums*, Goffman (1961) explained that it was only natural that people confined to 'total institutions' develop ways of thinking and acting that may appear bizarre and maladjusted when viewed from the outside, but that are perfectly reasonable and rational when viewed from the context of institutional life (Taylor and Bogdan 1989, 24). Despite the years that have passed since Goffman expounded these ideas the dominant discourse in relation to challenging behaviour is still fundamentally based within a medical paradigm, exemplified by service supports based upon the management and control of presenting behaviours. One of the significant risk areas that participants, in this research, reported was the risks associated with being in receipt of support services; in institutions and in the community. These risks to personal autonomy and sense of self are not reflected in the research literature on learning disability risks and challenging behaviour. Risk theory needs to develop an equivalent to the social model that exists in disability theorising, in order to provide a counter balance to the objectification of risk proposed by the technico-scientific perspective.

7.3 Reflections on the research process

'When routines and self-evident notions of everyday life are for some reason shattered, we always take reflexive distance from them and consider an event or encounter from other perspectives to figure it out. Some institutions, such as art and sciences, are specialized in such reflexivity. Perhaps the specificity of the social sciences in this respect is its attempt to create systematic methods by which such reflexivity is maintained; but quite often it is itself caught in its own routinised lines of thought'.

(Alasuutari 1996, 383)

Foucault (1972, in Yates et al 2008, 252) suggests that the concept of a prior essential subject is anathema, in this formulation the truth of learning disability is not waiting to be discovered by scientific research; systems of discourse 'systematically form the objects of which they speak'. Recognising this as the

approach that I wanted to adopt in this research was a radical departure from my inadvertent adoption of a positivistic medical paradigm, the point at which this study originated. The paradigm shift that occurred during the process of undertaking this research was more than a modification of the research method, it was fundamental to the nature of the discourse that informed knowledge development. As the interrogatory lens changed so did the story that unfolded (Simmons, Blackmore and Bayliss 2008). The domain of power is dynamically linked to that of knowledge; the decision to adopt a standpoint epistemology necessitated reflection upon the role of the researcher and more specifically the role of the practitioner as researcher. Having started out on this journey metaphorically invisible and value neutral the role of the researcher developed a voice, an influence and a being. Before moving on to discuss the implications of taking on the dual roles of researcher and practitioner it is worth detailing the scope of the research undertaken and the methodological limitations experienced.

The research methods evolved as the research progressed; however, there were some residual artefacts from the original incarnations of the research proposal that, located as they were within a positivist medical paradigm, placed restrictions upon the facility to adopt a truly emancipatory or inclusive research approach. As the research process evolved and an increased awareness of disability theory and politics developed, a greater understanding of the moral and ethical and political implications of the research as a process of engagement emerged. It became apparent that the research process was not neutral, 'scientific' or distant. Each decision made or for that matter not made was a practical embodiment of the values underpinning the research endeavour; to include or exclude; to interview or to talk; to question or to listen. Accountability was not merely a process of reporting to the bureaucratic institutions one needs to engage with when undertaking research of this kind. Accountability resided in an understanding of the significance of the contribution that the research would make to the body of knowledge on disability. Fundamentally would the research contribute to greater opportunities for the empowerment of disabled people and was it making,

‘a contribution to the process of advancing an inclusive society through addressing insider perspectives, which will bring tangible shifts in beliefs and attitudes’

(Roets and Van Hove 2003, 619).

The adoption of this defined theoretical standpoint informed the research process, and ensured that every step of the research journey could be measured against the empowering ideal.

The adoption of an evolutionary methodology drawing on aspects of grounded theory and informed by social constructionist tenets of the social model of disability did not ameliorate the fact that the research design was drafted by a non learning disabled researcher to meet the requirements of the academy. The tortuous process of gaining ethics committee approval, detailed in Chapter 4, not only absorbed a disproportionate amount of time and energy but also limited the options for revising the structure of the research interactions with research participants. In this respect the research did not meet the criteria for emancipatory research as the aims and the processes of the research were defined and conducted by a non disabled researcher (Zarb 1992; Oliver 1992). It would also be unrealistic to describe the research as ‘inclusive research’ the term coined by Walmsley (2001) to describe research that makes ‘no prior assumption about whether the research may be described as emancipatory’ (Williams et al. 2005, 8). The term inclusive research reflects an active attempt to establish a more equal balance of power in the research relationship that manifests itself in learning disabled people defining and undertaking aspects of the research activity. Given the origins of the research and the parameters within which it evolved it would be a misrepresentation to categorise the research undertaken for this study as either emancipator or inclusive. At no point did I liaise with the individuals involved or any self advocacy groups, for example People First or Values into Action, to determine whether the area of research proposed would be one that they would prioritise.

