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Original Citation

Shaw, Susan Angela (2007) An analysis of the discourses and discursive devices used to represent learning disability in the stories told in the classroom to students by learning disability nurse teachers. Doctoral thesis, University of Huddersfield.

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An Analysis Of The Discourses And Discursive Devices Used To Represent Learning Disability In The Stories Told In The Classroom To Students By Learning Disability Nurse Teachers

Susan Angela Shaw

15th August 2007

A thesis submitted to the University of Huddersfield
In partial fulfilment of the requirements for
The degree Doctor of Education

The University of Huddersfield

In memory of my father

Eric Bill.

Acknowledgements

There are many people who have played a part in the production of this thesis however due to space I am unable to mention them all. I have received support from colleagues, friends and supervisors over the years all which have contributed and become sources of inspiration in small and large ways to this final piece of work.

Firstly, I would like to thank my supervisors, Pete Sanderson, Ann Harris and Chris Ormonroyd for their help in completing this thesis. Their help support and belief in this work has been greatly appreciated over this last year when I needed it the most. I also thank Dallas Cliff for his painstaking proof reading and attention to detail.

I owe much to my fellow and extremely busy lecturer colleagues who bravely agreed to allow me to connect with their world and their professional histories. Without their total openness to my distracting observations, questions and not to mention my preoccupations, this thesis would not have been possible; to them I say a big 'thank you'. I also need to thank the cohorts of students who allowed me access to their classes and took an interest in my work.

My acknowledgement extends to my partner Graeme, to my family and to my friends whose endless support, encouragement and patience has played an important part in maintaining me as a healthy person whilst I endeavoured to finish this extended piece of work. To you all – thank you.

Abstract

This study explores the complexities of the social construction of learning disability. The focus is upon the ways in which learning disability nurse teachers represent their experiences of learning disability nurse practice in stories. The stories focussed upon in this study were identified in a series of 20 audio taped teaching sessions with student learning disability nurses. The research investigations centred upon the learning disability constructions in some 30 stories and were also supported by 5 subsequent interviews with the teachers and observations of 7 teaching sessions. The findings highlight some interesting ideas about the social construction of learning disability by nurse educators and also the personal tensions expressed by learning disability nurses trained in the past but faced with the dominant discourses of today.

As a qualitative study, this research drew upon the ideas of social construction and competing discourses most commonly associated with Michael Foucault in his works *Discipline and Punish* and *Madness and Civilisation*. In particular the stories were investigated for the influences of medicalising and professionalising discourses which construct people with learning disability as powerless and the learning disability nurse with the power to control. The investigations began with a form of Foucauldian discourse analysis which was used to examine the transcribed storied material, interviews and observations. Following initial engagement the investigations also developed with the aid of discourse analysis more heavily influenced by the discursive psychology of Potter and Wetherell (2004). Both forms of discourse analysis assisted the investigation of the many ways or *modes* in which learning disability was constructed by nurse teachers.

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Introduction

Overview

Learning disability is a social phenomenon, but is problematic as it shares many of the cultural norms we as a society ascribe to sickness and to incapacity (Barnes and Mercer, 2003). When recognised as a person with a disability, one is constructed by non disabled people as a problem and judged against a spectrum of normality (Oliver, 1990). These norms are constructed by variants of the language of illness, of abnormality and of tragedy (Oliver 1990). It is then argued that learning disability is socially constructed and is promoted by the cultural powers of this discourse (Clegg, 1993). The social construction of learning disability encompasses the language of the professional (Barnes, 1990; Clegg, 1993; Davis 1997). The professional (e.g. social, health worker, and physician) often draws upon language which assumes insight and knowledge and describes learning disability as a special category of people requiring specialist and therefore highly skilled professional care.

Those aiming for a professional career in learning disability nursing enter higher education and engage in adult learning practices intended to equip them as students with the skills and competence of professional practitioners (NMC, 2002). The curriculum is devised and delivered by experienced professionals, often with a number of years spent working in learning disability nursing practice. The students of learning disability nursing courses follow a programme of learning experiences aimed

at exposure to the topic of learning disability care and the transformation of lay ideas about learning disability into a professional and more informed perspective.

This study is intended to explore the scope of social construction situated in the language of the one set of learning disability professionals. This exploration engaged me as a researcher in a quest to identify learning disability constructions and to develop an understanding of the power of the dominant discourses operating within the culture of learning disability nursing. I was aware that the learning disability discourse posed challenges to the assumptions held in society about difference and exclusion and I was eager to explore how the learning disability nursing profession might represent learning disability in stories. One insight in particular interested me, the personal portrayal of learning disability as told through a personal experience, anecdote or story. My quest to explore learning disability constructions was then centred upon the tales of the past told by the educators of future learning disability nurses and what this might reveal about the construction of learning disability today.

Why look at narratives and stories?

Narratives and the study of their presence are difficult to ignore in our general social world (Connelly and Clandinin, 2000; Lakoff and Johnson, 2003). We, as social and cultural occupiers of personal and collective histories appear within what the anthropologist Geertz (1973) described similarly as the hallmark of inevitable instability and change. Although many of the images within narratives appear constant in time (i.e. photographs, pictures, appendices), the nature of the narrative changes according to the context, audience or position of the narrator (Connelly and Clandinin 2000). The learning disability discourse also changes over time and

continues to be constructed and reconstructed in the narratives of those with interests inside and outside the field. Examples of this are the stories told about the relationships between people with learning disabilities and their carers.

As a researcher with an interest in stories in general culture, I was intrigued by in the idea that narratives are units of language expressing an experience that can help us to learn (Dewey, 1933) and also what effects this has upon learning disability nursing education. Gee (2002) suggests there are connections between social language and cultural models in our society and a sharing between individuals of ethical and moral beliefs (e.g. the changing moral values and the changing language of sexuality). This sharing may be also vulnerable to the conditions of time and context, leading to an ever-changing emphasis in social policy and inevitably social and health care. I see this sharing as the creation of the learning disability discourse which resides almost exclusively with learning disability professionals.

As a teacher of learning disability nurses myself, I had experience of the communication methods employed by teachers engaging with students within classrooms. Many teachers, particularly those with personal professional experience, engage in the sharing of their own experiences (Dyer and Keller-Cohen, 2000). The resulting narrative, as Polkinghorne (1988) reminds us, can be a way in which the experience of teachers is made meaningful to themselves and to their students. This interested me in a number of ways and were developed into a research aim and a series on objectives

Aims and Objectives

To investigate the social construction of learning disability by teachers in the stories they tell to their students within teaching narratives.

This aim was to be realised through a process of qualitative inquiry and I took my theoretical guide from the ideas of discourse and language which appeared to fit with the development of such a study.

To meet my research aim I developed a number of research objectives that guided me through the research process. Initially, the first of these objectives was developed from the ideas within the literature that dominant discourses assisted the construction of learning disability. This was further explored and refined through the examination of various data collected. Objectives 2 and 3 developed out of the need to situate the research firmly within the classroom and to locate the narratives on which to explore the investigation and analysis of learning disability construction by teachers accessing the discourses identified primarily with learning disability care (I called this the learning disability discourse). All three of these objectives were the subject of evolution. The final development and regulation of this study were structured around the following;

1. To explore the use of discourse in learning disability constructions within teachers' stories

2. To identify any links between the teachers' learning disability constructions and the learning disability discourse

3. To investigate common themes appearing in stories, interviews and observations.

Although this study does not adhere to structuralist conventions (e.g. an in-depth analysis of the linguistic structure of language, conversation and intonation) it was necessary to begin with a narrative, which was reduced via its structure. The larger narrative is the teaching session or interview and I endeavoured to extract smaller units or stories to begin my quest to examine what these units could tell me about the social construction of learning disability.

This process of deconstruction enabled me to extract what I considered are the personal stories contained within the larger spoken narrative of the teachers. I had argued that there is a sense of shared history within both the personal narratives constructed and revealed by teachers (in various ways) to their students and the wider social picture painted by writers, theorists and policy makers, yet both can shape the nature of experience for learning disabled people.

If we consider (as I do) that human beings make sense of their world through a process of reconstructed and constructed narrative accounts of actions by themselves and others, narratives therefore become important vessels to understanding the social worlds past and present. It is important in this study to distinguish between the 'narrative' and the 'story'

What is a story in my study?

In this study I interpreted the personal stories told by lecturers to students in the classroom. The aim of this research was to investigate how the stories construct learning disability and the people described with learning disability, and what this

construction can reveal about the nature of the emerging learning disability nursing practice.

For me, the presence of a discrete story within the larger account (teaching session/lesson) signifies the narrator's relationship with a past event. The narrator in my collection is telling the audience "how it was for them" On most occasions the event is represented by a sequence in that it has a beginning middle and an end, and there is entrance and exit talk (Labov and Walezky 1967, Jefferson 1979). The sequencing and the structure are important factors in the identification of the story, but also other features are less obvious but equally important. The essence of the story, which separates it from a simple chronology, is less easy to define and even more complicated to analyse.

How and why did I select stories?

This section considers how and why this study focuses on the personal stories told by teachers during teaching sessions. Goffman's (1963) description of narratives as tapes or strips of personal experience from the tellers past, acting not only as reporting function but also as something to re-experience, provides some useful perspectives which can be applied to this setting. He is further helpful by suggesting that the re-experience may be not confined to the teller but that the audience can join in the experience also. Taking these ideas; the audio taping of whole teaching sessions are a way to capture the teaching narrative and what they say in the classroom.

As a teacher and practitioner with a keen interest in language, discourse and more recently narratives within stories, my research commenced as suggested by Colin

Robson (2003) " Starting where you are" (Robson, 2003. p.49.). The nature of the socially constructed labels of "learning disability "and "nurse" used together by lecturers as topics for their stories interests me both as a teacher and a nurse myself. My starting point was based on these interests and as a consequence the aims of this study were formed.

I will now explain the study outline as whole and how the chapters fit together.

Outline of the chapters

Chapter one. This study is essentially an investigation into the social and political implications of stories told by teachers about the lives of people with learning disabilities to student nurses. Social life investigation has undergone changes in both method and morality and has influenced both the design and analysis of subsequent research and development in learning disability care. This study is cognisant of this and is sensitive to the prevailing changes which have occurred in learning disability care over the past years. This chapter aims to outline the important works which have contributed to the learning disability discourse. The following intends to provide an overview of the topics covered.

Importantly, the demise of institutional care for people with a learning disability is accounted for by the social commentary which has drawn attention to the lives spent in institutions and the regimes which governed them. As a result of these and other changes the rise of the political discourse of disability has proved to be a strong influence over the way disability and as an effect learning disability is viewed in society and by those who provide caring services. Many of the other influences upon

learning disability care have originated in philosophies aimed at the emancipation of people with a learning disability in society. One theory, namely 'normalisation' was a highly influential movement which helped shape the learning disability discourse and informed the development of learning disability services (O'Brien and Lyle, 1987; Wolfensberger, 1972). The influence of normalisation informed the debates which developed from the need to relocate large numbers of people with learning disabilities from large hospitals to smaller community units. The debate has continued and together with social awareness of disability and exclusion, the learning disability discourse includes questions about rights and citizenship. Coupled with the issues of rights are the concerns that people with a learning disability experience unequal power relations with those who care for them. This debate is based upon the analyses of language, of power and of control in the professional discourse of learning disability workers and professionals. The challenges posed by those with disabilities themselves provide a useful background to this study.

Secondly, this chapter looks to the development of learning disability nursing and the professionalising discourse emanating from a long history of caring for people with a learning disability in the UK. As the principal health care providers for more than half a century learning disability nurses view themselves as experts in the field of learning disability care (Mathews, 2006; Mitchell, 2000b). Their contribution to the learning disability discourse is considerable and many policy changes for people with a learning disability have been advocated by this group of professionals.

Chapter two then moves on to consider the theoretical approach that underpins the research study. The development of a theoretical stance is explored and reflected

upon. The ontological position I took as researcher and the questions I wrestled with are explained. I also expand the discussion to illustrate the resulting research design, which followed my deliberations, and the reflections which formed the important decisions I made.

The three sections in this chapter uncover the research approach taken, the sample and the data analysis which followed. Each of the sections relates my reasons for the decisions taken and the arguments for and the arguments against.

In this chapter I situate my role as a researcher and the positive part active (or reflexive) involvement in research can make. Here I explain how the various facets of the research fit together and are informed by the social construction of learning disability. Finally, I explain the process and function of data analysis in this study and detail the steps taken to interpret the data. At this point I also detail the main social constructions I noticed and was influenced by in my engagement with the open coding of the data and the basis for the analysis and uncovering of the four discourses used to construct learning disability in this way.

Chapter three provides a significant examination of the four main discourses which became important to me on examination of the social construction of learning disability by the teachers. This chapter provides a framework on which the analysis of and interpretation of the stories is based. I identify the discursive practices as I saw them which are associated with the dominant discourses of medicalisation. professionalisation, politicization and the inclusion/exclusion of learning disability care domains.

Chapter four begins the first of two chapters discussing the analysis and the interpretation of the learning disability constructions as '*Cases to be managed*'. This firstly explores the dominance of the medicalising discourse, which constructs learning disability, together with the other three main discourses. The analysis which follows provides an insight into my interpretation of the three modes of discursive device used by teachers to construct learning disability. I interpret these three modes as; ways of reaffirming (or agreeing with) established or dominance discourses, ways of refuting (or encouraging criticality) the discourse, and finally, ways of identifying personally (self) with elements of the learning disability construction. These modes are used to provide my analysis of the learning disability construction drawn upon by the teachers in their story telling.

Chapter five further explores the language/discursive modes used to construct learning disability, and in particular my analyses reveal the interpretation of constructions which involve the dominance of the professionalising and the inclusion/exclusion discourses. This analysis explores the many ways in which teachers construct learning disability in the stories as *cases to be managed* but also as '*strange and different* 'and '*victims of professional domination*'.

Chapter six discusses some of the concluding comments arising out of this work and attempts to unify the study by discussing the findings of the research with respect to the research aims and objectives.

It is my intention that this study is presented both as an exploration of the phenomenon of learning disability construction and also as a story about the research process I embarked upon. The process was not intended to be seen as a linear progression and indeed much of the work explored has been revised and revisited in accordance with the interpretive nature of this type of study.

The chapter that now follows, an exploration of the learning disability discourse, is documented in a number of ways, mostly by those seeking to find some explanations in the history of learning disability nursing. It is my aim however to provide an analysis of the learning disability discourse from a unique and under researched perspective.

Chapter one

Literature review:

Disability and Learning Disability ideas in

Construction

Overview

This chapter reviews literature concerning learning disability with a view to explaining the socially constructed nature of the learning disability discourse. This begins my journey to meet my main aim; *To investigate the social construction of learning disability by teachers in the stories they tell to their students within teaching narratives*. This chapter will support the subsequent objectives of the study; *To identify any links between the teachers' learning disability constructions and the learning disability discourse* and; *To investigate common themes appearing in stories, interviews and observations*.

Introduction

The following four sections introduce the influential themes in this study. The first theme charts the development of learning disability nursing and extends the discussions particularly towards the professional role and identity. The second theme, power and control in learning disability, outlines the important debate between carers of disabled people and their clients and the considerations that have arisen with this awakening. The third theme; the development of the learning disability and disability

story is intended to set the scene for the history of learning disability care and the context of the discussions about the lives of people with learning disabilities. Finally the fourth theme; the education and learning context for adult students, contextualises the context of the study in an educational setting. These themes provide a theoretical platform on which I can begin to investigate the construction of learning disability by nurse teachers within classroom stories.

The development of learning disability nursing

This section provides a historical description of the development of learning disability nursing and the education that has emerged. I will chart the rise of learning disability nursing through history and its relevance to the main professional nursing model that developed. I will also detail the social examination and criticism lodged against learning disability nursing and the reforms in health care that have followed.

The history of learning disability nursing is complex and closely linked to the history of health care policy for people with learning disability (Atkinson et al. 1997; Dingwall et al. 1988). It is often argued that the relationship between learning disabled people and their professional carers has encouraged the care and control of people with learning disabilities at the expense of their independence and self-determination (Mitchell, 2000a). Factors affecting the development of these relationships are of particular relevance to this study, together with the development of these in the context of the learning disability nurse role.

History in the making

In the early part of the twentieth century most nursing, and in particular learning disability nursing, was unregulated and much work with people with learning disabilities was unpaid or low paid, attracting very low status and low social position. Mitchell (2003) describes the role of institutional worker in his analysis of the development of the learning disability profession. These descriptions detail routine and ordered work in a tightly regulated system not unlike other institutional health regimes of the time such as mental health asylums, isolation and general hospitals. Although the location of what were called learning disability colonies mirrored that of the isolation hospital or asylum the nature of early provisions did not. The early work in the learning disability colonies of the first part of the twentieth century however, tended to be less regulated with more informal and community like routines not unlike those of a small village or large family.

This informality of the work continued throughout the first decades of the twentieth century although some training schemes and development courses were accessed via the Medico Psychological Association (MPA) an organisation which catered for the small number of workers in institutions. .The Mental Deficiency Act 1913 prompted the MPA to offer some separate training schemes (none as nursing courses) for what were the developing mental deficiency hospitals (Mitchell, 2000a).

This continued until the establishment of the General Nursing Council in the 1920's, which attracted the affiliation of some but not all nurses for people with learning disabilities (Mitchell, 2000b). The rise of professionalism in nursing and the advent of statutory regulation by the General Nursing Council created a regulatory system for the profession based on a value base of paternalism and cure of the sick (Salvage,

1985). Although learning disability nursing embraced the professionalism of nursing it struggled with inferior status, compared with the larger majority of general trained nurses.

Although many personal stories of life in the closed institutions where people with learning disabilities lived and learning disability nurses worked, describe harsh treatment (Atkinson et al, 1997), the analysis of the nurse role within the institution reveals influences by the social situations of the time as a result of social attitudes (Mitchell, 2000a). Commenting on the many prevailing and changing social attitudes towards people with learning disabilities Mitchell (2003) attributes links between the low social status of the resident with learning disability to the low status of their carers the nurses.

As societal attitudes changed as a result of political and economic developments (Finkelstein, 1994), the need for nursing (including learning disability nurses) across the broad health spectrum increased. The expansion of the professional was strongly led by the General Nursing Council (GNC).

The need for learning disability nurses

Initially some role expansion of the learning disability nurse was driven by the mid twentieth century view of physically and mentally disabled people as in need of care and control (Brigham et al, 2000). This view is reflected by the development of large scale hospital type asylums which housed up to 1000 learning disabled and mentally ill individuals under one roof. As the population of learning disabled increased with the general population expansion the need did not diminish and the role developed.

For many in society the disabled individual (physically or intellectually) was viewed as either a menace or similarly as a diseased organism in need of protection or incarceration. This together with other socio-economic factors (Richardson, 2005) increased the growth of institutionalisation for many people with learning disabilities. As Ryan and Thomas (1995) write, many definitions of difference have led to many variations in attitudes over the years towards the social and medical treatment of people with learning disabilities. One attitude in particular demonstrated some of these negative values experienced by people with learning disabilities; this was the large scale residential housing of people with various disabilities in provision ranging from isolated hospitals to working village communes.

Since the early days of the National Health Service in 1948 the learning disability specialism of nursing has forged a difficult path through the ever changing social statuses and political priorities for the learning-disabled client group. As institutional care proliferated during the 1950's and 60's learning disability nurses expanded their role to include generic health worker, educationalist and therapist. These roles, dependent on the constraints of the institutional environment, became firmly defined and defensible (Brigham et al, 2000).

There were some problems

Major reviews of learning disability nursing such as the Report of the Committee of Nursing (Briggs, 1972) and the Report of the Committee of Enquiry into Mental Handicap Nursing (Jay, 1979) concluded that there was a need for major changes in the profession. The debate centred on the question of health versus social care for people with learning disability. Many of the principles of reform originated in the

growing concerns and recommendations arising in Wolfensberger's (1972) normalisation ideology. The concerns of those advocating better health care through improvements in social and health care policy has continued over time. As some of the social reforms have progressed, promoted by the modernising agenda of the present government, learning disability nurses have seen a return to the challenges of change, with many role alterations advocated by the white paper *Valuing People* (DOH, 2001)

It is the extremes of opinion which have driven many reformers to campaign for a greater acceptance of difference of all kinds as opposed to a preoccupation with the differences between the non-disabled and disabled (Atkinson et al, 1997; Walmsley, 2001b). As a result of these and many other political changes, learning disability nursing has been charged with the majority of health care for people with learning disabilities in the last fifty years. The changing health care agenda in particular has impacted greatly on the profession.

Changes in the NHS

Politically, The National Health Service (NHS) of the 1970' and 1980's was undergoing a series of technological and demographic changes increasing the demand for a highly skilled workforce. Socially, clients and patients empowered by technology and consumerist tools such as Patients Charter placed heavy demands for information upon the NHS and nurses in particular. Professionally, nursing, although slow to respond was quick to recognise the need for change at clinical, managerial and ideological levels (Davis 1996; Raffety, 1996). These changes, manifested through political pressure, emerged as Project 2000 (UKCC, 1996) the programme that would

develop all qualified nurses to a higher education diploma level, and eventually lead to nurse education within higher education sites, a move away from health sited schools of nursing.

However, it can be argued that learning disability nursing has suffered at the hands of the majority position that is general nursing. Notably the education of qualified nurses in the UK has changed undeniably in the last twenty years. Developed from traditional hospital based and controlled training schools to integrated programmes in universities and higher education institutions, nurse education is now exclusively subject based within the HE sector. Traditionally, nursing, including learning disability nursing, was taught to students in an apprenticeship style with the emphasis of skill development through 'doing' and throughout specific clinical experiences (Davis, 1996). This style had proliferated through out the 1960's and the 1970's without amendment, but as the demands on nursing changed the profession was under pressure to accommodate reform from a number of sources.

For many (mainly in the general nursing field) the recent policy developments in health and the move to higher education status have had a positive effect on the profession. The move is questioned by others for example the geographical distance from clients and practice, and the continued influences of medicalised nursing have perpetuated problems for learning disability nursing education (Elliot-Cannon and Harbinson, 1995; Kay, Rose and Turnbull 1995; White et al, 2003).

The initial reforms to learning disability nurse education should be seen in the context of political, social and professional change in nursing. Although major changes to the

training and education of learning disability nurses have followed reluctantly in the wake of the general nursing population (Norman, 1998), many challenges for role reform have come from within the learning disability nursing profession in an attempt to meet the changing needs of the learning disabled population. The learning disability nursing profession is often highly self-critical and many critiques of care for people with a learning disability are often from learning disability nurses themselves (Mitchell, 2003). Many debates within the profession have generally centred on who should provide support for clients and in what format. (Kay, Rose and Turnball, 1995). More recently DOH (2001) has debated the learning disability nurse as the major support provider. A generic versus specialism debate has continued in learning disability nursing before and since the development of the Project 2000 Diploma in Higher education (UKCC, 1996).

Summary

This section has set the scene for the historically situated learning disability nurse which has developed as a result of the social processes of health care and political reform. The development of the learning disability nurse profession has been strongly dominated by the larger and more medicalised group of general (adult) nurses. As a profession the group is relatively small in number but has a presence within the larger health and social care picture for people with learning disabilities receiving care.

The positioning of learning disability nurses as the main professional group working with people with learning disabilities is controlled by nurses aware of the stories told about the legacy of institutional care.

Power and control in Learning disability

The issue of power and the power relations between client and professional has become something of a political focus in the present government's modernisation programme (Gilbert, 2003). The focus, although primarily upon patient and health professional relations, has raised some awareness of issues of power and inequalities in both health and social care for some people considered vulnerable (DOH, 2000).

This section considers the visibility of power relations within the learning disability discourse and the changing constructions of people with learning disabilities from passive patients to individual advocates for inclusion. The three issues considered to be important issues in the analysis of power and control in learning disability are the influences of Foucault, the representation of learning disability, and the inclusion debate.

Introducing the Influences of Foucault and power and knowledge

The work of Michel Foucault (see, 1967, 1991 and 2004) provides a framework through which to view the paradigms that have interacted with the discourses of learning disability. The questions asked about power by Foucault in Discipline and Punish (1991) 'what are the effects of power'? and 'how is it exercised'? are not exhaustive but do provide this study with a lens through which to begin the analysis of power relations between people with learning disabilities and learning disability professionals. Alternatively, other analyses of power could have been drawn upon as the work of Foucault is not unchallenged. In particular the work of Agamben and some Marxist writers extend the discussions (not present in any detail in Foucault's

work) to the effects and the structures of power in bio power, and ideas that all humans are born as subjects of sovereign power (Agamben, 1998).

For Foucault, power does not reside in the dominant classes or in the state or sovereign control it is more a technology or strategy by which domination is achieved.

> …this power is exercised rather than possessed; it is not the 'privilege', acquired or preserved, of the dominant class, but the overall effect of its strategic positions- an effect that is manifested and sometimes extended by the position of those who are dominated. Furthermore, this power is not exercised simply an obligation or prohibition on those who 'do not have it'; it invests them, is transmitted by them and through them; it exerts pressure upon them, just as they themselves, in their struggle against it, resist the grip it has on them (Foucault, 1991, p. 26-27).

The power imbalance and resulting oppression of people with learning disabilities is widely debated. This study draws on the debates, which inform past and present issues of social and personal power for clients of learning disability services. The work of Foucault and other post-modern writers present a focus for the many issues pertinent to clients of services and in particular those who have been in institutions. A brief summary of some of the work is provide which enables a debate issues of power and influence between clients and their carers constructed in the stories told by teachers.

Foucault and discourse

For the purpose of this study, learning disability discourses are the practices developed over periods of time and which have and continue to have influence over the way learning disability is constructed in the language of learning disability professionals (Foucault, 1991). Foucault provides some guidance about possible utilisation of discourse to infer groups of acts or formations which lead to an understanding or field of knowledge.

> … by discourse, then I meant that which was produced (perhaps all that was produced) by the groups of signs. But I meant a group of acts of formation, a series of sentences or propositions… (Foucault, 1991. p. 120)

Foucault's (1975) work concerning agents of social control and the vested interests of powerful medicalising discourses has strengthened the social model debate amongst disabled people and has highlighted their own struggles with professional agencies such as medical practitioners and associated professionals acting as social gate keepers (Finkelstein, 1980; Stone, 1985; Zola, 1972).

For Foucault, the relationship between power and knowledge and discourses, resides in questioning the role played by science in the field of knowledge.

> Knowledge is that of which one can speak in a discursive practice, and which is specified by that fact. (Foucault, 2004. p.201)

In the Archaeology of Knowledge (2004) Foucault details four thresholds from or through which a discursive formation might emerge to form knowledge.

Threshold one, is positivism and this sees the initial development of a practice as individualised through a system of statements (e.g. fashions or terms used). Threshold two, of epistemologisation, starts at the point when statistics, figures or validation (e.g. facts and figures publicised and disseminated) claims begin to form a model of knowledge. Threshold three, of scientifity is crossed when new laws and rules are produced as result of the belief system. Finally, at Threshold four the formalisation of knowledge happens when scientific discourse produces or defines its own precedents.

For Foucault, the relationship between the formations of the human sciences over a period of two hundred or so years is related to the field of medical knowledge developed from originally the observation, and more latterly, the description of the human body. This move, from purely an observation, to a discursive practice has informed the more general debate about the emergence of the language of science (in particular medical science) and is a useful discussion when analysing discourses.

> Western man could constitute himself in his own eyes as an object of science…grasped himself within his language and gave himself, in himself and by himself, a discursive existence, only in the opening created by his own elimination: from the experience of Unreason was born psychology, the very possibility of psychology; from the integration of death into medical thought is born a medicine that is given as a science of the individual. (Foucault, 1975. p.197)

One theory of power offered by Foucault (1991) concerns the way society governs the behaviour of citizens. Hierarchical observation, according to Foucault (1991), encourages citizens as (objects of observation and discourse) to act in a disciplined manner because of the actual or perceived act of being watched or gazed upon by those with authority to punish. Those being watched are encouraged to act in a normalised way which is described by those with the ability (and therefore the power) to watch and regulate. The apparatus of this observation is further described by Foucault as a central architectural structure or 'Panoptican' from which those being watched are unsure if they are being observed or not but act as if they under constant surveillance just in case.

> The efficiency of power, its constraining force have' in a sense, passed over to the other side – to the side of its surface of application. He who is subjected to the field of visibility, and knows it, assumes responsibility for the constraints of power; he makes them play spontaneously upon himself; he inscribes in himself the power relation in which he simultaneously plays both roles; he becomes the principle of his own subjection. (Foucault, 1991, p. 202-3)

Simply interpreted, this has assisted social theorists to comment upon the disciplines imposed by social networks such as hospitals, schools and long stay institutions on pupils, patients and residents. In particular the theories have assisted the analysis of the power relations between people living in long stay institutions (such as mental handicap hospitals or nursing/residential homes) and those (the nurses) who care for them (Walmsley, 1994, 2001).

Additionally the work of Foucault has also contributed to the analyses of the relationships between people with disabilities and the welfare state. This wider view that power influences the lives of people reliant upon the state for their general welfare is useful when considering the development of the learning disability discourse. Firstly, Foucault suggests that the processes of government goes beyond the state and policies and enters social practices (Foucault, 1984). Gilbert (2003) and also Jolly (2003) suggest that the 'governmentality' of disability creates powerful structures or webs of administration and professional activity which are then dispersed through local social practices. These structures or relationships are described by Foucault as inevitably involving a struggle or resistance by one group over another. The central thesis is that a series of oppositions have emerged in modern western societies that cannot be ascribed to the dynamo of class struggle, namely concerning the power of:

Men over women, of parents over children, of psychiatry over the mentally ill, of medicine over the population, of administration over the ways people live. (Dreyfus and Rabinow, 1982. p. 211).

These are sanctioned and encouraged by society as legitimate ways of controlling and regulating (normalising) certain groups of people, for example people with learning disabilities. Secondly, the lived experiences of people with learning disabilities accounted through stories and personal biographies detail the medicalising effects of the welfare state upon their abilities to join society in a meaningful way (Walmsley, 2001b) and their struggles to effect the social constraints imposed by powerful professional groups employed by statutory agencies.

Power and the representation of learning disability

The representation of learning disability in wider society also influences the learning disability discourse. For many the medicalised discourse affects the abilities of societies to represent the body (disabled or non-disabled) as an object. Post-structuralist (and more recently post-modern writers) writers preoccupied with the social production of medical knowledge, have influenced the movements concerned with the representation of disability and the influences upon the discourse of learning disability , by encouraging the deconstruction of definitions applied to the body (Haraway, 1990). Many groups draw upon the lessons learnt from the suppression (by medicalised language) and liberation (through the mobilisation of discourses) of women's and gay rights movements to highlight representation of marginalised people by the media and in discourses (Jenkins and Northway 2002).

Although many attribute differing notions about the ways the body is viewed by society to the suggestions made by Foucault, the central notion in some disability literature is of the social constructed or created body (Morris, 1991). These ideas suggest that our image of our own and that of others' bodies is dependent on the social, cultural and historical context. (Greenway, 2003). For Oliver (1990) this representation of the medicalised body through the effects of a reductionist, mechanistic approach to science tends to encourage observation, categorisation and exclusion, leading to the inevitable discrimination and disadvantage experienced by many disabled people at the hands of a welfare society.

It is then argued that the biological focus (from the past) as the major view of the body has now collapsed, and is replaced with a meaning attributed to the linguistic cultural and social analysis of the body (Shilling 1993). This growing bank of literature sees the body as an unfinished product offering a site for seemingly personal and social control, in a sense the body has also become politicised offering to the world an opportunity in Foucault's (1991) terms to be observed and looked upon . The pathologising of difference in the field of disability studies originates in the idea that the medicalising discourse describes those with obvious impairments with the language of illness, deficit and problems (Oliver, 1990).

> The idea of disability as individual pathology only becomes possible when we have an idea of individual able-bodiedness, which is itself related to the rise of capitalism and the development of wage labour. (Oliver, 1990. p. 47.)

The idea of the medical gaze and the preoccupation with the body as a subject was developed by writers concerned with both the identities and representations of the disabled female image (Corker and French 1999; Morris, 1991; Shakespeare, 1994).

For some, parallels exist between the social meanings given to the female body by society and those given to the disabled body. Mairs (1986) presents some powerful and highly critical viewpoints based upon the disabled body as a brutal truth to be acknowledged, defended and not ignored. This and many other feminist contributions have politicised the position of disabled people against what are considered established norms of image, beauty, representation and usefulness (Hughes and Paterson, 1997; Morris, 1991). How these norms are communicated culturally and technologically add to the complexity of the disability discourse debate and are vividly demonstrated in the visual works of Hevey (1992) in the representation of disabled people in all forms of media. These highly emotive and explicit photographs and works of visual art illustrate graphically the 'tragedy principle' often seen as a main contributor to the construction of disability and learning disability as a medical problem requiring prolonged skilled intervention (Oliver, 1990).

Deeply rooted in historic European stories such as the 'Hunch Back of Notre Dame', disability has afforded a characteristic image in the minds of society. The freak show, once a novel and popular Victorian sight, interplays with cultural stereotypes of difference, fear, and flawed bodies (Bogdan, 1990; Morris 1991). Contesting these images and those of latter day media and institutional portrayal, Zola (1991) and Hevey (1992) have drawn interest to the metaphoric use of tragic and saintly disabled images to sell and endorse charitable appeals, thus perpetuating the tragic image of the disabled person and reinforcing the medicalising discourse. Hevey extends his discussion from visual images to literature and film, therefore considering the many historical viewpoints about disability embedded in mainstream culture (Bogdan, 1990; Zola, 1991).

Social policy and practice, influenced by the prevailing imagery and attitudes towards people with learning disabilities has developed from a view that asylum and incarceration was the preferable option, to an admission that mistakes were made by enforced institutional living (Barnes, 1990). The vested power of care and health professionals has never been more challenged with many groups now called to account for their previously unquestioned knowledge status (Brechin et al, 2000). More recently, some organisational changes in the health service and social care sectors have relieved professional groups such as psychiatrists and nurses or powerful decision making over people with learning disabilities and this has challenged their domination (Gilbert, 2003).

The legacy of Foucault and his followers has highlighted the power, domination and influence of social attitudes to historic and contemporary issues. These threads continue to inform the development of the learning disability discourse as spoken and discussed by professionals. A different discourse of empowerment, freedoms and choice is used by learning disabled people themselves.

Power and the links with inclusion

Inclusion has recently become an everyday discourse and is used within political rhetoric in many guises. The need for inclusive values and attitudes has arisen in the debates concerning the lives of people with learning disabilities over a long period and originates beyond the current political rhetoric. With the establishment of groups such as the People First movement and other local movements aimed at integration and inclusion via the arts, education and media, many individuals have developed as active campaigners at venues including conferences, seminars, and form the lead in

some local service planning groups across Britain. It can be argued that not enough has happened to include learning disability services users in the planning of services.

Many people who use learning disability services are uninformed about the nature of the services they are using and issues of power and knowledge are real to those who experience oppression (Oliver and Campbell, 1996). As Clegg (1993) comments, many people are struggling to escape what he calls 'ventriloquisation' by their carer's advocates and facilitators, leading to unheard experiences about unheard problems. Therefore many call for the rise of the political voice as opposed to the therapeutic plea of learning disabled people (Szivos and Griffiths, 1990).