There was however, from the outset, a genuine belief that the outcome of the research would inform the development of practice with regard to the perceptions of risk relating to adults with learning difficulties. However a number of methodological limitations undermine the suggestion that this

research could be regarded as emancipatory or inclusive. An illustration of the limitations of the research approach adopted can be illustrated in the experience of a number of research participants. The research interaction with participants, defined within the research proposal eventually approved by the ethics committee, involved meetings of approximately an hour's duration one year apart. This format proved not to be appropriate or conducive for two participants, Mr. Yellow and Mr. Orange, who experienced significant difficulty engaging meaningfully with the research. It is reasonable to contest that the difficulties they experienced lay with the inflexibility of the methodological approach not with their individual ability to contribute to the research had the interactions been appropriate to their needs. In addition the data analysis, a crucial component of the research process was undertaken by the researcher and the relevance of the emergent themes was identified by the researcher. This aspect alone would seriously curtail any serious consideration of framing this research as an emancipator or inclusive endeavour.

Having stated the bureaucratic and methodological obstacles that impeded the opportunity for truly emancipatory or inclusive research considerable effort was made to increase the participatory nature of the research undertaken. An increased mindfulness of the ethical dilemmas that may arise through the conduct of the research was brought to bear, particularly when writing about the 'other' and recognising whose voice was in the foreground (Baez 2002, 54). Changing the style of research interaction with participants from a semi-structured interview format to a 'guided conversation' (Stalker 1998, 7) approach was an active attempt to redress the power imbalance inherent within the former methodological approach. The conversational approach adopted also increased the participants' agency and involvement by providing the space for them to elaborate on and inform the agenda of the research interactions. The reflexive approach adopted also ensured that the research process could adapt and evolve as themes emerged, an example of which was the question arising about the participants' ownership of the labels of learning disability and challenging behaviour that had been assigned to them. The use of graphic facilitation was another aspect of the research methodology that was adopted to try to maximise the participatory aspects of the research process. Through the medium of graphic facilitation participants could, it is proposed, more readily

control the information they imparted. The use of hand drawn graphics also provided a useful aide memoire for participants in terms of continuity of purpose for the second research conversation.

It is difficult to consider the trajectory that the research may have taken had participants been afforded greater 'agency' in the research process. Certainly one would consider that Mr. Yellow and M. Orange may have experienced greater engagement with the research process thus enabling them to articulate their perspective on risk in a more meaningful way than was possible within the existing research methodology. There was clearly a great deal of untapped potential among those that participated in the research, however, I suspect that it is almost a further form of research colonisation for an 'outsider' researcher to try to predict how participants may have chosen to develop the research process had it not been bounded by exiting parameters. My intuition would be that the experience would be akin to that detailed by Williams et al (2005,13) when undertaking inclusive research with the Swindon People First Research Team,

'Sometimes it felt like bringing a rough package of research tools to Swindon, in order to have the package unwrapped and almost completely refilled with self advocates' own ideas about research'.

Undertaking truly inclusive research exploring perceptions of risk of adults with learning difficulties with adults with learning difficulties would be a fascinating area for further research.

There is a growing recognition of the value of the situated knowledge that people with learning difficulties hold.

'People with learning difficulties may be 'doing' the social model, although not writing about it or articulating it in theoretical language. Therefore it is crucial that researchers support people with learning difficulties to articulate these actions and look for more innovative research practices which capture *doing* as well as rhetoric'

(Chappell et al 2001 49).

However there is also a growing body of literature detailing the tensions involved in including people with learning difficulties as active researchers some

of which will be touched on briefly here. Managing the competing demand of academia and/or funding bodies and the necessity to ensure that research is conducted at a pace directed by learning disabled researchers can provide a source of tension particularly when trying to conform to externally imposed research deadlines, as McClimens (2007, 272) highlights,

‘after almost a year of false starts, missed deadlines and a generally shared failure to produce even few lines of genuinely shared writing I reached a point...where I felt I had to withdraw’.

The role of the research supporter or the non-disabled co-researcher can also be considered an area of some contention. Unlike the aspirations of the emancipatory research model which proposes that disabled people own the means of research production, it is according to Walmsley (2004, 66),

‘widely accepted that, in contrast to emancipatory research, in participatory research, non-disabled people have an enduring role’.

If one accepts this premise the challenge then becomes how to negotiate a role for non-disabled researchers that ensures that the traditional power dynamic is not merely replicated and tokenistic research is being produced in the guise of participatory research. Wamsley (2004, 69) warns of the ‘mystification of the process’ when non-disabled co-researchers are not explicit about the hard work and ‘self restraint’ required to produce honest inclusive research.

A further challenge to developing a full inclusive role for learning disabled researchers is the reliance of traditional research on a requirement for a relatively sophisticated grasp of language and the written word. This issue would be surmountable with the investment of considerable time and effort to develop alternative more appropriate means of communication and recording research results, however it has been recognised that,

‘...for people with learning difficulties the problem is compounded by the inaccessibility of the written word, and complex jargon-ridden language’

(Williams and Simons 2005, 11)

Bearing in mind the limitations of research methodology adopted in this study in terms of its inclusive credentials, the adoption of a reflexive approach to the emergent research process enabled assumptions to be challenged and the research design to evolve. The question of whether it is possible to ‘write about the oppressed without becoming one of the oppressors’ (Roets and Van Hove 2003, 617) challenged the very assumptions upon which the research had been based. Inherent within the original research design was an understanding that participants recognised and acknowledged the labels of learning difficulties and challenging behaviour as applied to them by professionals involved in their support. These assumptions were questioned in the research design for the second set of conversations. The process of incorporating this area of risk for consideration revealed a new layer of understanding about risk and learning disability and recognition that,