Williams and Shoultz (1982) definitive work charting the development of advocacy rights and the skills needed to be a self advocate when learning disabled, has provided a foundation for the progression of the advocacy movement across Britain from the United States. The self-advocacy movement often recognised as a minor political activity comprises of a number of groups aiming to change the way society disables them (Goodley 2000). A number of studies have captured some of the essences of the energies within self advocacy and have detailed both individual and collective actions bringing about changes to the lives of people with learning disabilities over the last 20 years (Mitchell 1997, Shearer 1972, Simons, 1992). As a result of work by supporters of advocacy and empowering practices, people with learning disabilities are now increasingly involved both in policy development and engaging in research in a participatory and co-operation basis. (Atkinson and Walmsley, 1999; Barnes, 1996; French and Swain, 1997; Minkes et al, 1995; Walmsley, 2001a).

Originally many of the academic disability debates failed to include the learning disabled person and their experiences. Over the last ten years this debate has grown to include the parallel plights of fellow learning disabled activists. As the discussion has developed with individuals more able and willing to discuss their life as learning disability service users, it has been essentially impossible to discuss the marginalisation of a disadvantaged group without considering those specific groups such as learning disabled people (Chappell, 1992; Goodley, 2000). Increasingly, these groups are becoming involved in research and some policy development, acting both as co-authors and co-participants thus extending the remit of the learning disability agenda and increasingly the influences on social and health care.

Many critiques have discussed the extent to which the administrative approaches to disability care have marginalised disabled people and developed whole industries of professional power and dominance (Barnes 1994; Oliver, 1990; Oliver and Campell, 1996). Service interventions have been heavily criticised as viewing disabled people as socially dysfunctional to the extent of what Miller and Gwynne (1972) described as 'socially dead' or more conveniently as a shifting priority. The many discussions centring on the powerful relationships imposed by the medical/individual model of care over the disabled person have highlighted over time the discourses (Abberley,1987) of dominance and disempowerment by agents of control over powerless and voiceless recipients of what is often now termed inappropriate care (Walmsley,2001b). This discourse development has enabled many more disabled voices to be heard documented and to be acknowledged. Although many people with a disability have often found the intervention of professional services helpful, many

others criticise the implicit control and restrictive practice of services (Abberley, 2005).

Swain, French and Cameron (2003) in their critique of the care professional provide personal accounts explaining the dependent positions of disabled people perpetuated by professional rhetoric. This position was earlier debated and criticised by Finkelstein (1991) in his commentary regarding user participation in administration of services. This influence was particular relevance to this study, which is sought to interpret the narratives of the learning disability professional within present day practice.

Care services are generally considered more stigmatised if they are free at the point of delivery as society often values that which is paid for above that which is state provided (Swain, French and Cameron 2003). Other care services used by those in need such as nanny, health trainer etc, are often paid for directly and attract more status. Learning disabled people are often passive recipients of the care on offer and are not given the choices attributed to those who can and do pay for help and support. There is a growing debate calling for the welfare system to empower the receivers or trainers of the people who assist them in their lives. (Morris, 1993). This empowerment is often seen beyond the reach of individuals with severe and profound disability, and is interpreted by their carers in a number of ways. Many professionals have attempted to take the lead in the empowerment of people with learning disabilities. Of particular interest to this study were the stories, which some ex carers/LD nurses (now teachers) use to illustrate care practices for people with learning disabilities they have seen and participated in.

Tensions have always existed about the status of learning difficulty and learning disability as both a label and an experience (Walmsley, 1997). Generally, discussions are limited to the contrast between different disabled experiences. However many look now to Foucault and his theories of competing discourses to comment upon care for people with learning disability (Gilbert, 2003, 2005b; Jolly, 2003), or alternatively to the social constructionist analyses of the opposing labels of normal versus disabled, to locate the political and social debate arising from the disability movement. This study looked to both standpoints as a basis to understand the relationship between the construction of individual story and the general learning disability discourse.

Power and the social construction of learning disability.

The ideas of social construction originate in many disciplines. Although most look to the definitive work of Berger and Luckmann (1976) and Mead (1934), the constructionist movement has gained strength from the debates questioning the nature of reality and of truth in philosophy and in social science. These debates enable qualitative researcher's freedoms to look beyond the claims that medicalised and objectified people with learning disabilities.

> '…reality is socially constructed and that the sociology of knowledge must analyse the process in which it occurs…' (Berger and Luckmann, 1976, p.13)

Research informed by social construction ideas can reveal the social origins of phenomena seen previously as 'naturally occurring', rather than 'purely social' or as part of a given reality rather than a human creation (Hewitt, 2001). Gergen (2001) asserts that the social construction debate is 'born of opposition'. He continues to suggest that the traditional claims to scientific knowledge of positivist/empiricists fuelled the need for a challenge from those who believed that reality could be traced

to a relationship between the personal and events and not only to a causal effect. In addition social construction also makes assumptions about the world based upon characteristic attitudes of social injustice, effects of poverty and history (Hewitt, 2001).

In looking at information, the researcher (especially those seeking to interpret the socially constructed realities expressed through language) can avoid some of the problems argued by critics, that any close analysis of textual material can lead to many contested alternative interpretations of any one narrated event (Frosh and Emerson, 2005).

The contemporary conception of learning disability is widely assumed in the UK to be a label used to describe a person with a set of features or behaviours (such as Down syndrome) using medicalised terms which can enter everyday language. The social constructionist approach seeks to reveal 'what are the origins of learning disability'? 'what makes it obvious to other people that a person has learning disability'? and in effect 'how is it constructed'? In this study the language of learning disability was shared within a context of education and enlightenment, the constructions taken as given were based upon a set of criteria which has developed over time (Berger and Luckmann, 1976).

It was important for this study to look beyond the ironic constructions of learning disability which have centred upon the lives of those living in institutions and instead to look also at the historical debates which consider power and the body and the institutionalisation of everyday knowledge (Gergen, 2001). In psychology, Gergen

(2001) characterises historical traditions in education as both within the exogenic (world centred) and endogenic (mind centred). These traditions are highly obvious within higher education and in particular learning disability nurse education today.

Dewey (1933) viewed the institution of education as able to produce true democracy and believed that knowledge is value neutral and objective. The social constructionist view is of knowledge as value saturated, and therefore to enter into the particular domain of knowledge such as learning disability is to step into a form of life (Gergen, 2001). Such a step does not necessarily move us towards democracy but can in fact give rise to one strong voice over a weaker one. Thus, (although this was not a claim made by this study) some studies of this kind, drawing upon social construction, can indirectly effect those featured with a weaker voice, such as people with learning disabilities.

Sociology views the pedagogical fashioning of the institution of learning disability knowledge as constructed dialogically. The three positions within this dialogic suggested by Berger and Luckmann (1976) are that society is a human product, society is an objective reality and that Man (collective) is a social product. This study looked to social construction ideas in order to establish how and why teachers constructed stories originating in the learning disability discourse during teaching situations with students.

Summary
This section has considered the strong arguments that power imbalances are present in the relationships between people with learning disabilities and those who are paid to

provide support to them. The power vested in professionals is said to originate in the ways in which learning disability is viewed and is therefore represented in UK culture. The social construction of learning disability is regulated by the dominant discourse that includes the medicalised language of the learning disability professional. This language has developed from the past when institutional denied people with learning disabilities control over their lives, to the present when more involvement from people with learning disabilities in decision making is encouraged. learning disability nursing has contributed to some of the changes in the learning disability discourse. The next section will consider the development of the learning disability discourse from the origins of learning disability care.

Important works in the disability and learning disability story

This section will chart the major social and political issues of the last century, which have influenced the debates in disability and in learning disability and influenced the development of the discourse. The two greatest influences, the rise of the disability movement and the demise of institutional care, will be discussed widely with a particular focus on the impact upon the learning disability discourse and the changing emphasis of statutory provision for this client group. In particular, the focus will be upon the demise of institutional life, the development of a political discourse in disability, the result of the normalisation movements.

In the political and social world of learning disabled people influences have arrived from many sectors. The major source of political discussion about learning disability has developed from the arena described as the disability movement (Swain et al, 1994, 2005). This arena of debate has impacted upon the working practices of learning

disability nurses and the social policy of learning disability care and was a particularly important in this area of study. The political debates arising from the disability movement about inclusion and disability awareness have helped shaped the care of people with learning disability. Although, at times early debates missed out people with learning disabilities and were considered incongruous with the lives of learning disabled people the political power of the disability movement activists have more recently highlighted similar and shared issues (Goodley, 2005). One shared issue, care in institutions, has prompted a strong and effective debate resulting in a heightened social awareness of how important these care issues are.

The awareness of disability as a concept of oppression and social disadvantage has recently been described as a developing academic discipline (Barnes, 2005a), that subscribes to a body of knowledge developed from first hand experience and from an awareness of the personal circumstances of disability. This development of knowledge, based in awareness, has origins within many sociological, psychological and philosophical debates of the last century (Davis, 1997). In particular the debates are further fuelled by the socio-medical discussions arising from the health and medical care concerns of people requiring the long term care of the private and statutory providers in the UK.

Institutional life and beyond

This sub section will describe the literature which charts the social and personal developments that have informed the learning disability discourse over the last century. This account begins with the early sociological and ethnographic stories of life as a disabled person.

The story of life for disabled people starts with the institutional regimes imposed upon many people with physical and other disabilities The rise and fall of institutional care for people with learning disabilities has been well documented (Goffman, 1961). Some of the details of events and the stories depicted in these works were of interest to this study. People with learning disabilities as receivers of institutional care forms the basis for some of the discussion and debates in the learning disability discourse (Edgerton, 1967).

Many important studies have informed this general debate. Ethnographical studies of institutional life (Goffman 1961; Miller and Gwynne 1972; Ryan and Thomas, 1995), sociological studies of social exclusion (Bourdieu 1973, Asch and Fine 1988) and the research of the sick role and the disabled role (Haber and Smith 1971; Safilios-Rothschild 1970; Parsons 1951) all interpreted a lived experience of oppression and social disadvantage for those occupying long stay institutions. Early writers described the social implications for disabled people as 'cared-for individuals'. Goffman (1961) also provides vivid sociological and anthropological commentary about institutional life. The scene is set by Goffman, and his seminal work provides an ethnographic picture of institutional life in large scale institutions in the USA during the twentieth century. His representation of the 'total' institution and its facets explored the relationships between those with power and those without it. Ryan and Thomas (1995) shocked many with their careful description of life within a learning disability institution. Again, their story of everyday regimes of depersonalisation and dependence creation provides a backdrop for analyses of care for people with learning disabilities which has been a struggle to justify.

Ryan and Thomas (1995) provide a vivid description of life for residents of an institution for people with learning disabilities, and their struggles for power within and withheld by the routines of the staffing structures. Life, for many residents of hospitals (for the mentally sub-normal as they were termed) was determined by their dependence on those around them. Notably, many profoundly disabled people were cared for by their apparently more able neighbouring residents who supplemented the work of the paid workers. Many accounts from residents of these institutions substantiate the images of an integrated regime of routines and subordination amongst differing hierarchies (Brigham et al, 2000).

These studies suggested that the care regimes in institutions for people were socially ignored by general society as a result of the generalised effect of stigma associated with learning disability and the constructed images of defective and un-usefulness of people with learning disabilities. As a result of stigma, the depersonalisation of the residents by their carers had dehumanising effects. The studies by Ryan and Thomas and other candid reports of institutional life further added political and social outrage and fuelled a whole range of inquiries and policy changes for learning disabled people. These early texts were seen as important and have been used as a basis on which to present philosophies of care in work involving care of people with a learning disability (Mitchell, 2003).

It is easy to objectify people in what Goffman (1961) describes as 'Total Institutions' and often it appeared that regimes were dependent on the categorisation of division, and terms denoting different grades from high through to low grade (referring to IQ) used to denote the abilities/disabilities of the clients (Brigham et al, 2000) .Other

ethnographic and biographical accounts detail the struggles for personhood and identity by clients contained in a segregated service that functioned upon dependence creating regimes and staff power (Goffman, 1961; Menzies,1970).

Who is in control?

Within the learning disability discourse some issues have become more significant over time. The issues in particular of care and control by both professional and non-professional carers, have increasingly been seen, scrutinised and measured by social researchers, observers and commentators. Outside of the institutional care debate issues of power and control prevail in the relationships between clients and their care givers, leading to criticisms about the nature of the client/professional relationship (Barnes, 1996; Brown and Smith 1992; Chappell, 1992). Often as Brown and Smith (1992) discuss the focus of discussions by critics highlights the powerful professional and the powerless client engaging in 'languages of power' as described by Foucault (1972), often leaving the powerless without adequate representation and in powerless positions.

Deeley (2002) described the internal conflicts of professional engagements with clients in learning disability services. She considers that the prevailing orthodoxy of learning disability care has developed from the legacies of past institutional care and is informed by ideologies such as normalisation and social inclusion. In addition Deeley also comments on the internal conflicts caused by the increased expectations of improved care by the clients, their carers and families. For many observers the institutional regimes of the past strongly influence present care provisions offered to

people with learning disabilities in need of support (Brigham et al, 2000; Henley, 2001).

Institutional life for people with learning disabilities features strongly in the literature charting the exposure of their oppression and social mistreatment. Led by academic observers the exposure has been further opened to include the personal accounts and stories of those who lived the experience. Those who contributed to the lives of people with learning disability over the years have been included in these stories (Mitchell and Smith, 2003; Mitchell, 2000b). As a result of these first hand stories told by the people who lived and worked in institutions the learning disability discourse generally regards the institutional legacy with unease and with a degree of regret (Mitchell, 2002, 2003).

Changes in policy: Adding to the discourse

The advent of policies for example, the government white paper Valuing People: A New Strategy For the 21st Century highlighted some problems and solutions in the communication with professional services experienced by families and the people with learning disabilities (DOH, 2001). Many personal accounts describe life in various living combinations. The personal biographies and narratives describe the lives and experiences of clients and their care givers both before community care policy changes and after, when individuals occupy highly different and challenging lives (Aspis, 2000; Atkinson and Walmsley 1999; Brechin and Walmsley, 1989; Glouberman, 1990).

Community care is used generically to describe life for people with learning disabilities outside of the institution. Although many people with learning disability never lived in institutions but lived with their families, many recent government policies suggest a model of integrated living in a variety of residential settings provided by either statutory or non statutory organisations (DOH, 2001). Many commentators link the failures and successes of community care to the ideologies that have prevailed (Mcvilly and Rawlinson, 1998; Sines, 1995) often blaming the lack of social priority attributed by governments to the issues of learning disabled people and their carers. Other writers have commented that the community care policies are socially constructed, and that community care for people with learning disability is very difficult to define leading to a vague and problematic implementation of an ill-defined social policy (Potter and Collie, 1989).

In the last thirty years many government reports, recommendations, white papers and acts of parliament have elaborated on the idea that people with learning disabilities should live like other members of mainstream society. This premise is likened to the basic notions of normalisation and deinstitutionalisation (Smith and Brown, 1992). The literature database about programmes of integration and community care resettlement encompasses both North American and British literature (DOH, 2001; Lakin and Bruininks, 1985; Philpot and Ward, 1995). Many personal accounts of people with learning disabilities have further added to the literature and discussions, (Atkinson et al, 1997; Goodley, 1996; Walmsley, 1995**).**

<u>Origins of normalisation as a service principle</u>

Although the history of learning disability care provision has been affected by social and political events the learning disability discourse developed a field of its own. The main energies originated in the normalisation philosophy in addition to the ideas arising from the challenges posed by those advocating change from within the disability movement (French and Swain, 2001).

The prevailing orthodoxy in the last 30 years which has guided learning disability care ideology and the learning disability discourse in Britain and some areas of Europe and the United states is normalisation (Brown and Smith, 1992). Wolfensberger (1972, most prolifically described the concept of normalisation as;

> Utilisation of means which are as culturally normative as possible, in order to establish and or maintain personal behaviours and characteristics which are as culturally normative as possible' (Wolfensberger, 1972, p.28).

Others have commented and developed Wolfensberger's ideas to form a vast body of literature which applies normalisation to theory and to the practice of learning disability provision. The main body of work originally discussed human rights and how the devaluing practices such as institutional care and segregation affected the lives of people with learning disability (Kings Fund 1980; O'Brien and Lyle, 1987). Wolfensberger developed his ideas from his Scandinavian roots which stressed the successful transformation of people into devalued citizens involved person change (Parmenter, 2001). His early ideas stood along side the emergence of humanism and the platform of human rights legislation developing in Europe in the 1970's. Although not the only advocate of his kind Wolfensberger's ideas were the main ideology adopted in western countries. The normalisation ideology has continued to be present within many care philosophies both in the UK, Northwest Europe and North America.

Wolfensberger's normalisation work was derived from a belief that people experiencing devaluation as a result of being seen as deviant or ill-fitting members of society could achieve an enhanced status if they lived lives supported by services which promoted culturally normative values (Wolfensberger, 1972). More discussions have commented upon the initial impact of normalisation theory and the adoption by services. Race (2005) comments upon the likelihood that normalisation as a theory and the variation Social Role Valorisation (Srv) as a set of service principles later promoted by Wolfensberger (1998), are linked closely to positive changes in the life styles of people with LD.