‘...research does not merely address or discover the objects of its enquiry, but it begins to create them from the first moment of the identification of a topic’

(Barton and Clough 1995, 2 in Coles 2001, 503)

A concentration on the areas that are being ‘othered’ or made absent was a useful approach to adopt in the analysis of research material collected. Recognising that research is a process of bringing to presence and absencing, including and excluding added another dimension to the analysis and interpretation of data, particularly when considering the different types of absence that are made with different forms of presence. Law (2003) suggests that there are two different forms of absence, ‘manifest absence’, that which is acknowledged by presence for example in this research project the institutional experience as described by participants would be a manifest absence, ‘it is explicit but absent’ (Law 2003, 8). The second type of absence suggested by Law (2003) is ‘otherness’, absence that is not acknowledged.

Some examples of issues that were ‘othered’ at one point or another through the process of undertaking this research would be, the voices of adults with learning disabilities until establishing their views was incorporated in the research design; the social model until the research design was reviewed, particularly the implications of using a psychometric tool to quantify levels of challenging

behaviour of the research participants. The vignette based work that was undertaken but was not the focus of the final research project could have been 'othered' in pursuit of neatness, avoiding disclosing the 'mess' of method. An attachment to predefined method could be seen as an ideal vehicle for 'othering' research developments and findings that do not 'fit a metaphysics of common-sense realism'.

A further significant issue that arose as a result of the paradigm shift that took place within the research was the ethical dimensions of undertaking research as a practitioner. Interestingly the most contentious ethical deliberations that arose were not addressed by the formal ethics committee approval process. One such situation involved Ms. Silver, a participant who withdrew from the research on the basis that she felt she had disclosed more than she wanted to. As a researcher I was able to set aside any information obtained from the research conversation. As a practitioner it was not possible to un-hear, un-process, un-know the information gleaned from the research conversation with Ms. Silver. On the simplest level it was possible to ensure that no information disclosed would be used overtly in a professional context, however, it was not possible to guarantee that the information disclosed would not subconsciously inform the thoughts behind future intervention and supports to Ms. Silver. The dual role of researcher and practitioner, to a significant degree, negated the intent behind Ms. Silver's destruction of the audio mini disc recording of our conversation.

Two other incidents during the course of the research possibly reflected on the positive aspects of the practitioner as researcher duality. One incident involved a fatal accident in the home of one of the research participants. This subsequently led to a major change in his support arrangements. As a practitioner I was aware of these events and avoided contacting Mr. Green until a reasonable amount of time after the event; at which point I contacted a senior Manager in the organisation supporting Mr. Green to seek advice about the appropriateness of proceeding with the second conversation. When I met up with Mr. Green for the second conversation it was clear he was preoccupied with the events that had taken place in his home. Without the insider knowledge available to me as a locally based practitioner this research meeting could have been very difficult and potentially distressing for Mr. Green. Another potentially

distressing conversation took place after one participant had attempted to commit suicide. Again with insider knowledge I was prepared for the issue to be raised in conversation and was able to respond appropriately. On both occasions the guiding principle was the Foucauldian ethical principle of 'care of self' (Koro-Ljungberg, et al. 2007, 1090),

'By problematising individual actions and engaging in critical reflection, researchers grow as ethical beings and learn within and from the historical and discursive context that influences the constellation of ethical research practice'.

A critical factor to bear in mind given my duality of roles was the perception of research participants of my role at any given point during the research interaction. I cannot be sure to what extent my professional involvement with research participants influenced the data gathered. The recognition that I was not invisible in the research process enabled me to accommodate an analytical perspective that allowed for opinions to form that were not directly voiced by the research participants. I allowed myself to acknowledge my role 'within the research process rather than above, before or outside it' (Charmaz 2006, 180).

Acknowledging the influence of Bourdieu and Wacquant (1992), Schelly (2008, 720) outlines the usefulness of reflexivity as,

'For the researcher reflexivity should reduce biases associated with being an outsider; for the fieldworker reflexivity should reduce biases associated with being an insider. In each case reflexive writers should examine the social position they occupy and the social forces that determine their attitudes and beliefs, rather than the attitudes and beliefs themselves'

The implications of adopting a reflexive approach to this research project are detailed in the next section of this chapter.

7.3.1 ***Reflective Practice***

Undertaking this research was not an easy process, my emotions echo the concerns expressed by Noy about the development of her thesis,

'felt quite bad about the directions things took....I felt I was doing something wrong....I had promised something that I had failed to

deliver, and I delivered something that I was not asked for...looked at narrowly, one large conceptual step or phase was missing between the initial proposal and the final dissertation; seen more broadly, what evolved was simply a different work all together'

(Noy 2003, 5)

It is now that I look back with astonishment at the certainty with which I started this study. I assumed that undertaking this research would be a straightforward journey starting with a 'conceptual map' that had sketched ideas of the terrain I would encounter. In my naiveté I thought I just had to follow the sign posts and get to the endpoint within a prescribed time frame; that there needed to be little of me, as a person, as an individual, as a researcher, as a practitioner involved in the journey. If I adopted a role as a researcher, as a student I would complete the task at hand.