For many the ideas of social devaluation liken to normalisation and Srv are attributed to the changed ways oppressed groups are devalued and thus has helped drive much needed reform and policy change (Race, 2005). Alternatively for others the narrow culturally defined assumptions of the Wolfensberger ideologies provided fuel to the consumerist technologies of rights and consumer responsibility taking shape within political agendas in the late seventies and early eighties (Brown and Smith, 1992; Walmsley, 2001a). This is linked to what was emerging as economic Thatcherism of the 1980's and early 1990's and which sought to convert individual choice to responsibility and accountability (Chappell, 1992; Brown and Smith, 1992). However, this and other contemporary work by social commentators across Europe and north American States provided strong justification for the closure of long stay institutions for people with learning disabilities (Bank- Mikkelsen, 1976, 1980; Nirje, 1976).

Two writers also advocating forms of social change; Bank-Mikkelsen (1976) and Nirje (1976) took differing positions to Wolfensberger on issues of everyday life for

people living their lives with a learning disability. Bank-Mikkelsen (1976) in particular was concerned with citizenship issues and the social processes which lead to social injustices. Nirje (1976) concentrated on the human experience and inevitable cycles of social and economic life as a means by which people with a learning disability could become integrated and productive members of society. Other operationalising works followed offering interpretations of the normalisation principle, which led to the growth of a normalisation discourse within professional work in learning disability services (Tyne and O'Brien, 1981; Kings Fund, 1980).

Normalisation although criticised for being no more that a technical – fix in the 1970's and 1980's within a time of seemingly over optimistic change (Chappell, 1992; Emerson and Hatton, 1996) became something of a 'sacred cow' in some service philosophies because it was heralded as the only way to provide a quality service and was implemented widely and into care service philosophies. Some criticisms noted that the proponents of normalisation are non-disabled and speak for and not with learning disabled people (Chappell, 1992) with the views of people with learning disabilities left un represented. It can also be argued that this linked to the notion that technologies of power such as normalisation provide the discipline (or medicalisation) required by society to silence and regulate those who they feared or mistrusted (Foucault, 1991).

The civil rights groups of learning disabled people disliked the principles of normalisation for its emphasis on change within the individual to fit into society, rather the societal changes to accommodate difference advocated in the social model of disability (Campbell and Oliver, 1996; Race; 2005; Walmsley, 2001b).

Arguably, normalisation and political disability theories have impacted not only upon the lives of people with learning disabilities in many ways, but also upon the working lives of the professional groups such as learning disability nurses. Professionals have experienced a changed practice environment from institutions to more complex and varied community based settings (Mitchell, 2003) in which the relationships between those cared for and those doing the caring have changed. The principles first outlined by Wolfensberger have now become integrated into practice and have been superseded by other priorities and principles such as inclusive research and emancipatory working (Walmsley, 2001a). The legacies of the early years of normalisation are more difficult to trace. The impact of Wolfensberger's ideas should be considered in the social and economic context of Britain in the 1970's. Gripped by a political and economic crisis the closure of long stay institutions for both the people with learning disabilities and Mental health needs was seen as one way to save the nation much needed money (Malin et al , 2000).

This changing discourse in learning disability as result of the political and social developments and the pressures brought to bear by disability movement advocates also highlights the differing power positions of staff in learning disability services and the people using them. The next two sections explore this in more detail.

The development of the political discourse: The rise of the disability movement

The importance of the disability movement lies in the impact both politically and socially upon the lives of disabled people. Sparked by the early ideas of Oliver (1990) attention has been turned to the marginalisation of disabled people made dependent by an industrialised society. Professional systems of care for people with learning

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disabilities originate in the belief that dependence is inherent and that independence needs to be learned (Noble, 2005). Professionals charged with the responsibilities given by society within legislation such as 'community care' have prioritised making people with learning disabilities independent a political aim. Professionals often interpret their interventions as a process of ensuring people with learning disability rehabilitate (re enter somewhere you have left) rather than gain control and direction over the destination (Richardson, 1997). This process often increases the dependence of people with learning disabilities upon their professional carers.

Many disabled writers and activists have resisted the dependency creating regimes advocated by professionals and have turned the discussion to a political debate which critiques the role of professional carers in the lives of people with disabilities (Noble, 2005). In recent years the campaigns of the disabled activists have promoted social change and heralded a much needed reform of the social and welfare system for people with all forms of disabilities, leading to more awareness about the vested interests of professional groups. Disabled people have challenged collectively the medicalisation of welfare schemes and advocated a more inclusive approach which assumes a persons ability to manage their own affairs with some assistance, a diverse change from old schemes which assumed inability and promoted dependence (Hasler, 2005)

The descriptions based on the disabling experience of oppression and social disadvantage were earlier dominated by writers who are themselves disabled (Barnes, 1990; Oliver, 1990). Writers forged links between the experience of being disabled and sociological, psychological and cultural theory (Barnes, 2005a). As a result

disability has become a broader discipline encompassing more than the original personal concerns about health and welfare rights of disabled people.

Arising from the integration of theories and experience some disabled writers have encouraged debates based upon them as cared for individuals but set in the wider context of the social implication of caring and the relationships involved. Barnes (1990) discussed issues developed by physically disabled people in receipt of care. His accounts of rehabilitative regimes of care such as: the 'lion tamer approach' the 'entertainer' and the 'new romantic technique' act as sharp metaphors for many care practices. The 'lion-tamer' approach describes the social distancing of cared-for and carers via a series of punitive devaluing care practices. The 'entertainer' relates to the patronising view of rehabilitation as occupation of long hours with unproductive pseudo manufacturing activities, for sale at charity outlets. The 'new romantic' approach often attempts to provide and encourage self-development and new growth in an attempt to stimulate self worth and acceptance. These and other frameworks have provided the basis for the analysis of the care givers and care receivers in health and social care provided for people with various disabilities.

The social model develops

The arguments put forward by many (Barnes, Mercer and Shakespeare, 1999) within the disability movement positioned the general debate about the rights and position of disabled people clearly within the social framework. This view point aimed to promote that disability should be viewed as a social problem imposed by social processes and not just a set of impairments suffered by an individual. This is seen as extending the coverage of disability issues beyond the medical gaze which has been

the dominant view held about people with disabilities (Priestley, 2003, 2005) into the social and the political arena.

As a result of the marginal and major disability debates of the last 30 years the stories about their lives told by disabled people have entered mainstream and research discussions of service planners and social commentators requesting improvements and reform (Barnes, 2005b). One such debate which has dominated service planning over the last 30 years is that of valuing and appraising the devalued person. The disability debate has done much to inform the learning disability discourse and has helped to draw attention to the powerful knowledge based positions of non-disabled policy makers and professionals working in learning disability services. Critics comment that the major disability movement was late to embrace some of the strong ideology which has informed changes to the learning disability service patterns of the last twenty or so years (Goodley, 2001; Walmsley, 1997).

These accounts and many others (Barton, 1988; Finkelsteinn.1980) strongly argued against the traditional assumption that disability and the associated impairments reside solely within the individual. Oliver (1990) developed a strong challenge to the bastions of medical power and authority, to consider that disability has social interpretations based on the product of oppressions and disadvantages imposed by societies.

Oliver used examples from culture, social history, political ideology and ethnography to illustrate his view of life as a disabled person. Initially, in the early days of disabled consciousness raising, many accounts described experiences of chronic illness and

disability and related problems with the established views of impairment. Then, (as even now) many services and professionals used the traditional medical (based on individual ability versus disability) model of the world health organisation (WHO, 1980) classification of impairment, disability and handicap on which to base the philosophy of care which segregates those with disability to one side of the illness and wellness spectrum. The debate that has developed considers the 'social model' of disability in contrast to the established 'individual model', which had placed heavy emphasis on the limitations not abilities of disabled people as society members.

The impact of the social model of disability upon the philosophy of health and social care practice has been wide ranging and promoted strong debates about reforms (Oliver, 2005). In practice however the care of people with learning disabilities has criticised for its failure to fully accept the social model of disability, and instead services have often adhered to conventional service models with people with learning disabilities as passive receivers of care, (Chappell, 1992; Goodley, 2005). However, the learning disability discourse was more heavily influenced in the 1980's and 1990's by political philosophies and ideologies advocated by a number of writers concerned with the social positioning of people considered outside of social acceptance by the lack of their physical proximity and locked away in distant institutions (Bank-Mikkelsen, 1976; Goffman, 1961; Nirje, 1976; Wolfensberger,1972). One philosophy, normalisation or (alternatively) social role valorisation (Srv), provided a platform for both political and social changes for people with learning disabilities.

The problems of the professional control over learning disabled people either directly through deliberate regimes or indirectly through social inequalities are now more visible and debated than previously (Gilbert, 2003). The influences of Michel Foucault and the post-modern analyses of political and social frameworks provide useful insights into the construction of learning disability by teachers and their vested interests.

Summary

This section has considered the main ideas that learning disability discourse has emerged from the history of a problematic past. The negative images of institutions and harsh regimes have informed the language used to reinforce the need for political reform and a change in the shape of learning disability health and social services. The most negative images have been constructed by social commentators in ethnographic research and are mirrored by those with learning disabilities able to explain their experiences. Both have been highly critical of the care regimes and staff practices in learning disability institutions. Although individually no-one is named, one of the main staffing groups implicated are the carers in institutions, often specialist nurses in learning disability matters.

Over the last hundred or so years the political discourses were focused upon the human issues of disability and highlighted the strength of feeling among those who could express dissatisfaction with the predominantly held medicalised views controlling social and health assistances services. This political force has only recently embraced some of the additional problems people associate with having a learning disability.

The learning disability discourse was championed and influenced at a time of political and economic change by a normalisation discourse which helped shape the ideology of de-institutionalisation. Although normalisation was not the instigation of change it helped to inform and strengthen the cause for community living and shaped the language used to discuss the exclusion problems experienced by people with learning disabilities. This language can be found in the professional discourse of the learning disability caring services and informs the philosophical basis for many learning disability nursing interventions. The next section will consider the context of professional learning disability nurse education which has positioned teachers outside of their practice work and in a classroom with students.

Education and learning contexts

> Educators extract bodies of discourse (and a limited number of instantiations) from the professional disciplines and pass these extractions on to those beneath them in the hierarchy. (Gergen, 2001 p. 125)

Given that the purpose of learning disability nurse education is to enable the student to develop the knowledge and skills of a capable and competent professional it is a traditional assumption that those positioned as the expert or teacher already possess these qualities. As discussed earlier, the learning disability discourse positions the professional with knowledge and skills to control the client with a learning disability. The role of learning disability nurse education can then be argued as providing a pathway to the development of these controlling mechanisms.

In the following sections I will consider the educational contexts which bring together two groups of people: nurse teachers and nursing students, and the stories which are

constructed and told by teachers in the encounters. I will consider the adult learning encounter and the context of using stories as a method in adult learning.

Influences of educational encounters

The situation or educational encounter is influenced by the nature of the intended outcome which in this case is adult learners attending an established course of learning which leads to a professional learning disability nursing qualification

Most higher education establishments that provide professional courses concentrate their teaching and learning to achieve the application of theory as applied to professional practice (Dale 1994; Lowe and Kerr, 1998). Critics of the traditional models of adult education comment on the positive influence of the learner's own beliefs personal qualities, and theories upon their development as capable practitioners (Bandura, 1997; Dweck, 1999). The majority of literature on adult student learning within higher education, concentrates primarily on the outcomes based approaches to higher education spending less time on the process of self-development implications of learning. For the purpose of this study however, it is important to consider the development of the professional 'self' of the learner practitioner and the learning methods affecting this type of learning.

If, as suggested by Brookfield (1995), adult learners become aware of and appreciate the values and beliefs of work conduct which are culturally transmitted by their educational encounters, then the importance of the encounter can't be underestimated. Macintyre (1988) further reinforces that we reconstruct the past with reference to how we understand the present and that this understanding is social, but may act on an

unconscious or conscious level. Learners and their teachers therefore can't fail to be influenced and to influence the encounters they have in professional practice.

Jarvis et al (2002) comment that in a deliberately planned teaching session as also in the social world of learners, learning is experiential, in that we all (learners or teachers) learn from their experiences we encounter. As Rogers (1983) and many other advocates of humanism in education and adult liberal approaches tell us (Brookfield 1995; Heron, 1992; Knowles, 1978), most significant learning occurs when the learner relates to experiences they have encountered (Jarvis, 2002). Experiential methods in teaching normally relate to a complex process of facilitated action and reflection. For writers such as Rogers (1983) and Knowles (1978) the learner is most likely to be motivated to participate in the learning if they become involved personally in the teaching encounter. In some instances learners relate their personal feelings towards highlighted events and recall experiences of practice based learning to a group or in a one-to-one teacher-learner encounter. Although experiential approaches to teaching are well supported many criticise the claims made by so-called self development/reflective exercises and call for a critical view concerning the use of personal narratives by both students and teachers within the classroom (Rich and Parker, 1995). Rich and Parker (1995) specifically noted the potential within both reflection and experiential teaching methods as a deeply powerful teaching medium not to be underestimated.

Connelly and Clandinin (1999) introduce reports of personal reflection told as stories in teaching situations. These ideas have subsequently influenced the views about the nature and purposes of telling stories in personal and professional life. Furthermore,

their work has also influenced the ways we might view the context of a teaching encounter between teachers and learners (Huber and Whelan, 1999). If , as Connelly and Clandinin (1999) suggest, teachers tell their stories to students/learners for a variety of reasons (ranging from identity reaffirmation to relationship building between themselves and students) it was important for this study to consider the complexities of this reflective engagement. This next section will cover the use of spoken narratives through personal stories of past experience in educational, psychological and sociological contexts.

Narrative and story as method in teaching

This study was interested in the use of teachers' stories in the classroom. I aimed to extract the stories and to investigate them using a qualitative approach and drawing upon interpretative research methodology. I wanted to see and hear how learning disability was constructed by teachers in their stories and how this interrelated with the grand narrative of past and present learning disability care. I was also interested in what the construction of the stories reveals about the nature of emerging learning disability nursing practice.

Bourdieu (1973) suggests that we tell stories to a listener derived from personal experience as a means of bridging the gap between individual experience and cultural social patterns. Many differing views exist regarding the role of culture and the role of story telling within society. This study acknowledged the key disciplines of education, psychology, and sociology and some of the views held regarding narrative and story telling.

Within mainstream education and teaching Connelly and Clandinin (1999, 2000) present the ways that teachers navigate a professional landscape and extend their identity through the use of stories based in classrooms. These ideas were useful to this study in a number of ways. The stories told by teachers often involve issues of professional competence which student nurses have to discuss and reconcile in their practice learning. Stories from the past often contain recollections of a bygone era when nursing roles were different to the present day, additionally the identity of the teacher is dually both of teacher and nurse within the teaching situation.

Within psychology, story telling and the analysis of narrative discussed initially by Sarbin (1986) and Riessman (1993), then further by Crossley (2000) and Hollway and Jefferson (2002) indicate the many ways in which stories in many contexts are useful indicators of social and personal knowledge. It was useful for the purposes of this study to explore the interpretative meaning associated with stories told by teachers and to establish common themes, which emerged. Images of self and the theories of identity highlighted in the many views held about narrative psychology and its uses within the fields of teaching, learning and of learning disability were important features .

The broad study of stories in culture, society and in education highlighted by commentators such as Macintyre (1981,1988), Polkinghorne (1988), Geertz (1973), Ricoeur (1984) and others, enabled this study to extend discussions and to relate the larger questions of the role which stories have to play within discourses. Macintyre (1981) in particular takes a view that as story tellers we are living out our lives as we see it and that a story has to be personally lived before it is told. Polkinghorne (1988) provides some useful definitions of narrative form and function, which can be used to

identify the stories within narratives used by teachers. The ideas that narratives are emplotted by individuals in a form of chronology that reflects their lives (Ricoeur, 1984) has relevance to the narratives of lectures given by nurse teachers in this study who are retelling stories from the past to form a present narrative. The work of Geertz (1973) and others such as Gergen and Gergen (1983) provided this study with a framework to discuss cultural forces within the discourses and narratives of education, health and learning disability.

Summary

This section has introduced the ideas that professionals intending to impart knowledge to those who want to listen can do so in a number of ways. Formal teaching is a way in which knowledge can be transmitted. The methods employed by teachers who themselves are professionals can vary in style. Story telling appears to be a way that some teachers can negotiate a space in the classroom for the identification of their personal self and the collective identify of learning disability nursing. The next section concludes the chapter.

Conclusion

This chapter has highlighted the knowledge and ideas of the learning disability discourse and the ways in which it might be communicated. These formed the platform on which I based my ideas and my research decisions. This discourse has been largely shaped and developed by those non disabled and often in greater control over welfare services than its services users. The absence of voices from people with learning disabilities from the greater part of the literature is very obvious and reflects the in-balances that exist in the past and also in the present influences. The journey

through this review was intended to lay the foundations for my research design and the methodologies I drew upon in order to investigate the social construction of learning disability as viewed in teacher told stories in the classroom context. The next step of my journey takes me further into the background and rationale for the grounding of this study within the theoretical arena of social construction.

Chapter Two

Method and Methodologies

Overview

This chapter will describe and discuss the research method and the decisions taken to investigate the construction of learning disability in the collected teacher stories. As a qualitative study (Ely et al, 2001; Morse et al., 2001; Robson, 2003) this process, from original inception to final operation, followed a development influenced by researcher inter-subjectivity and institutional constraints.

The nature of this inquiry was to investigate some of the stories used within classrooms. The study took cognisance of the many debates and presuppositions about the way learning disability is presently and formerly constructed by professionals invested with power and authority within health and social care. The study design was fuelled by my belief that teachers construct meanings via stories based upon their use of various discursive resources. Taking the centrality of language, and the notions of the essential constraints of power and knowledge (Foucault, 1972) this study was designed to investigate how teachers, as powerful professionals, construct reality in stories.

In the previous chapter I charted a journey through the literature associated with the learning disability discourse which revealed many important issues which have influenced the narratives of development and change within the social lives of receivers and deliverers of learning disability provision in the United Kingdom over

the last century. The literature revealed that the learning disability discourse tends to construct people with a learning disability using medicalised language. These constructions give rise to the power and dominance of the professional carers over people with learning disabilities and formed the focus for my exploration of learning disability constructions in stories of the past. This next chapter discusses the rationale for a study of this type which draws upon ideas of social construction, narrative and discourse.

Introduction

The research method chosen forms the main introduction to the overall picture of the study and is followed by a rationale for the methodology I utilised. The chapter progresses to a detailed description and discussion about the participants and the sample I chose to investigate the social construction of learning disability by professionals. I continue with an explanation of the data collection techniques and data the analysis processes employed to meet the aims of the study *To investigate the social construction of learning disability by teachers in the stories they tell to their students within teaching narratives.* And in particular the objective *To investigate common themes appearing in stories, interviews and observations* I finish finally with an evaluation structure for the overall study.

The approach taken

This section will present an argument for staging this study using a qualitative approach and using an interpretative framework based upon two versions of discourse analysis.

<u>The starting point: qualitative research</u>

It is argued that the central feature of research is to develop knowledge (Lincoln and Guba, 1985).The processes by which knowledge is developed are based upon the need to be rigorous, meticulous and demanding. Many of these criteria originate in the scientific community's need to maintain elements of the discipline that demonstrates a careful adherence to established processes often categorised for example as; 'theory generation' (as in Grounded theory) or 'culture development' (as in ethnography).

The belief that the qualitative aspects of social life can be meaningfully studied via the constructions evident in narratives provided the basis of this study. Essentially this belief informed the epistemological structure to collect and analyse both involvement of stories in the narratives of teachers and what was said and observed about these stories by me the researcher.

In a search of the literature on qualitative research one would find many different terms to define research which does not necessarily fit established qualitative research (Caelli et al, 2003). The difficulty in some studies arises in the typifying of the approach taken as fitting the rigid characteristics demanded by some well known methodological standpoints. As a result many researchers, especially in the disciplines of education and health/social care have looked to an approach to qualitative enquiry which allows the freedom to ask questions and define the phenomenon in its context rather than focus the qualitative gaze through a known methodological lens (Caelli, et al, 2003). These freedoms to question and to develop strategies based upon the phenomena of the learning disability discourse formed the motivations behind this study.

<u>Narratives, discourses and stories</u>

The focus of this study was to establish the constructions used by teachers in their stories. Teachers tell personal stories about their work with people with learning disability and that the stories are ways in which learning disability is socially constructed (Swindler, 2000).

The words narrative, discourse and story were used throughout this study to mean very different things but are interrelated and warrant definition. For purposes of understanding this study these terms will be defined and explained. Although this study does not solely adhere to structuralist conventions it is useful to acknowledge the structural forms of language that makes up a *teacher's story* within a *teaching narrative* that is influenced by learning disability *discourse*.

Narratives

It is possible to define a narrative in many ways. Structuralists tend to concentrate upon the representations of past events and actions by a performer or actor to an audience (Labov and Waletzky, 1967). Gee (2002) sees the story as linguistically different from the narrative in that it is culturally shared with the audience in a social context. This sharing enables established patterns and rhythms (or stanzas) within stories unlike a narrative, which may not. In this study I identified the teachers (particular event) story from the teaching narrative (the general teaching session) in order to capture the story as an event constructed by the teacher drawing upon certain language devices.

According to Crossley (2000) when conducting research we should consider if '…*we are not overplaying the significance of the storied form in the human experience?...*' (Crossley, 2000. p 52). Thus the primary function of a teaching narrative is to establish for the teacher a form of order to the event or events they have experienced and not necessarily to replay what they exactly saw. This argument reminded me that the narrative aspects of the teaching sessions and the stories contained may reflect both the individual and the socio cultural characteristics of learning disability care and changes which have occurred.

My version of a narrative as being the spoken aspects of the teaching session was informed by the concerns that teachers are utilising various discursive devices within their lectures with students. These devices contributed to the teaching narrative and were affected by the discourses of past and present learning disability care. This narrative was important in a variety of ways and was informed from the experiences of the teachers (Connelly and Clandinin, 2000). To analyse the teaching narrative was to analyse elements of the professional learning disability nursing practice.

Narratives and stories

Confusingly, some writers tend to use the narrative to mean all forms of human communication and the story a part of the whole (McLeod, 1997; Riessman, 1993). Jefferson (1979) talking of stories indicates that speakers indicate in a particular way that a story is coming with signals such as " Once upon a time" " I remember when" and conclude with some form of closure or bracketing devices "Lived happily ever after" or other physically behaviours such as pausing. The stories in this study were identified by some of these devices with many involving some indication of reflection

'…when I first when to work at (a local mental handicap hospital)…' or *'..I once remember someone…'*. My position was informed by many of the above arguments. For the purposes of this study I will used 'story' to indicate a unit of the whole teaching session narrative. The story was identified as a specific personal event narrated by the teacher during the larger and longer teaching narrative.

Discourses

For the purpose of this study, learning disability discourses were the practices developed over periods of time and which have and continue to have influence over the way learning disability is constructed in the language of learning disability professionals (Foucault, 1972). The discourses which are influencing, and influenced by, both the teacher and the students' listening and contributing to the teaching narrative are located in the experiences each has of social practices. For the teacher, discourses of learning disability nurse power over learning disabled clients are evident and have influenced what was accepted nursing practice some years ago. Other more recent forms of learning disability discourse of empowerment and increased decision making for learning disabled clients may have influenced the current learning disability nursing practice and language taught to student nurses. All these discursive influences were acting upon the stories and teaching narratives in this study.

Summary

In summary, the three terms narratives, stories and discourse appeared in this study as ways to discuss the language, language devices and discursive modes drawn upon by the teachers constructing learning disability in teaching sessions. The importance of these became ever clearer as the study proceeded and the analysis of data progressed.

Taking a methodological approach based upon the analysis of discursive practices

To analyse data in a research study is to ask questions about data. The nature of the questions then guides the process of data analysis (Morse and Singleton, 2001). This study aimed to investigate phenomena about the nature of realities constructed by a group of learning disability professionals. The research questions that I posed aimed to uncover some of the complexities of a social world constructed by a powerful group. Foucault (1972) reminds us that the discursive practices of language used by powerful groups serve to protect and promote their own interests.

In looking at information, the researcher (especially those seeking to interpret the socially constructed realities expressed through language) can avoid some of the criticisms that close analysis of textual material can lead to many alternative interpretations of any one narrated event (Frosh and Emerson, 2005).

The key to organising a qualitative inquiry of this kind according to Connelly and Clandinin (2000) is by adhering to the research question/aim and what the questions raised can tell you about the text. The analysis lies somewhere in your relationship between the texts in what they call the three dimensional space. Taking into account the history (or temporally situated), place (or occupied) and the personal plus social aspects of this study the data analysis engaged with the element of the three dimensional space.

The idea of a three dimensional narrative inquiry space thus described by Connelly and Clandinin (2000), helps the qualitative researcher to be alert and 'wakeful' to the

critics of over formalism or reductionism which can arise out of an engagement with stories and narrative. This becomes of particular importance when the research activity moves from data collection to data analysis and interpretation.

Discursive psychology or Foucauldian discourse analysis?

Discourse analysis and the versions drawn upon in this study are not merely data collection and analysis methods, but are also ways of thinking about the role of discourse in various modes in learning disability stories. Two versions of discourse analysis are said to share a concern with language and social construction (Willig, 2004). I will now discuss the arguments for using elements of two distinct but similar influences.

At the heart of this study was the quest to discover more about the nature and impact of the construction of learning disability by professionals. This quest involved both the acceptance that language is a powerful tool in cultural life and that meanings are established through the power of discourses which surround individuals and groups. The approach taken embraced two standpoints about language. Firstly, that language expresses something about the individual and his/her actions (Potter and Wetherell, 1996, 2004) and secondly, that language expresses the social conventions and practices of the community (Foucault, 1972).

The first standpoint, discursive psychology is often criticised for the preoccupation with the psychological processes attributed to knowledge and the individual. Frosh and Emerson (2005), although supportive of the need to 'ground' the investigation of language and in particular of personal narratives in the person, provide some

questions as to the usefulness of this to some elements of professionalism. Other critics of the more psychoanalytical forms of discursive psychology challenge the use of preconceived notions such as identity and personhood (Burr, 1995) and in turn call for a synthesis of ideas about the individual their actions and language (Schmid and Fiedler, 1999; Wetherell, 1998). This influence helped me to discover the discursive devices used individually by the teachers in their learning disability constructions.

The second standpoint of a Foucauldian origin looks to the nature of discourse and the role of language to answer questions about social life and in particular social constructions of learning disability beyond the immediate classroom context (Hook, 2001). Foucauldian discourse analysis employs some grand notions of how discourses are enacted in cultural practices (Frosh and Emerson, 2005). Foucauldian discourse analysis is sometimes criticised for applying theoretical concepts using a vocabulary of psychoanalysis to situations in a 'top down' fashion (Hollway and Jefferson, 2002). Other criticisms are aimed at the ability of Foucauldian discourse analysis to explain the emotional investments individuals make in taking discursive positions (Harré and Gillett, 1994), for example in the relationships between teachers and their clients with learning disabilities did they like them personally ? In this study is was also useful to consider how the various social practices attributed to learning disability care have affected the learning disability discourse drawn upon by teachers in their stories.

Summary

In summary the research approach taken in this study was influenced by versions of discursive analysis and description most commonly associated with discourse psychology and that of Michael Foucault. The resulting methodology was designed to

enable me as the researcher to follow my quest to examine how and to what effect the learning disability construction operates in the classroom.

Methods employed: A series of stages

Some writers suggest that qualitative researchers move through a series of stages during their progression from an original fascination or interest in a topic through to a formulation of ideas based upon observation interactions and participation with other people (Agar, 1980; Lincoln and Guba, 1985). In-between they design and redesign their methods according to the issues and interests they discover. In this study the first priorities were based upon the interest in collecting teacher's stories as they were told to students in the classroom, and therefore this formed the central focus of the study. The design was intended to be flexible enough to utilise any themes from the initial analysis of the stories collected from early teaching sessions. The themes generated from this early stage were intended to be used to inform and develop the identification of story extracts used in the generation of interview questions and themes. Essentially the data collection and the analysis were intertwined with one driving and informing the other (Ely et al, 2001).

The following figure 2.1 explains the design of the study and the relationships between the early phases of data collection (teaching sessions) and the later decisions to use some of the stories as extract prompts for the purposes of the interviews.

Figure 2.1

Teaching Sessions (x20)
7 Observed & 13 Non-observed
Transcribed Verbatim

Stories extracted using a structural
framework

Story Extracts

Themes

PHASE 1

PHASE 2

5 Interviews
- One with each teacher
Transcribed Verbatim

Observations and
diary entries

Teachers

Interview Situations
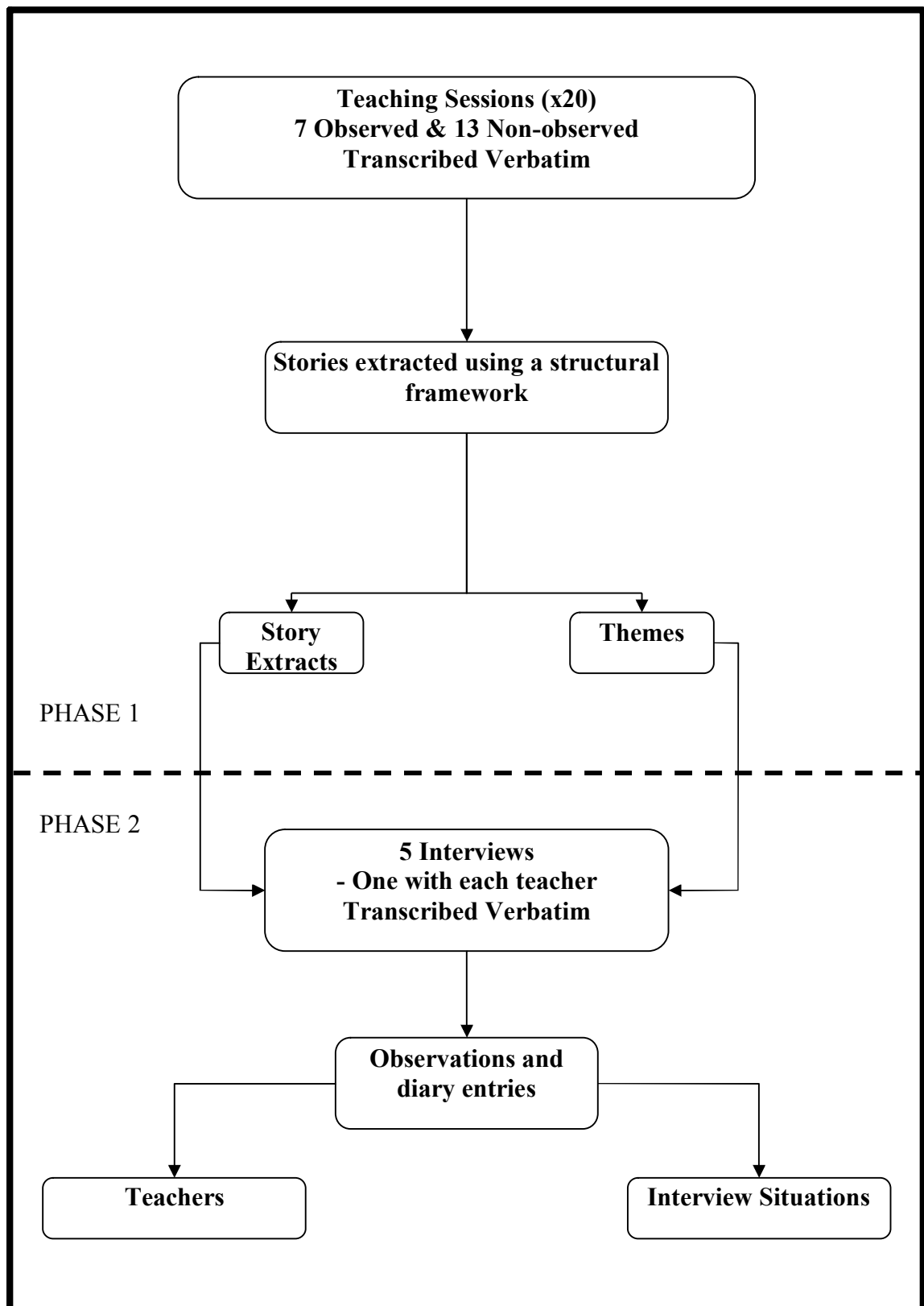
Summary

This section has explained the overall research approach plan taken in this study. I have attempted to consider the importance of the research aim which informed the decisions I made about data collection, the analysis techniques and the inclusion of my research participants. The decisions made were enhanced by my thoughts and reconsidered in light of the research aim to explore the social construction of learning disability demonstrated by the stories told by teachers. This section has also considered that my beliefs in the power of discourse and its influences upon the constructed world of individuals fuelled this study. I have acknowledged that there are many ways to look at the social world of others and many of these ways are governed by our experiences and our interpretations of them. Narratives and stories are ways of capturing the world individuals construct around them. The next section expands upon my journey and aims to trace the reasons for the sample I used of teachers and students in my own university department.

The sample

This next section explains the research participants who formed the sample and their relationships with me as the researcher. I will also aim to reveal my motivations and considerations which influenced the ways I designed this study and made decisions about the sample whilst attempting to respect them as participants.

> Decisions about the sort of sample to be selected in discourse analysis are similar to those in any other research, in that the sample should be relevant to or representative or the phenomenon of interest. (Wood and Kroger, 2000, p78)

Sample size, sample shape and issues involved are important factors in any research design. This study design acknowledged these complexities and considered the rationale for the selection of the sample. The following section will consider the complexities and establish the argument on which they are based.

Using teachers

Morse (2000) suggests that the ideal sample is best achieved by considering a number of factors. She suggests that there is no 'ideal number and that the nature of the study will dictate the size shape and constitution, however, there are considerations.

The scope of the study was to establish learning disability constructions and to draw some conclusions from the use of language applied locally to learning disability nurse student's learning contexts. Although it is not always possible to set controls on the scope of any study, the researcher is obliged to consider issues of and the application and relevance of the research to the given audience (Potter and Wetherell, 1996, 2004). It would have been inadvisable to attempt to collect stories from other departments or other courses as learning disability stories may not be told in the context of care for people with learning disabilities.

The nature of the topic is also an important consideration in deciding the sample (Wood and Kroger, 2000). From the start of the study it was clear that the intention was to explore the construction of learning disability by learning disability professionals. As a learning disability professional myself I had some knowledge that teachers tell learning disability stories. As Morse (2000) further admits if you don't get what you want you need to find more. The sample gave me the stories I needed.

In any study the quality of the data is important. Although some researchers advocate a breadth of data collection (Robson, 2003), this study produced a rich supply of teaching narratives from the teachers and also interviews and observations which were used to meet the study aims.

The study design should ideally match with the sample type used (Morse, 2000). This study aimed to produce information from the teachers which could be subjected to interpretation and discourse analysis. Critics of qualitative data collections often worry about such small and available sample sizes (Robson, 2003), but my study design produced a vast amount of teaching sessions and a small set of interviews and observations (Potter, 2005).

This study used a variety of data collection types from the teacher sample (teaching session narratives, classroom observations and interviews). Again critics state that some research methods are non genaralisable and too small to be representative (Silverman, 2000) . This study was designed from the original collection to the data analysis to collect meaningful and rich data from the teachers' sample.