In keeping with the tradition of the positivist objective research approach I initially endeavoured to be metaphorically invisible both during the research and in writing this thesis. This attempt to be 'invisible' ultimately led to a lack of coherence and sense of dislocation from the reality of the research process, a process during which I had been truly present. This lack of coherence was compounded by my dual role as researcher and practitioner. The dissonance I experienced manifested itself in the experience of writing as a ventriloquist; the sense of filtering or projecting my voice and understanding through, what I mistakenly believed to be, an academically acceptable front.

I have come to accept and celebrate the transformative effect that undertaking this research has had on my intellectual understanding of disability research and in particular my understanding of risk as perceived by people with learning difficulties who have been assigned reputations for challenging services. The transformative effect has had a positive effect upon my professional practice and upon me personally as a researcher.

'As I write these lines now I ponder: Doesn't a "different work" amount to a "different researcher?" Isn't writing a becoming? Are we not in writing ourselves changing, transforming?'

(Noy 2003, 5).

Was I the same person as when I started out on this research journey or could this thesis be seen, in part as a journal, detailing the terrain covered and the challenges experienced during this research journey. Sometimes understandings change, brought about by thoughts and ideas whirling around in a darkened recess of the mind until enough grit is amassed to abrade the consciousness into recognition. Sometimes the landscape within which you travel changes you.

During the process of undertaking this research some physical changes in landscape took place that I have no doubt influenced the direction of travel of this research project. I changed jobs moving from purchasing services for adults with learning disabilities on behalf of a Health Board and Social Work Department to setting up an organisation providing self directed support. I also moved academic departments a number of times within the University and each time I was affected by different influences, not least as my study supervisor changed with each physical change of location. All of these experiences brought opportunities and challenges and informed the final version of this thesis,

‘that change, or shift, I began to see, was a natural consequence of intellectual and scholarly growth, and it unfolded within, social organisational and research contexts’

(Richardson in Noy 2003, 5).

7.4 Conclusion

‘Articulating the lived experiences of oppression and resistance seems essential.....to revalue disqualified knowledge’

(Roets and Goedgeluck 2007, 91).

This research has been an attempt to ask questions that uncover new worlds of knowledge and understanding. Using risk as the lens through which to view these new and interesting landscapes, enabled insights into the processes by which adults with learning difficulties are materially constituted as other, client, patient and challenging. Danforth (1997, 99) suggests that, ‘Post modernism is an arena of dialogue and possibility, allowing individuals and groups to claim their voices, call out their identities and forge paths of action’. I can only hope that this research makes some contribution towards achieving this aim.

Chapter 8: Conclusions – the rear view mirror

‘Social scientists may only be able to contribute to the creation of the cultural and structural conditions within which self emancipation flourishes when they recognise that culture and structure are embodied and expressed in everyday social practice’.

(Davis, 2000, 203)

This thesis explores the concept of risk from the perspective of adults with learning difficulties who have been assigned reputations for challenging services and charts the reflexive journey that informed the development of the research process. The field of learning disability research, as relates to those who have been assigned reputations for challenging services, has been dominated by discourse based on the medical model. The views of those assigned the label of ‘challenging behaviour’ have remained silent within the pages of research journals and academic tomes. The research on which this thesis was based evolved from a research proposal initially based upon a technico-scientific approach located within the medical paradigm. Through an emancipatory process of what could be described as ‘perspective transformation’ (Mezirow 1981, 66) a more inclusive and discriminating integration of theory and research practice evolved. The evolution of the research drew on the understanding that,

‘Reflexivity and praxis should enable us to understand how our personal needs, culture, values and commitments and morality affect our capacity to be critics of our own work’

(Nunkoosing 2000, 61)

The ‘perspective transformation’ undertaken was described using the metaphor of a journey; detailing both the process of reflexive research practice and the emergent nature of the research methodology. The term ‘lighthouse moments’ was used to describe the points when the research process reached a critical juncture; when new directions needed to be navigated, informed by the reflexive process. The research activity was planned and unplanned, constructed and deconstructed a process described by Carr and Kemiss (1986,

187) as a 'self reflexive spiral'. The research process also followed the example of Garner and Lehmann (1991, 17) who intimated that they had,

'Chosen to take a positive view on the unexpected - these events provide us with the opportunity for deep learning and development of reflective practice in evaluation and research activities'.

This thesis describes the process of questioning the natural notion of risk (Foucault 1980) inherent within the original research proposal, located, as it was, within the medical paradigm. The ongoing reflexive process manifested itself in a growing recognition of the absence of the voices and perspectives of those most affected by risk decision making, namely adults with learning difficulties who have been assigned reputations for challenging services. Examining the historical development of learning disability policy, practice and theory compounded reservations about the validity of a value free scientific approach to disability research,

'Ways of viewing disability, of developing research questions, of interpreting research results, of justifying research methodology and of putting policies and programs in place are as much about ideology as they are about fact'

(Rioux 1997, 147)

The experience of 'perspective transformation' profoundly affected the development of the research process culminating in the adoption of a standpoint epistemology and the realignment of the research within an emergent methodology drawing influence from social constructionist grounded theory (Charmaz, 2006).

'Scholars argue that power relations that are manifested in particular culturally situated research encounters must be examined because they shape research relationships, ethics and politics of knowledge construction'

(Koro-Ljungberg et al. 2008, 339).

The adoption of a participatory research approach liberated the research from the perceived confines of empiricist 'objectivity' and enabled the acceptance of a non linear research approach,

‘Though researchers can never hide the larger structures of power and privilege that produce them at university and governmental level, they can temporarily open a space for others by allowing sensitivity, vulnerability, and uncertainty to become part of the methods’

(Koro-Ljungberg et al. 2008, 353)

Setting aside the vignette based work undertaken to investigate professional perceptions of risk opened up the opportunity to explore risk from the perspective of the subjugated knowledge (Foucault 1980) of adults with learning difficulties who had been assigned reputations for challenging services. The criteria for the acceptability of research processes evolved from that outlined by the professional codes and modes of practice constituted by the ethics committees to a Foucauldian ethical consideration based upon “care of self”.

The origins of the research based as they were within the medical paradigm had sought to ‘other’ participants as ‘patients’, as having the label ‘challenging behaviour’ quantifiable through the application of a psychometric test. Locating the research within a social model paradigm afforded the opportunity to challenge the passivity often assumed of people with learning difficulties and challenged the ‘silent logic’ of the ‘natural’ (Sevenhuijsen 1998, 131 in Watson et al. 2004). In keeping with Atkinson’s (1993, iv) observations about the participants involved in her oral history project, who emerged ‘in their accounts not as victims, but as people who survived, and often defied, the worst aspects of the system’ (in Chappell, Goodley and Lawthom 2001, 48), participants in this research had much richer and more interesting lives than the literature would suggest. They also had knowledge about what worked for them and what did not and were able to participate in the research ‘process as subtle and not-too-subtle negotiators of reality’ (Stansfield, in Koro-Ljungberg et al. 2008, 352).

The emergent and reflexive process adopted challenged assumptions about ownership of labels such as learning difficulty and challenging behaviour. It also facilitated questions about participants understanding of the architecture of ‘serviceland’. The standpoint epistemology enabled consideration to be given to the role of research in giving voice to those who are often silent in the worlds of policy, practice and academia. If systems of discourse form the objects of which they speak (Foucault 1972), then the subjugated knowledge of adults with

learning difficulties should be heard and should inform the development of policy and practice. Developments in legislation increasingly require that people with learning difficulties are active participants in the processes that affect their lives. The Adult Support and Protection (Scotland) Act 2007 requires that 'regard is given to the adults ascertainable wishes and feelings (past and present)' and stresses the importance of 'the adult participating as fully as possible in the performance of the function'. The way we talk about the world and the way we experience it are inextricably linked, the names we give things shapes our experience of them and our experience of things in the world influences the names we give them. If the professional world of learning disability research and practice is dominated by alienated knowledge then the opportunities for adults with learning difficulties to participate in forming new agendas for policy, practice and research are seriously curtailed.

The findings of this research challenge prevalent assumptions about the passivity and lack of articulacy of adults with learning difficulties who have reputations for challenging services. They also challenge the framework within which much research is conducted. People with learning difficulties need to be afforded the opportunity to frame decisions about their lives on a personal, political and an academic level,

'One of the most pervasive ways of marginalizing men and women with learning disabilities is to deny them a role in the construction of knowledge about our shared world and about their situations'

(Nunkoosing 2000, 53)

The participatory processes that evolved through the course of this research and the findings of the research itself offer the basis from which to develop a more participatory approach to engaging with adults with learning difficulties who have been assigned reputations for challenging services. Within this research when the interrogatory lens changed, so did the story being told (Simmons, et al 2008). A participatory model for assessing and managing risk that focussed upon participation and positive outcomes could be developed however this would require professionals to surrender the role of 'experts' in the lives of adults with learning difficulties. It would also require an explicit recognition of the risks to 'self' experienced by adults with learning difficulties in contact with

‘serviceland’ and that these risks be recognised when working with adults with learning difficulties.

Participants in this research described their behaviour as a form of communication. Historically such activity has been reinterpreted and pathologised as challenging behaviour. The findings of this research attest to the fact that adults with the labels of ‘learning difficulties’ and ‘challenging behaviour’ have knowledge that wider society could utilise, were efforts made to include the experiences of all citizens in our academic and policy deliberations.

‘A debt must be acknowledged to the disabled people who have expressed dissatisfaction with the social meanings conventionally attached to disability and their determination to overturn them’

(Chappell 1992, 37)

While undertaking this research other areas of academic interest arose that were beyond the scope of this current work. This research highlighted the fact that there is no credible equivalent of a social model of risk. Establishing a social model of risk would act as a counterpoint to the pervasive models of risk drawn from the technico- scientific tradition and this would be a positive development. The findings of this research highlighted the need for further work to explore the impact of congregate living on the life experience of adults with learning difficulties who have reputations for challenging services.