<u>Willing partners</u>

This study had two groups of participants. The first group, were teachers who were studied in the classroom lecturing to students. This enabled me to collect stories most economically as they happened. The teachers were also interviewed at their work place about the stories they tell to students, again for economy of time and also for the ease of the teachers who were busy with tight schedules.

<u>The Students</u>

The second group of participants, are the students who were enrolled on a learning disability nursing course and were lectured/taught by the teachers studied. The majority of discourse in lectures is directed by the teacher with the students participating.

Both groups agreed to participate in the study before any observations began. The teacher population was a purposive sample of five with only any one person involved at any one time. The student population was less determined and was also a purposive sample selected from a population of learning disability students enrolled at any given point, with only those who turn up for the lecture being included. I did not intend in a small scale or case study of this kind to make any statistical generalisations to any population beyond the participants. (Robson, 2003). The design was aimed to make maximum use of available teaching sessions over a given period.

The choice to use the particular teachers and student groups within this study was a pragmatic decision based upon a subjective evaluation of my interests in interpretative research. The availability of colleagues in my department willing to participate with me in this study was important in my choices. The research would have taken on a different direction if participants from another university had been central, and my abilities as an interpretative research may have been altered. However, serious consideration was also been given to the ethical behaviour expected of a researcher/ colleague both working and researching in one department (Morse et al, 2001; Robson, 2003). The following considers the complexities of the participants and the setting in this study.

<u>The student group demographics</u>

The nature and scope of any sample should be justified by meeting the aims of the study (Morse et al, 2001). For purposes of this study and to collect a meaningful set of learning disability stories on which to base an analysis it was essential to access learning disability student nurses. All of the students had completed the first year of the course and were either in the second or third year. Students in their first year of the course were taught by a variety of teachers from the nursing department and the majority are not learning disability nurses and therefore the opportunities to hear learning disability stories would have been limited in this first part of the course. For this reason lectures given to first year students were not included in the sample.

The students were aged between 19 and 50 years old with the majority female (1:5). The group sizes range from 10 – 20 and were from a mixed ethnic group of White-British, African and Asian, some of the students were non-British born and were using English as their second language. The population of students in this study was determined by being present/enrolled on the learning disability nursing course. Again, this was to ensure maximum utilisation of available teaching sessions with a maximum number of students thus trying to ensure a wide selection of teaching opportunities. The sample scope also took into account possible error and wastage of taped material.

An information sheet (see appendix 2) similar to that given to the teachers was handed or posted to all students on the learning disability nursing course, no-one came forward to decline participation. I also offered to give additional information on request.

<u>The setting</u>

The setting for this study resembles that of a case study. Many of the problems associated with case studies are not applicable to this study design. Case studies tend to address a range of questions about a set of individuals across a variety of contexts which can lead to a neglect of the role of the context in the constitution of meaning (Silverman, 1993).

The study is based in one department with a set of staff all working with one set of students (Bogdan and Biklen, 2003). It could be a criticism that this study is small scale and non genaralisable (Bogdan and Biklen, 2003). The methodology for this study however, aimed to examine the phenomena of the learning disability discourse from the psychological (or individual) level of the teacher and from the learning disability professional culture (or collective) levels and to this extent the study takes account of the forces acting outside of the small case or department. The findings of the literature review for this study reinforced that the learning disability discourse constructs and is constructed by the practices of the past and the more recent changes in learning disability care. It was not in the remit of this study to comment upon or make suggestions about other departments in other universities; however the examination of the individual and social learning disability discourse is widely published and commented upon in the literature (Swain at al. 2005).

<u>Respecting the partners</u>

This research study was based within a large university department with a strong reputation for professional and vocational courses. The participants in this study were a team of five teachers who teach and supervise students on a three-year course

leading to professional qualification in learning disability nursing. The researcher (myself) was also a teacher on this course and a member of the team. The teachers are three woman and two men aged between 33 years and 52 years. All but one teacher was full time in teaching, with one a visiting teacher. An individual information sheet (see appendix 1**)** was used to give brief information about the nature of this study and an option to decline participation offered, but no one declined.

Ethical strengths

Although, as was mentioned above the research in this study utilised a non conventional case study as a sample unit, the nature of the quest to look for learning disability constructions pressed me the researcher to consider all the positions.

> We have been taught not to contaminate our minds with the information obtained from the others' research when we use qualitative methods. However, this does not mean that the investigator can approach the topic innocently; ignoring what is well known about a topic and the result of others' research. (Morse et al , 2001, p191-2)

The main considerations in collecting narratives (teaching and interviews) from the teachers were ethical. There is an argument in some research arenas that the researcher should work towards becoming aware of his /her own influences and biases in the research situation and attempt to leave them to one side when interpreting textual material (Morse et al, 2001). This bracketing or consciousness raising was a consideration in this study. However, as advocated by Connelly and Clandinin (2000) the tensions associated with writing about those you are familiar and in an area of work in which you are involved in the construction of the discourse should be considered in the narrative form of the final text. In this study the narrative form is ethical and is drawn from the body of work already in the public domain that of the learning disability discourse. The interpretations made of the textual materials (stories

and interviews) take cognisance of the social influences upon the learning disability construction that the teachers draw upon in their work (Potter and Wetherell. 2004)

All the teachers were qualified learning disability nurses and qualified adult-education teachers. The choice to use only learning disability teachers was made based upon my interest to hear the learning disability constructions developed through stories by teachers. Other subject teachers teaching these students such as those qualified in mental health or adult nursing tend to construct other discourses based upon experiences with ill physically patients or mentally disturbed clients. Again some of the criticisms lodged at case studies are that the presence of the researcher can change the participant's views of their work (Silverman, 1993). The study design acknowledged these concerns and the interview situation asked the teachers questions about the stories they used and why and was aimed to give a degree of what Silverman (1993) suggests in *respondent validation* by adding to the analysis and interpretation of the learning disability constructions.

The learning disability nursing course mentioned in this study was modularised, consisting of two teaching periods per year of six weeks with three practice placements. Each module ran across the two periods. Teachers had teaching and administration responsibility for a module which incorporates teaching and learning activities both in the university and out on practice.

<u>Introducing the teachers</u>

Kit

Kit is an experienced teacher with 26 years spent in teaching in learning disability education. She previously worked as a learning disability nurse in residential areas for 9 years. Kit is qualified to master's level and holds a professional teaching qualification and a registered learning disability nurse qualification.

Mike

Mike is also an experienced teacher with 12 years teaching pre registration learning disability nursing. He previously worked in learning disability residential services for 7 years. Mike is qualified to doctorate level and holds a professional teaching qualification and a registered learning disability nursing qualification.

Charles

Charles is an experienced teacher of 12 years and has spent the last 10 years teaching pre and post registration learning disability nursing. He previously worked as community nurse for people with learning disability and also in residential learning disability services. Charles is qualified to master's level and has a professional teaching qualification and has held a learning disability nursing qualification for 22 years.

Sheila

Sheila is an experienced pre registration nurse teacher of 14 years. She previously worked in learning disability residential services and community services for people with learning disabilities for 15 years. Sheila has a master's qualification and a professional teaching qualification and is also a qualified learning disability nurse

Jacky

Is an experienced learning disability nurse of 15 years. She has worked in a residential and community services for people with learning disabilities. She has taught part time on pre registration learning disability nursing course for number of years. Jacky is qualified to master's level with a professional teaching qualification and has a learning disability nursing qualification.

Collecting the Sample : Data types

The initial data collection began over five years previous and followed the progression of cohorts (normally one per academic year) of learning disability nursing students starting from January 2000 until 2005. The following presents (table 2.1) the data collection types and is followed by a discussion of each data type and collection method.

Table 2.1:- Data types

TYPES OF DATA	METHOD OF COLLECTION	AMOUNT COLLECTED
Date type 1 Learning disability teacher lectures given to learning disability nursing students (ranging from I hour to four hour classes)	Audio taped and transcribed	20 separate teaching sessions given to 6 cohorts of students. Delivered by 5 different teachers. Total of 39 stories.
Data type 2 Observation notes made by the researcher during teacher lectures	Written observations	7 teaching sessions 1 with each teacher plus extras (N.B except for Sheila not observed as she was away sick)
Data type 3 Interview between the teacher and the researcher	Audio taped and transcribed	1 interview with each teacher =5
Data type 4 Researcher observation upon interviews	Written observations	1 set of notes for each interview = 5

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┌─────────────────────────────────────────────────────────────────────┐
│ Data collection timescale                                           │
│                                                                     │
│ Collection of teaching sessions                                     │
│                                                                     │
│ Year 1  ══════════════════════════════════════════►  Year 5        │
│                                                                     │
│                                                                     │
│                                                                     │
│ Observations of Teaching sessions                                   │
│                                                                     │
│                        Year4 ═══════════════════►  Year 5           │
│                                                                     │
│                                                                     │
│ Interviews with teachers                                            │
│                                                                     │
│                        Year4 ═══════════════════►  Year 5           │
│                                                                     │
└─────────────────────────────────────────────────────────────────────┘
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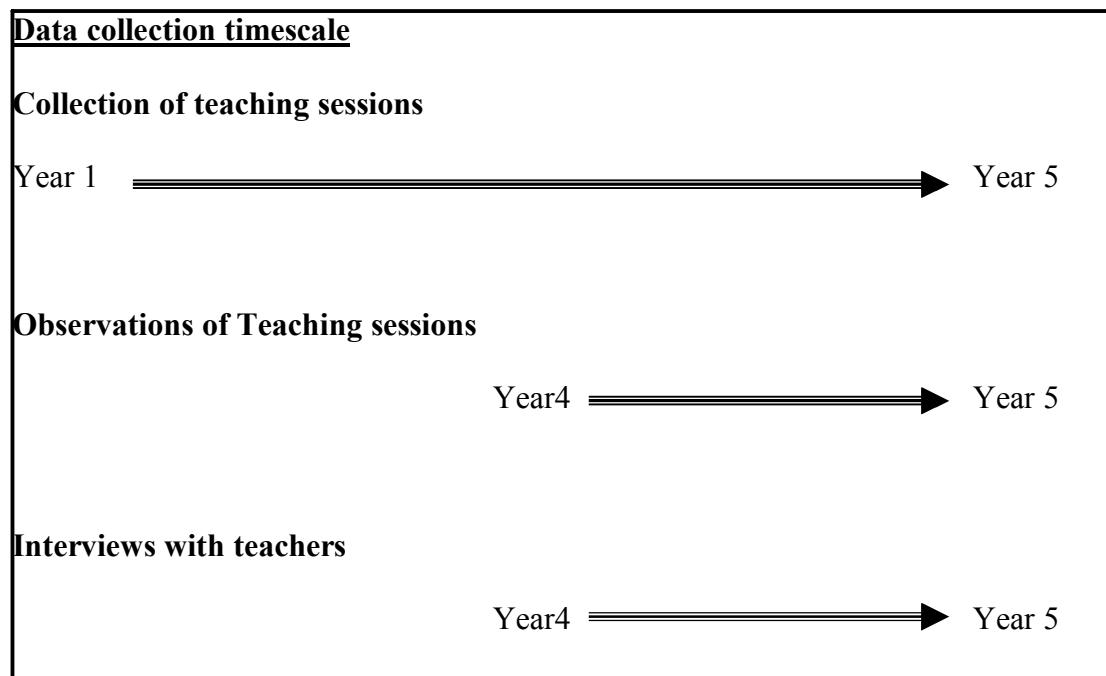
Data type 1: Learning disability teacher lectures given to learning disability nursing students.

It was evident from the early explorations in this study that some teachers told stories more frequently than others did and some sessions contained many stories and some only one. Therefore the collection of data across many topics, cohorts and time periods ensured a variety of stories were collected and a rich and varied selection of data was sourced (Morse et al, 2001).

This study utilised the events occurring in a number of teaching sessions across a given period of a time. It was important to audio-tape whole teaching sessions some lasting between 1 hour and four hours and across all types of learning disability topic to give a full flavour of stories told by teachers. The audio taping of material is an established method of collecting large amounts of spoken narrative. The advantages are that a wide scope of language use is captured and it is possible to gain some

understanding of the context also (Potter and Wetherell, 2004). The disadvantages of participant (teacher) reaction to the recordings was acknowledged but no attempt made to hide the Tape-machine as ethically this could have posed problems potentially associated with surreptitious recordings against teachers' or students' knowledge.

Although the difficulties of researcher presence and effect are acknowledged (Crossley 2000; Hollway and Jefferson, 2002; Morse et al , 2001) I decided that this could be minimised by the use of a tape recorder placed in the classroom/lecture room where it could be seen during the lecture/lesson (without my initial presence). To ensure an open and transparent understanding of the research intentions all the students and teachers were given an information sheet explaining the intention to collect and utilise the data for the purpose of research and reassured about anonymity. In the event of any queries, I aimed to offer further opportunities for discussion and explanation (none came forward). The relationships between the researcher and 'students-as-participants', and the researcher and 'teachers-as-participants' differ in levels of power and influence. As a colleague/researcher, my relationships with the teachers were based upon negotiation and an equal power balance. All of the teachers were given brief information and all chose not to ask for more. As a teacher/researcher my relationship with the students is of me as the most powerful. This is inevitable and the students' participation is based upon their discussion to remain, decline permission or turn up for the teaching session for which they are forewarned will be audio taped. I accepted that students have less ability to decline participation than the teachers given that they are also students of mine. It was a given part of the study that the differences in power balance between the two groups may

mean that students were unlikely to refuse participation. I did however, engage in extensive debriefs with some students (at their request) groups and prior negotiated the access to their lectures. This enabled me to prepare them for my presence in the classroom and for the taping of sessions. The classroom narratives were expected to form the main depth of data collection to be enhanced later by interviews and observations based upon what I saw in the classroom and heard in the stories.

Through this process I successfully collected the first two years of initial data (un-observed teaching). The sessions contained the teachers' lecture speech and the students' comments, and it is this narrative dialogue that formed the main data for this study.

The goal of many qualitative researchers is to provide ways of understanding and explaining the perspective of those who themselves have lived it (Bailey and Tilley, 2002). This study used stories collected during teaching sessions (narratives) as primary data, which as Dyer and Keller-Cohen (2000) comment;

> The recounting of narratives has been acknowledged as important not for its objective representation of a past event, but for the subjectivity of that construction and what that can reveal about the narrator as an individual, and the society by which she is shaped and within, at the same time, she is a shaping agent. (Dyer and Keller-Cohen, 2000. P 284)

Citing phenomenology, Dyer and Keller-Cohen (2000) argue that narratives given by individuals are inseparable from the identities they experience, and that this can give us clues to the world described in the language they use. This had particular relevance to this study which aimed to explore the stories told about the lives of learning disabled people by professional nurses.

<u>Key indicators of the particular stories.</u>

Most of the stories were told by lecturers to students in a classroom situation. Some stories were told by students but this was rare. It was usual for the stories to start with "when I was a student", " I actually nursed somebody", " I worked..", " When I trained", "In my days as..".

It was clear that story telling in classrooms was utilised by some more than other lecturers and in some lectures more than others. There were key themes, which ran through the stories, which were influenced by a variety of probable factors. The course in which the teaching sessions were based had a tightly constructed curriculum. The curriculum devised in conjunction with the other three types of nursing course (adult, child and mental health) originated in a common framework intended to educate all nurses with core skills and knowledge (UKCC, 1996). More modern/recent curriculum also attempts to meet this aim. As a result the medicalised discourse of the other types of nursing influenced the curricula of all, including learning disability nurse education. Other influences arose from the political discourse of health and community care re- producing the priorities of de-institutionalised for people with learning disabilities and reinforcing the need for learning disability nurses to be educated to work in non institutionalised settings.

The curriculum contained what are considered important features, teaching themes and topics (such as reflective practice development) which were integrated via modules. The teaching content of the modules reflected the overall course content. Therefore certain topics are taught to students. This could have accounted for some of

the content themes (e.g. community care, inclusion, and normalisation) which arose during teaching sessions/accounts.

Data type 2: Observation notes made by researcher during teacher lectures
By observing the stories as they were told to students by teachers the research was informed as to the context of the story and the observable effects upon students as they listened and engaged with the story. This dimension essentially further added to the interpretation of the meanings attributed by teachers to the learning disability discourse as they constructed it in stories.

It was accepted that observation alone does not offer a simple solution to the triangulation deemed by some to be essential to securing the reliability of participant observational studies (Willig, 2004). However, it is argued that overt/visible observation can offer some variance and richness to the subjects under investigation, but that an account is needed for the potential rhetorical effects of 'seeing one particular point of view' or omitting that which is not relevant (Potter and Wetherell, 2004).

The observational notes made were progressively developed throughout the period of research and tended to concentrate upon the actors, the physical place, the sequence of events and timing, and my feelings and reflection as an observer (Ely et al, 2001). The field notes helped to establish my own abilities as an observer hoping to collect meaningful data and make a limited impact within the classroom.

<u>Early influences on later design</u>

The observer role was important feature and the design of this study hinged upon the decision to observe teaching sessions. Bogdan and Biklen (2003) comment that the observer role in research is to reflect upon a number of categories. In particular, they recommend reflections upon the processes and method used, any conflicts and dilemmas, points of clarification and the frame of mind of the researcher. The original plan I made to seek only data from unobserved teaching sessions was modified when I listened to the first audio-tapes and read the first stories within them. My observations of this original and preliminary data caused me to reconsider both the methods used and to seek further clarification from myself about the nature of the evidence which would enable me to investigate the stories.

Potter and Wetherell (2004) comment upon the nature of observing for oneself what it is your research seeks to investigate. With this in mind I decided that an observational record of a teaching session would enable my interpretation of the situation and enable me to reflect upon any points for clarification (Bogdan and Biklen, 2003; Potter and Wetherell, 2004).

In listening to the initial audio tapes, I observed the quality and resonance of the stories. In particular the detail and language used in the learning disability constructions which I recognised from listening to the tapes was very distinct from the rest of the teaching narrative affirming my interest in learning disability constructions in the stories. I endeavoured to include some observed teaching sessions in the data collection, with which I could then gain a clearer picture of the story construction and its place within the teaching narrative.

Data type 3: Interview between the teacher and the researcher

This study used interviews as an additional research method which can be described as:

> Purposeful conversations usually between two people (but sometimes more) that is directed by one in order to get information.(Bogdan and Biklen, 2003, p. 135).

Face to face interviews are commonly used in qualitative research and are the methods by which researchers can find out more how people attribute their experiences in context (Hollway and Jefferson, 2002; Mishler, 1986; Robson, 2003). In an attempt to understand the audio taped data and a different view of the teachers' constructions the interviews were intended to enhance the ability of the study to investigate the complexities of the social constructions of contested topics such as learning disability. In this research, the interviews were designed to give the teachers opportunity to comment upon the stories they used and to elaborate upon their origins and perceived function.

The interview was structured around a welcome and introduction, demographic questions and a series of open-ended questions with opportunity to elaborate on particular issues at the end (see appendix 3). This format was loosely planned to encourage some elaboration of the themes that were already present in the stories the teacher had told and I had collected. Showing them the selections of their own stories, I hoped to increase my understanding of how the teachers use their particular type of social constructions of learning disability in teaching student nurses.

The participants were not offered the opportunity to view the transcripts of their teaching sessions before they were interviewed, although it was indicated that they would be available on completion of the research. This decision was made based upon an assessment that the transcripts were of interest to the teachers and could influence the collection of the future data collection, for example deliberate addition or omission of stories in teaching sessions to assist the research process. This did impose a potential issue of anonymity and ownership (Connelly and Clandinin, 2000). Anonymity was offered to each participant, and this was assured during the welcome aspect of the interview. However, the rights of those third parties disclosed during the personal reflections were to be assured and efforts made to guard the information given second hand by the interviewee (i.e. stories of past care experiences or family incidents).

The first interview conducted served as a pre-test and informed my skills and development as an interviewer with the need to continue with field notes after each interview. The test also informed my need to formulate each interview individually based upon the initial reading of the teaching narrative transcripts. The early pre-test did confirm the abilities of the interviewer (myself) to use the extracts as prompts and also clarified the need to concentrate upon using open ended questioning techniques to elicit an open discussion based upon the teacher's experiences (Hollway and Jefferson, 2002). Informed by my reflections upon the pre-test interview I considered the questioning techniques a means to empowering the interviewed teacher to elaborate further upon their stories. For example my questions in the pre-test tended to be closed type questions which tended to produce yes or no answers. This could have

caused the answers to be potentially confrontational to someone unaware that they used stories to a great extent, making me as an interviewer sound critical of story use in the classroom. I wanted to avoid this in the in the aim to encourage confident participation by the teachers (Hollway and Jefferson, 2002). My field notes also gave me enhanced skills and confidence to focus upon the issues I needed to cover without leading or closed questions (Ely et al , 2001).

Using story extracts

There is then an argument for an empowering approach to interviews, Mishler (1986) warns of the suppression of the story telling tendencies in the traditional question and answer technique, and as I wished to find out more about learning disability constructions in teaching I therefore considered there were alternatives to be tried. It was important to focus on individual content in each interview. To achieve this focus I chose to extract stories from earlier transcribed teaching sessions and to use them at the interview as a focus for discussion sessions (see appendix 4).

Although, traditional interviews methods are challenged by such as Mishler (1986) and Stanley and Wise (1983) for the unequal power relations and the inappropriateness of the question and answer technique, this study looked to the interview as a way to interpret the learning disability constructions in teaching sessions. As is already established, the relationships between the interviewer (researcher) and the interviewee (teacher) were close and pre-defined. The interviewer held privileged information from teaching session transcripts to which the teachers had no access.

For Hollway and Jefferson (2002) the concerns of the interviewer often reside in unconscious susceptibilities with both interviewer and interviewee subject to the powers of internal fantasies, and suggests that either party hold strong internalised attitudes towards interview situations. These are affected and affect the interview situation. As an interviewer with a close relationship with all the interviewees it is probable that both parties felt anxious and took up a defended position. This could potentially have provoked unease and affected the interview situation (Connelly and Clandinin, 2000).

The interviews were planned to utilise prompts in the form of the story extracts in a non-threatening manner with the aim of easing some of the anxieties associated with defended subject positions (Hollway and Jefferson, 2002). This approach of focusing part of the interview upon a piece of narrative with which the interviewee was familiar was an attempt to provide an open and transparent approach (Potter and Wetherell, 2004).

As a researcher I aimed to make observational notes after each interview in a further attempt to record my frame of mind as interviewer/researcher and help me improve my interview skills by adjusting the method accordingly. In one instance I reflected upon my physical proximity to the interviewee as being too close and perhaps affecting the ease of the discussions both for me and my colleague. The next time I interviewed I set the chairs and table differently (Robson, 2003).

<u>The interview setting</u>

It is widely recognised that the place, conditions and degree of formality shape the interview. For me this was conditional and it was appropriate to conduct interviews at convenient times and in a quiet place without distractions at the work place. This helped set the scene at an appropriate meeting place for the research pair (colleague and myself). The interviewee was aware of the research nature but was not aware of the content of the data collected. I found this worthy of consideration given that the aim was to preserve a trustworthy and open approach to this study by treating all participants as valuable contributors. However, I found the issue unavoidable given the close nature of the professional relations between the subjects and myself (Hollway and Jefferson, 2002). The aim was to treat any information with respect and to answer any questions levied about the study with care and transparency.

As is good practice in qualitative research, the interviews were planned mutually between the research pair. Often, prevailing conditions can dictate that interviews are rescheduled if interruptions occur. In the planning of interviews I attempted to provide an environment free from interruptions, at a time a place suitable to the interviewed teachers without disrupting their busy schedule. The contingencies (Robson, 2003) for this were to rearrange given the working nature of the interviewee to another convenient time. Other contingencies of over running time were be dealt with by only planning single interviews without follow-on to the next. Therefore, the research pair could continue to discuss at length any important themes. It was not expected that subjects would find the information given in the extracts stressful or difficult however some appreciation was given to the sensitive nature of personal information and was

be disclaimed in the Welcome part of the interview (Hollway and Jefferson, 2002; Silverman, 2000).

Timing is everything

In order to maintain some structure to the valuable time offered by the teacher a time period was negotiated. A one-hour time slot was discussed/negotiated at the welcome part of the interview. The intention was to be flexible according to the discussions and to the conditions of the day with the opportunity to extend beyond the hour if necessary (i.e. depending upon appointments and other people needing use of meeting/interview room). I expected to indicate the end of the interview by thanking the subject and giving a brief summary and clarification of topics covered, this is intended to close off the discussion and to give the participant the opportunity to add anything to the discussion uncovered in the main interview before closure.

Using prompts

Given that the general idea of interviewing the teachers is to find out more about the learning disability story constructed both within teaching and the general practice of learning disability care, I aimed to explore any anecdotes and personal experience/ reflections which are used to illustrate the bigger picture of learning disability care past and present.

The stories extracted were of specific events, which the teacher had recalled to students during the teaching session. I selected the extracts based on their visibility within the narrative of the session. This visibility was based on such prompts as '*I remember when…*' , '*I always thought…*', ' *When I did my training…*' These cues

often indicated the use of an example from the teacher's past work in learning disability care or personal experience of the topic under discussion.

I intended to use the extracts as early prompts to the discussion by handing the teacher a copy of a story extracts and reading out aloud. Informed by the early pre-test this was appropriate and it seemed most appropriate to adopt open-ended type questions, which encourage the interviewee to expand on the origins, history and awareness of the extract. As the discussion developed and the interviewer and interviewee engage in what Potter and Wetherell (1996, 2004) call conversational encounters, I aimed to investigate the importance placed on these personal stories within the classroom and how the teacher may construct learning disability care. Part of the interview focused particularly upon topics or themes raised within the teaching session. This required some clarification of the topics used, as it can not be assumed that teachers would remember extract details from the teaching sessions. By reminding the interviewee of the story contained in the extract, this avoided over generalised assumptions between interviewer and subject as pointed out by Hollway and Jefferson (2002). The story extract used was intended to prompt discussion and not to form the whole focus of the interview.

It was envisaged that the story extracts would help the research pair to discuss particular and specific significance about the use of personal and professional knowledge that could potentially enhance a teaching situation. It was also expected that this could encourage the teachers to share the part played by the learning disability constructions in their teaching sessions.

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Due to the nature of the interview and the relationship between the research pair it was envisaged that the end of the interview would be dictated by when all the aims had been covered, and not by a time limit. As familiar colleagues, both the teacher and I could potentially have extended the interview period with discussions unrelated to the interview. Therefore the setting of the interview scene was important and essentially established the aims of the discussions (Robson, 2003). This was planned to be achieved by sharing the interview schedule and the aims with the teacher at the onset of the interview.

Data type 4: Researcher field notes and observations upon interviews

Investigating the construction of learning disability by teachers involves a systematic and engaged process of data collection and analysis. The process in this study aimed to tease out learning disability within the stories constructed (Ely et al, 2001). Qualitative research of this kind involves a continuum of visiting and revisiting the data collected by focussing upon the threads, ideas and themes arising from the many facets (Connelly and Clandinin , 2000; Morse et al, 2001). Much of this takes place in the field or during engagement with the participants. This is captured in this study in the form of field notes and observations.

In order to make deeper and more general sense of what is happening in qualitative research it is often necessary to observe and make notes of events (Silverman, 2000). Coffey and Atkinson (1996) comment upon the importance of notes and observations as additional sources of interpretative information. Although primarily used within ethnographic research, field notes of interactions with research participants,

diary/journal entries, logs and analytic memos are essentially tools on which the researcher becomes increasingly sensitised to the research question and data analysis (Ely et al, 2001).

In this study I made use of observational notes of interviews and teaching sessions and also of a journal detailing important theoretical ideas generated during the study phases. The interview observations afforded me the opportunity to both review my own development as an interviewer and also focus upon themes and opportunities emerging that could be used in the next interview, teaching observation or theme analysis. This *Gestalt* or pulling together of the issues and themes generated across the many facets of this study ensured some degree of contextualisation which can be easily lost in interpretative studies (Hollway and Jefferson, 2002). The notes made after interviews also served the purpose of giving the researcher a personal dialog on which to face the self-as-instrument (Ely et al, 2001). In this study this dialog allowed me to express my thoughts, insights, biases and ongoing ideas about the methods I employed to develop each interview to best address my research aims.

Ethical considerations

Within any qualitative study ethical consideration forms an essential part of the research design (Ely et al, 2001; Robson, 2003; Silverman, 2000). This study took seriously the ethical principles of anonymity and respect. Although it is accepted that the teacher participants formed a small group of easily identifiable people, their rights to anonymity were acknowledged within the study. The study design was not required at the time of conducting the research to obtain any formal ethical approval although the ethical conventions of the university department were strictly followed The

commitment to protecting the names and identities of those appearing within the personal stories or interview was attempted and this was communicated to teachers and students alike in the information sheet and was verbally reiterated at the start of the interview.

Summary

This section has outlined the research decisions I made based upon the situation and contexts I experienced when aiming to collect meaningful data from a sample of teachers. I have charted the processes of my personal growth as a researcher and the embryonic development of the study from an original and basic design to a mature and thoughtful research study. I have moved through a series of stages and have reflected upon necessary amendments with my research aim as the focus. This journey has taken me from the naïve ideas in which I aimed to place a tape recorder in a classroom then return later to retrieve it, through to the decisions to observe teaching sessions, conduct interviews and field notes.

Data analysis section

This section aims to outline the processes of analysis undertaken and the influences that effected the stages of the analysis of data.

The Quest

This study generated data from many forms; teaching session transcripts, extracted stories, teaching session's observations, interview transcripts and field notes. Guided by the ideas of Willig (2004) the analysis in this study aimed to draw together the

ideas generated by the initial research inquiry to investigate the discursive resources used by learning disability teachers in classrooms encounters with students.

The final analysis of information collected in this study took place away from the field and alone with the data. Connelly and Clandinin (2000) call this transition the move from field texts to research texts and remind us of the difficulties incurred however mindful the study design is to the emerging ideas and complexities of qualitative research.

The verbatim analysis that followed involved the coding and re-coding of extracted stories, interview transcripts and field notes/ observations (Ely et al, 2001; Morse et al, 2001). The diagram figure 2.2 The Research Plan, below indicates the relationships between the various facets of the plan and the various ways that the data types were open coded and examined for common themes.

Figure2.2

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                    ┌──────────────────────────┐
                    │   Teaching Narratives     │
                    │     (Audio taped)         │
                    └──────────────────────────┘
         ┌──────────────────┼──────────────────────┐
         ▼                  ▼                       ▼
┌──────────────┐   ┌────────────────┐     ┌──────────────────┐
│  Teaching    │   │  Transcribed   │     │ Observed Field   │
│  Narratives  │   │                │     │     Notes        │
└──────────────┘   └────────────────┘     └──────────────────┘
         │                  │                       │
         ▼                  ▼                       ▼
┌──────────────┐   ┌────────────────┐     ┌──────────────────┐
│              │   │ Stories Isolated│    │                  │
│              │   │  From Teaching  │    │                  │
│              │   │   Narratives    │    │                  │
│              │   └────────────────┘     │                  │
│              │          │               │                  │
▼              ▼          │               ▼                  ▼
┌──────────────┐   ┌────────────┐ ┌────────────┐  ┌──────────────────┐
│  Open Coded  │   │Story Extracts│ │  Themes   │  │   Open Coded     │
└──────────────┘   └────────────┘ └────────────┘  └──────────────────┘
                            │
                            ▼
                   ┌────────────────┐
                   │   Interview    │
                   └────────────────┘
                            │
                            ▼
                   ┌────────────────┐
                   │  Transcribed   │
                   └────────────────┘
                            │
                            ▼
                   ┌────────────────┐
                   │  Open Coded    │
                   └────────────────┘
                            │
                            ▼
                   ┌────────────────┐
                   │ ANALYSIS AND   │
                   │INTERPRETATION  │
                   └────────────────┘
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86
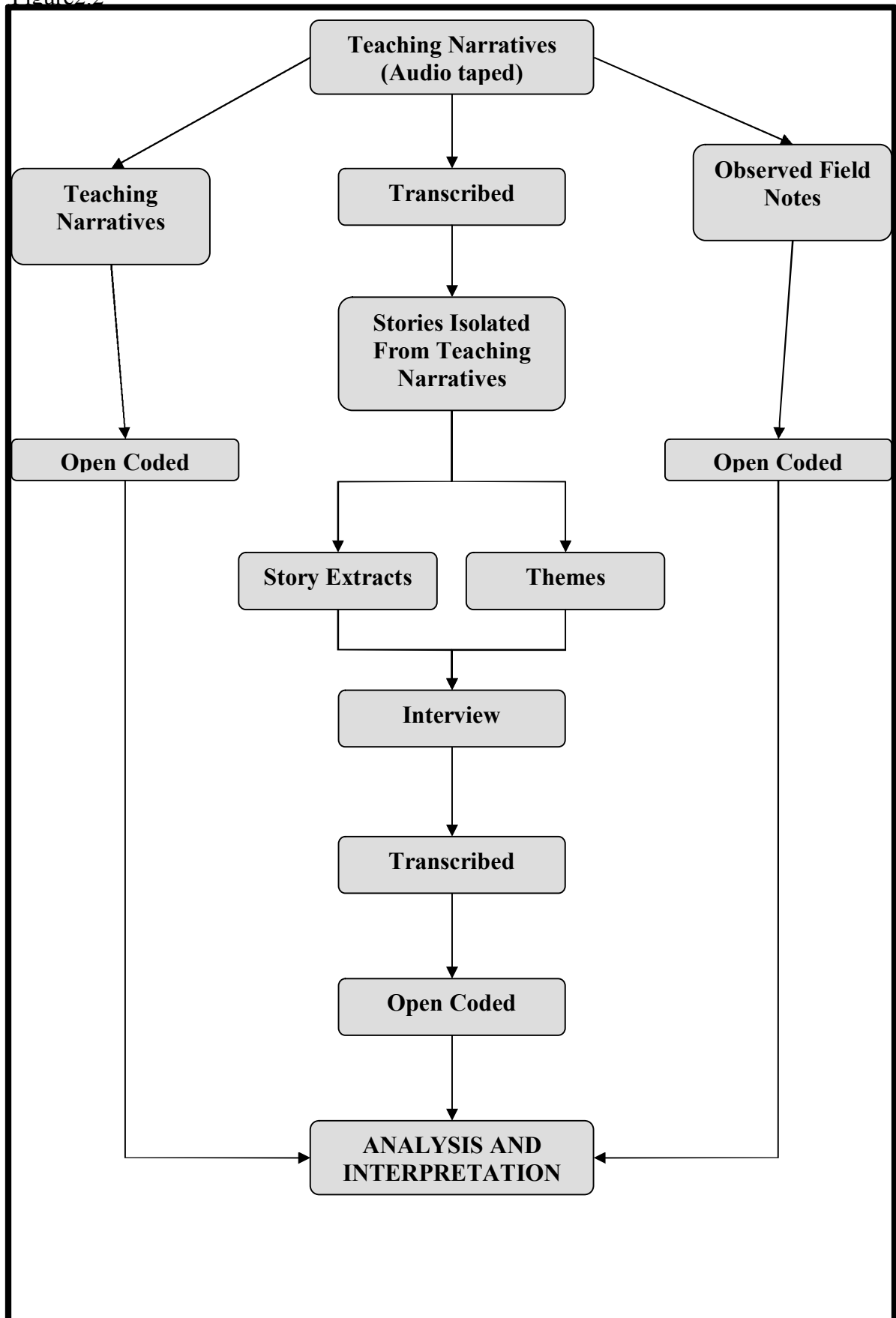
Open coding

The next section discusses the main data organisation method used to conduct the analysis and forms the basis of the interpretation of the learning disability constructions. The main method I used for the early examination of the stories (extracted from the teaching narratives) the interviews and my observations was open coding. All the audio taped teaching sessions and interviews were transcribed verbatim into transcripts. This next section discusses my reasons and explores the benefits of this process.