Research exploring the relationship between experiences of abuse and perceived challenging behaviour may establish whether the correlation that appeared to exist in this research was symptomatic of a wider phenomenon. Research to establish a discourse on risk that is accessible for people who use social care services should also assist in the process of demystifying ‘service land’.

Appendix 1



Participant Information Sheet

Living With Risk - To what extent do perceptions of risk influence the decision making process affecting the lives of adults with learning disabilities who have reputations for challenging services.

Who am I?

My name is Sam Smith and I am a part-time student at Glasgow University. The research I am doing is part of a PhD.



What is the study about?

The research I am doing is trying to find out how people think about risk. I particularly want to know if people think about risk in different ways and how that affects the lives of people with learning disabilities.

If you take part in the research what would you have to do?

If you agree to take part in the research I would arrange to meet with you, this could be at your home, at my office or somewhere else that you might suggest, it is important that it is somewhere where you feel comfortable.

I would want to talk with you about the choices that you make, and other people make, about the things that you do and how you feel about this. I would want to meet with you twice in the space of one year. Each meeting should take no longer than one hour.

I would also want to talk with your support workers, your social worker/care manager, community nurse, advocate (if you have these) and anyone else who works with you. I would be speaking with them about the same thing, the choices that you make and the risks that take and how they feel about them.

Confidentiality - What will happen to the information?

Any information you or the people involved with you tell me will be kept strictly confidential. All information will be stored in a lockable filing cabinet.

If you don't want to take part in the research what will happen?

You don't have to take part in the research if you don't want to and you don't have to give any reason why.

If you say yes and then change your mind what will happen?

If at any point you decide you do not want to be involved in this research you can say so. You do not have to give a reason.

Who can you contact for more information?

If you want to ask any questions about anything on the information sheet or about the research please contact me on the number below, I would be happy to talk with you.

Sam Smith - 0141 418 7167 (Work) 0141 330 4545 (University)



Participant Consent Form

Living With Risk - To what extent do perceptions of risk influence the decision making process affecting the lives of adults with learning disabilities who have reputations for challenging services.

1. I understand what I will be expected to do if I agree to take part in the research with Sam Smith.
Yes / No
2. I understand that I can say no if I don't want to take part in the research.
Yes / No
3. I understand that if I agree to take part I can change my mind at any time and that I can do this without having to give a reason.
Yes / No
4. I would like to take part in the study.
Yes / No

Signed..... Date.....

Name.....

Name of person witnessing consent.....

Consent was given verbally Yes/No

Appendix 2

Conversation Guide 1

Introductions:

1. Thank individual for agreeing to participate in the research.
2. Go over the purpose of the meeting - refer to research information sheet.
3. Clarify consent – refer to consent form – inform participant that they can stop the conversation at any point.
4. Detail confidentiality agreement.
5. Ask permission to audio record the conversation.
6. Set up and test equipment.
7. As permission to draw a graphic record, ask participant if they want to assist.
8. Clarify role as a researcher/practitioner – ‘I may ask question that you think I know the answers to’.
9. Confirm that we will be having a conversation, I might ask some questions but there are no right or wrong answers, I want their ideas/views and thoughts.
10. Check that individual has understood the above and obtain permission to start.

Conversation Guide 1 – Themes

What does the word risk mean to you?

Can you think of any risks in your life?

Relationships

Who are the important people in your life?

How often do you see them? Who chooses? Why?

Where do you go? Who choose? Why?

What do you do? Who chooses? Why?

Do you see them on your own? Why?

Do you have a boyfriend/girlfriend? Do you spend time with them on your own?

What are some of the good things about family?

friends?

boyfriend/girlfriend?

What are some of the bad things about family?

friends?

boyfriend/girlfriend?

Home environment

Where do you live? Was that your choice?

Who do you live with? Was that your choice?

Support

Do you get support/help? Who gives you support you? Do you like them?

Do you get to choose who works with you?

How did you choose?

What would happen if you didn't like them?

Do staff sleep over in your house?

Whose choice is that?

Neighbours

Do you know your neighbours?

Do you get on with your neighbours?

Household

Who does the housework in the house?

Does anyone help?

Whose furniture is it in the house?

If something breaks who pays to get it fixed?

Who locks the doors?

Why do you have to be careful with this?

Do you have a fire? Who lights the fire? Why do you have to be careful with this?

Who does the cooking? Why do you have to be careful with this?

Finances

Do you have a bank account?

Who pays the house bills? how?

How much money do you get per week/day?

What do you spend it on?

Who decides what you spend it on?

What are some of the good things living where you live?

What are some of the bad things about where you live.

Community and social inclusion

What kind of things do you like to do when you go out?

Do you go out on your own?

Do you feel safe going out on your own?

How do you keep yourself safe?

Do you feel safe crossing the road?

How do you keep yourself safe crossing the road?

What would you do if someone started calling you names?

Has this happened to you?

When? How often?

What would you do if someone you didn't know asked you to go with them?

What would you do if someone you didn't know asked you to give them money?

What is good about the things you do just now? Are there any bad things about the things you do just now?

Are there things that you would like to do in the future?

Physical and emotional health and wellbeing

What things make you happy?

What things make you unhappy?

What do you do when you get angry?

Do you ever shout? At who?

Swear? At who?

Hurt yourself?

Hurt other people? Who?

How often does this happen?

Have you ever been in trouble with the police? What for?

Do you ever feel lonely?

What do you do when you feel lonely?

Do you know what sex is?

Would you mind telling me what it is?

Have you had sex?

Do you know what safe sex is?

Do you know how a woman gets pregnant?

Do you know how to stop a woman getting pregnant?

Do you know what a condom is?

Do you know how to use one?

Have you ever used one?

What are the risks/ bad things that could happen if you have sex?

Round up

1. Recap conversation using graphics – make amendments as necessary
2. Ask if there are any questions about what we have discussed today.
3. Next steps – inform participant what will happen with the information provided.
4. Seek consent to meet again.
5. Thank individual for participating.

Appendix 3

Conversation Guide 2

Introductions:

1. Thank individual for agreeing to participate in the research.
2. Go over the purpose of the meeting - refer to research information sheet.
3. Clarify consent – refer to consent form – inform participant that they can stop the conversation at any point.
4. Detail confidentiality agreement.
5. Ask permission to audio record the conversation.
6. Set up and test equipment.
7. As permission to draw a graphic record, ask participant if they want to assist.
8. Clarify role as a researcher/practitioner – ‘I may ask question that you think I know the answers to’.
9. Confirm that we will be having a conversation, I might ask some questions but there are no right or wrong answers, I want their ideas/views and thoughts.
10. Check that individual has understood the above and obtain permission to start.

Conversation Guide 2

Review the first research conversation using the previous graphics as a prompt.

Risk themes

What does the word risk mean to you?

Can you think of any risks in your life?

Challenging Behaviour

Have you ever heard the words challenging behaviour?

When did you hear these words?

Has anyone talked about you having challenging behaviour?

What did they say about you and challenging behaviour?

Were there things that you did that were seen as being challenging behaviour?

What were the risks?

Can you remember why you did that?

What help did you get for this? Support? Medication?

Do you do any things now that could be called challenging behaviour? What are the risks?

Can you remember living with other people who had challenging behaviour?

Where was that? What kind of place was it? What was it like? What were the risks?

Did you ever live in hospital/institution? Did you live in a challenging behaviour ward? What were the risks?

Serviceland

Are there any people involved in your life now because of challenging behaviour?

Have you ever heard the words Robust Services Project?

Do you know the name of the support organisation that supports you?

Why does this organisation work with you?

Reputations

Do people still talk about you having challenging behaviour? What are the risks?

Do you talk about having challenging behaviour? What are the risks?

When did it change (if it did)?

Do you still have challenging behaviour? What are the risks?

Why is it different? (if it is)

What is different in your life now than where you lived before (hospital)?

Round up

1. Recap conversation using graphics – make amendments as necessary
2. Ask if there are any questions about what we have discussed today.
3. Next steps – inform participant what will happen with the information provided.
4. Confirm consent to use the information provided.
5. Thank individual for participating.

Appendix 4

Mr Pink

'I'm fair'	'I want a 49 th birthday party'
I'm a fast thinker and a slow worker'	'I'm a smoothie'
'I was born in Blackhill'	'I have got a nice personality'
'My family is important to me'	'I remember birthdays'
'I'm kind'	'I'm good'
'I'm an Elvis fan'	'I'm a good thinker'
'I like a beer/lager but I cannae get it'	'I was reared with the Jews'
'I lived in the Gorbals'	'I am unique'
'I am honest'	'I smoke'
<i>"People take a liking to him"</i>	'I am such a nice guy'
'I have got a decent streak'	

Mr Yellow

'I like dressing up, looking smart'	'I like the ten guitars (song)'
'I like Tom Jones'	'I like coffee'
'I like visiting my sister'	'Like hair washed'
'I like Mars bars'	<i>'Godfather to two nieces'</i>
'I had a friend called Snoopy'	'Like the pictures'
<i>'Likes cooking'</i>	<i>'He can be very funny and sensitive'</i>
'I like Knightswood'	'Like visitors, my house'
'I like taking Amber (dog) for a walk'	'Like bingo'
'I like : Irn Bru, fish and chips, smokey bacon crisps'	'Like going out'

Ms Gold

'I've got a good memory'	'I'm a good sister'
'I'm very kind'	'I like animals'
'I'm generous'	'I'm good at planning for Christmas'
'I'm a good mum'	

Mr. Blue

'I've got a good sense of humour'

'Sometimes I need a little encouragement to go out, but when I do I enjoy it'

"He's a ladies' man"

'I make tea myself'

'I like my food - fish and chips'

'I am going to start collecting fridge magnets'

'I am a Rangers fan'

'I can be happy with people and be good with people'

'I collect key rings'

'I like the dancin' '

'I am a good dominoes player'

'I like to go shopping'

"He has a tremendous memory"

'I am young handsome and good looking'

'I put my own washing on'

'I've had friends for a long time'

"He's always learning how to do new things"

'My team is really great - fantastic, I get on great with my team'

Mr Orange

'I like telly'

'I like bus'

'I like dancing'

'I like pictures'

'I like Scottish music'

'My family'

'I like swimming'

"he's got good neighbours"

'I like cornflakes'

"He has is a very happy person, full of energy"

"He really loves pens, papers and bags"

'Like house clean, tidy pal'

Ms White

'I would give people my last rollo'	'I have good friend at the art class'
'I have got a big soft heart'	'I like to stand up for peoples rights'
'I like to be involved in any activities, take the first chance, be right in there'	'I've got a good sense of humour'
'I like to protect other people'	'I'm a comedian - I do things that are funny to other people'
'I would like to do more things with my life - be given more of a chance'	'I am generous'
'I like doing mosaics, screen printing, you can go on the internet and see my work'	'I am very kind hearted'
'I've been going to art classes since 2004'	'I am good natured'
	'I will go out of my way to help anyone with any problems'

Ms Lilac

I like looking after people, if they are not well.

I like everybody in the office.

I don't like a messy house.

I like music, the charts on the T.V.

I like spending money.

We like kidding each other on.

I've got a friend called W.....

I like clothes and jewellery.

I like animals.

I like to change things around, furniture in my front room.

I like a hot bubble bath.

'She likes a joke and a laugh'

I have got a friend called A...

I like getting the washing done

I like to be glamorous, dressed up and fancy tights.

I like shopping and going for lunch.

'She doesn't link anyone serious in her team'.

I like spending time with my team's family.

I like 'soaps'.

I paint my house as often as I can.

I can be funny.

I like beauty treatments, my eyebrows waxed and my hair done.

I like things to be clean.

I like to lie down in my room and relax.

'She is generous'.

Mr. Green

'I like buying radios, music and CDs'.	'I like buying dvd's'.
'I like living here'.	'I am a quiet person'.
'I lived in the handicapped place'.	'I like punk music'.
'I lived in M***hill'.	'I like films Live and Let Die'.
'I like going to the pub with staff'.	'Making tea and drinking makes me happy'.
'G*** is my friend'.	'I'm forty'.
'I have a girlfriend called C*** she works here'.	'I broke my arm in the handicapped place'.

Mr. Purple

'I am very easy going'	'I am a 28 year old Scottish man'
'I am quite nice all the same'	'I believe in freedom for all, everyone has a right to have their voice heard'
'I am a loyal supporter of the Celtic'	'I believe that all team members should do a six month probation when they join a team'
'I believe that all team members should be given a chance'	
'I do like to treat everybody the same'	'I am better now for taking things on the chin. I don't mean literally, now if I think someone is being unreasonable I will say'.
'I am the most challenging person you support - Researcher "Do you want me to write that?" - Mr. Purple 'No, No, No!'	'I believe in consequences for action, reasonable consequences'
'I don't believe in sacking your support worker if they make a mistake'	'I don't believe in holding a grudge'
'I am a peer consultant'	

Ms Scarlett

‘I am quite a nice person when you get to know me’.	‘I know sometimes I can be comical’
I’ve got nice skin for my age’	I still say I am only 16’
‘I like a laugh’	I am kind to wains and dogs’
‘I like to dance’	‘I don’t hate nobody, no matter what they are.’

Mr. Grey

No self description available

Ms. Silver

No self description available

Appendix 5

Transcription: Ms. Pink	Level One Coding	Level Two Coding	Level 3 Coding
Sam: Have you ever heard the words 'challenging behaviour'?	Familiar with term? Non committal one word answer.	Familiar with the language	
Ms. Pink: Yep.			
Sam: What would that mean?	Hesitant about definition of challenging behaviour	Not owning the label of challenging behaviour	Feeling out of control, lack of control
Ms. Pink : Emm... Behaviour is em,	Behaviour linked to ill health	Not in control behaviour linked to health	
When...when you're not well.	Behaviour linked to anxiety, being worried.		Behaviour linked to ill health
When you're worried about things.	Behaviour linked to health	Not in control	
When you're not well.	Behaviour linked to pressure	In need of support	
When all the pressure.	Not in control, not understanding what is happening	Seeking affirmation	Seeking understanding and empathy
Because I don't know what's the	seeking affirmation	ill health	

<p>matter with me sometimes.</p> <p>You know what I mean?</p> <p>I tell the staff sometimes,</p> <p>you know,</p> <p>when I'm no well.</p> <p>Sometimes it's hard for me.</p> <p>People don't understand.</p> <p>I don't know what's the matter with me sometimes,</p> <p>I'm just no well.</p> <p>And my mind goes away with it sometimes.</p>	<p>seeking support and help from paid support</p> <p>seeking empathy, affirmation, understanding</p> <p>ill health</p> <p>feeling of pressure</p> <p>a feeling of isolation and lack of understanding in others</p> <p>confusion and distress at not understanding. feeling of not being in control</p> <p>ill health</p> <p>physical sensation distance from self separation of mind and body</p>	<p>seeking sympathy/empathy</p> <p>isolation, separateness</p> <p>feeling out of control</p> <p>ill health</p> <p>physical manifestation of ill health, lack of control</p>	<p>Physical manifestation of ill health</p>
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