What is open coding?

Guided by the theories that powerful discourses influence our social worlds (Foucault, 1972,) together with the view that language is used in a complex and diverse manner producing the social constructions on which we base the views we hold of our selves and of others (Goffman, 1963; Harre', 1979; Potter and Wetherell, 2004) this study looked for questions and answers in teachers' construction of learning disability .

One way to elicit meaning from text data is to open code by establishing themes and categories (Bogdan and Biklen, 2003). This system is widely used in qualitative research and can be either theory driven, that is the researcher imposes structure based upon their view of the world. Codes and categories are developed from what he/she sees in the information/data. Alternatively coding categories can be imposed derived from other existing systems/ ways of seeing the phenomena i.e. social class, gender difference or psychological theories. This study took the former route and aimed to look for the emerging learning disability constructs (if any) across the stories using

ideas generating by supporting observational notes, interviews and field diary entries (Hollway and Jefferson, 2002).

Self as instrument: Interpretative authority

The concept of self-as-instrument indicates that the interpretative researcher creates an on going meaning out of the evolving and evolved (Ely et al, 2000). Thus, the early and later coding schemes employed were influenced by and continued to influence the design making processes taken. This type of process has much in common with theoretical sampling which involves the collection of data in light of the emergence of categories from earlier research stages (Willig, 2004). One example of this was in that of early stages of engagement with the raw and un-drafted stories (extracted from the teaching narratives) which enabled me to relate to the emerging themes and categories. My position as a teacher and learning disability nurse situated me equally alongside the teachers in this study in knowledge, but with the acceptance that I was not there when the events of the story happened. I therefore quickly grasped the terms and language of the story as a precursor to interpreting the meaning the teachers attached to the stories and the discursive devices they used to construct learning disability (Potter and Wetherell, 2004).

The open coding scheme I had planned, involved me reading each story, until I had read all the stories as a whole. My second reading was then informed by emerging patterns (through the types of language used); some I recognised as vaguely issues of power and control in learning disability practice, some as practice issues, and as I recognised other themes I gave them coded numbers which I marked alongside each. Therefore, each story had between 1 and 22 numbers scribed upon it denoting the early themes/codes. As reflexive researcher I made detailed notes as my coding

scheme progressed from a simple reading and rereading to a more complex negotiation between the theoretical and epistemological nature of the study and my own knowledge of the world.

As Angen (2000), in a review of the arguments for validity lodged at qualitative research, reminds us, effective and valid research needs to be trustworthy but does not intend to prove, and this is not a simple trait to prove in the climate of qualitative debate (Gadamer, 1994). There is an acceptance that others seeing the same data at a different time, coming from a different position and different experience would see a different picture (Angen, 2000). Therefore the coding scheme adopted in this study can not and does not lay claim to any objective reality that could be replicated or subjected to specific criteria.

<u>Categories and themes</u>

Creation of categories triggers conceptual schemes that suit the data and inform the generation of ideas (Connelly and Clandinin , 2000). In this study this process was particularly useful as the generation of themes from the early teaching sessions were subjected to provisional open coding. This enabled me as the researcher to utilise and clarify ideas that progressed my thinking behind the interviews schedules and subsequent detailed analysis of stories extracted from all the teaching sessions. I was able to develop ideas generated early in the data production. Ideas developed early in the initial coding became a strong indicator of the presence of the later learning disability constructs which I explored in my observations and in interviews with teachers.

Some critics argue that the creations of categories and themes creates a perception bias and that the there is responsibility of qualitative researchers to provide validity checks (Denzin and Lincoln, 1998). For purposes of this study it can be argued that the validity of the data, the collection and the interpretations are assured by my adherence to the integrity of the research aim and the adherence to a post modern design which seeks to interpret knowledge and inform practice (Willig, 2004).

Coding continues until no further codes are found. (Ely et al, 2001; Morse et al , 2001; Willig, 2004). The intense conversations between the researcher the data has implications for the ongoing method and the theory building. Approaching the open coding of a text, the researcher becomes fully acquainted with the data. In this study this involved the reading and re reading of early teaching sessions transcripts, observation notes and journal entries (see earlier figure 2.2).

Through a process of conceptual development, it is possible to 'see' specific patterns and themes or repertoires, which run through the various facets of the data (Bogdan and Biklen, 2003; Potter and Wetherell, 2004). By giving the data codes it is possible to ask questions such as 'what is going on here?' 'I find this interesting but Why?'. The continuing questions can then shape the process in line with the data (Ely et al, 2001). In this study, the early coding of teaching session transcripts helped to generate and conceptualise the development of interview extracts and questions which have then informed the observational notes and further analysis.

<u>Turning codes into learning disability constructs</u>

Following the categorising of the data defined by the codes. My interpretations began to view certain similarities across the codes. Guided by Willig's (2004) suggestions this study utilised ideas from the versions of discourse analysis known as discursive psychology and Foucauldian discourse analysis. Although the two approaches differ in approach to my research question, discursive psychology offers opportunities to discover *how* individuals use discursive resources and Foucauldian discourse analysis aims to interpret *what kinds of subjects* are constructed through discourses. I consider my analysis of learning disability constructs is strengthened by both influences. (Parker,1992; Potter and Wetherell, 2004).

From the earlier literature review is was possible to make some assumptions about the discourses which appeared to dominate the constructions of learning disability in past and present care. The power vested in professionals is said to originate in the ways in which learning disability is viewed and is therefore represented in UK culture. The social construction of learning disability is regulated by the dominant discourse that includes the medicalised language of the learning disability professional. This language has developed from the past and institutional care when people with learning disabilities had little control over their lives to more recent times when involvement from people with a learning disability in decision making is encouraged. Learning disability nursing has contributed to some of these developments in the learning disability discourse.

Driven by the theoretical foundations of this study I began to view social constructions and the discursive devices used to produce them as indicators of the

meaning the speaker attaches. My interpretation of the codes produced three learning disability constructs which appear commonly across the teachers' stories. The constructs *'problem to be managed'*, *'victims of professional dominance'* and *'strange but different'* appeared in many of the stories but in different ways or modes and drew upon various discourses.

Analysing the discourses and modes: staging the analysis

Willig (2004) suggests a six stage plan which can be worked through in the quest to map out discourses and discursive devices. This was particularly useful and provided this study with a structure on which to base a detailed analysis of various themes originating in different data types.

The first stage occupied me in the search across the coded transcripts, interviews and field notes for instances which appear to construct learning disability . Combined with the three constructs (see previous) identified I began to see a pattern emerging in the discourses being drawn upon by teachers.

In stage two it was possible to highlight the discourses which appeared to contribute to the learning disability constructions and I began to locate these discourses in wider dominant discourses of health and social care. At this point it was also possible to begin to make links between the constructions which appeared in the stories and those which the teachers identified in their interviews.

Stage three enabled me to examine my interpretations of the learning disability constructs and to identify how the teachers used various discursive devices in three

particular and very distinct ways (or modes) in their constructions of learning disability (Potter and Wetherell, 2004).

The following table 2.2 explains some of the ways in which the three main learning disability constructs *'problem/cases to be managed'*, *'victims of professional dominance'* and *'strange but different'* appeared across the stories and related to the dominant discourses which are used by the teachers. The indices of this framework will be discussed in the forthcoming chapters.

Table 2.2 Main learning disability constructs

Examples in the stories	Related Constructs	Common discourses
Problems to be sorted out	Cases to be managed	Medicalising Professionalising
Learning disability as special knowledge	Strange but different	Professionalising
Unknowing and vulnerable	Cases to be managed	Medicalising Professionalising Political
Controlled lives	Cases to be managed	Medicalising Professionalising Political
The end justifies the means	Strange but different	Professionalising Professionalising Political
Ill and in need of care	Cases to be managed	Medicalising
The more disabled the more visible	Victim of professional dominance	Professionalising
Everyone is a person	Strange but different	Political
It's a shame it's a tragedy	Case to be managed	Medicalising
Learning disability is ugly	Victim of professional dominance Cases to be managed	Medicalising
Strange is not Ok	Victim of professional dominance	Medicalising
New labels – same person	Victim of professional dominance	Political
Learning disability is misunderstood by society	Strange but different	Political
Two dimensional – lacks colour, shape and form	Cases to be managed	Medicalising Professionalising
Abnormal and at mercy of parents	Cases to be managed	Medicalising Professionalising

Stages four and five afforded me opportunities to interpret any obvious subject positions occupied by the teachers in relation to the student (Davies and Harre′, 1990). In this stage I could draw upon the observational notes of teacher and student behaviour made during teaching sessions. In addition stage five gave me the opportunity to investigate how the practice of story telling enables teachers to

construct their own identities and to appear as expert or knowledgeable to their students (Dyer and Keller-Cohen, 2000).

In the final sixth stage of Willig's model I explored the relationships between the learning disability discourses and the role of the learning disability nurse as explained through the learning disability constructions found in the stories told by teachers. It was then possible to identify the particular consequences of these learning disability constructions (Connelly and Clandinin, 2000).

<u>Summary</u>

This section has further outlined some of the ways in which I treated the data I gathered and the frameworks I used to organise the coding of the data and provide a basis for the interpretation of the social construction of learning disability. My relationships with the participants and my researcher position generated a movement towards a type of data analysis which acknowledged the influence of my own ideas upon the research process.

This section has also described and discussed the process of data collection in the various forms inherent in this study. As I have already alluded to, the data analysis and data collection were intertwined and informed the developments of myself as the researcher engaging with the essentials of collecting information to help me understand more about story telling and learning disability construction. The research decisions I made were based upon a number of factors including the following, availability of learning disability teaching narratives, access to participants and existing relationships. All of these factors were considered to be important features of

the investigative nature of this study and as such I attempted to deal with them sensitively.

This section has discussed the techniques of open coding and the various investigating stages formed in the research plan of this study. I have explored how the open coding across the data then continued to help me produce useful themes and identify the three main constructs and their interrelationships with the learning disability discourse. The next section explores my justifications for the techniques I employed to produce and handle my qualitative data.

Evaluating: checking out what I checked out!

Morse et al (2001) warn us of the dangers of not acknowledging the positions occupied by the researcher who is also a practitioner. The positivist position in research would often seek to minimalise or hide from this obvious and important feature of research in an attempt to ensure objectivity (Morse et al, 2001). However, a post modern or post structuralist (or non positivist) position on research seeks to acknowledge with honesty the validity of the personal accounting' (Denzin and Lincoln, 1998). This view does not privilege knowledge solely to the researcher (as this is shaped by culture, gender, ideology etc) and that the varied understanding through interpretation of texts, stories and observations contributes to the constructions of discourse and the overall picture of the world around us.

As a learning disability nurse and teacher I could be criticised for by those seeking to establish that reliability of this study and the validity of my data generation were compromised by my presence. Justification for the approach taken in this study can be

found by posing a number of questions commonly aimed at qualitative research (Bogdan and Biklen, 2003).

My reflexivity as researcher was a consideration throughout this study. I was fully aware of what Connelly and Clandinin (2000) usefully comment as 'narrative smoothing' or becoming the 'I, critic'. Narrative smoothing can lead researchers down a process of research decisions (based upon their engagement with the data/narrative) and creating the ideal plotline and ending to a qualitative study. Alternatively, becoming the I, critic can lead to a heavy monitoring of researcher presence within the writing up/analysis, leading to limitations and over formalising of the engagement. So a position of alertness or 'wakefulness' is somewhere in between, and was my aim as Connelly and Clandinin further suggest.

> A language of wakefulness allows us to proceed forward with a constant, alert awareness of risks, of narcissism, of solipsism, and of simplistic plots, scenarios, and unidimensional characters. (Connelly and Clandinin, 2000. p. 182).

Trying out a framework

This section provides an overview of the external considerations necessary when conducting research involving specific qualitative design techniques. Conducting research of the kind in this study places me as the researcher in a vulnerable position. Doing qualitative research is a contested activity with many different perspectives and prejudices originating in myself (which is a good motivator) and in others who may read and comment (the unknown critique) upon my perspective (Silverman, 2000). My approach was to demonstrate a degree of awareness of what constitutes quality in qualitative research and to what extent this study can be perceived as quality.

According to Denzin and Lincoln (1998) there is a general debate within qualitative research about the need (or not) to check the quality of research practice. Many criteria are adopted principally for the positivist paradigms of research and stress the need to measure the quality of scientific research via a series of checks based upon the reliability and validity and objectivity of the processes and results. Other schools of thought have suggested that this type of rigid testing is inappropriate to promote good practice and evaluate meaningful designs. They suggest other ways to meet the need for clarity, transparency and honesty in qualitative inquiry (Willig, 2004).

It is considered to be difficult by many in the qualitative research tradition to guarantee an absolute adherence to a convention externally demonstrated as sound practice (Denzin and Lincoln, 1998; Hammersley and Atkinson, 1983; Willig, 2004). I considered it more appropriate to discuss the value of this study in terms of its application and adherence to its epistemological foundations of social construction. My attempts to examine my work using an advised framework are purely an exercise to demonstrate this.

Given that this study is concerned with spoken language/narrative which is converted to text and interpreted and analysed it is appropriate to evaluate the nature of these conversations.

Analytic depth

The analytic depth of a study attempts to bring alive the conceptual frameworks of language used by the general discourses which construct learning disability in health and social care practice. This study mobilised the social constructionist theories which

help us to understand the power and influence of social practices developed over time (Foucault, 1972). In particular I drew upon the medicalising, professional political and the inclusion/exclusion discourses which operate both in the wider learning disability discourse and also more locally in the construction of learning disability by teachers in the stories they tell to their students. This searching for analytic depth is a way to ensure that this study was based somewhere within a high quality framework.

Why should we believe in qualitative research?

The aim to ensure analytic integrity in this study was centred upon the analysis of the data. The analysis of all the data produced for this study was preceded by a system of extensive open coding to determine shared meaning across and within the data types in order to determine if some of the knowledge is privileged more than others.

I was particularly concerned with three issues. Firstly, my own reflexivity as researcher and learning disability nurse and the effects this has upon the interpretation of texts. Secondly, the credibility of the teaching narratives, interviews and operational notes as converted to texts and thirdly the transferability of the discussions I generate from the stories/ narratives to the general learning disability discourse. I found the following seven category framework advised by Elliot et al. (1999) a useful guide for my discussions.

Owning ones perspective

Interpretative researchers consider themselves to hold perspectives or a prejudice which is not necessarily erroneous or a distortion of the truth. These 'prejudices' (Gadamer, 1976) derived principally from a Heideggerian perspective encompass the

'rightful place' of the researcher's value positions brought to the research situation. The research design, coding schemes and interpretative decisions of this were impressed by the beliefs system, I as the researcher brought with me.

Throughout, this study promoted the presence of my own position as an learning disability nurse and teacher (and peer to the teachers appearing in this study) to feature in my discussions. Asking questions of myself such as *To what effect do I assume my own knowledge*? And *what effect does my position as learning disability nurse privilege me?* was my attempt to remain in a responsive research position. There are many heated debates in qualitative research about these issues (Denzin and Lincoln, 1998. p.278) and I was cognoscente of the debates that call for an awareness or wakefulness in the reflexive position of the researcher in the researcher process he/she engages heavily in

Situating the sample

The group of participating teachers contributed considerably to this study and their full participation was valued. In an attempt to give the participants more space in the study many of the details of their demography and their professional careers appear in the interview data. Although much of this has not appeared explicitly in the interpretation of the learning disability social construct the teachers' personalities and values do appear and are accepted as a consequence of the learning disability construction.

The transferability of the issues raised in the narratives/story was reflected back to the teachers as a sample story (or extract) which I shared back with them and formed the

basis of the interview. This did enable both the teachers and myself to discuss the language and situation of the sample story and helped me establish a shared understanding about the learning disability construction with the teacher in my role as researcher.

Grounding the examples

The basis of this study was to investigate the construction of learning disability by learning disability teachers in the aim of further understanding the nature of learning disability constructions in the professional learning context. Extracts and full/complete narratives of the types of data collected appeared as a feature of this study. The interpretation of learning disability constructions was based upon and was illustrated by examples of stories, interview notes and observations.

Providing credibility checks

As a qualitative researcher it is important to be aware of the perspective of those you research (Willig, 2004). As a peer and colleague it was an important to accept that the participants are personally professionally involved with the learning disability constructions which appear across the stories they tell. Whilst their full participation was valued I also appreciated as a researcher that the learning disability discourse was formed from a wider base than the individual (Foucault, 1972) and that the power to shape the discourse was beyond individual teachers. This study positions teachers as experts within a larger paradigm of professional education. Teachers were given the opportunity to explain their reasons for telling stories during interview when examples of their stories were presented for discussion.

Coherence

The issue of providing integration of theory and the relationships between the learning disability discourse and the learning disability construction was also an important feature of the study. I identified the relevant dominant discourses which appeared to be assisting the constructions of learning disability in teacher stories. These four discourses; medicalising professional, political and inclusion/exclusion are characterised in this study as arising from the literature but also from the stories themselves. I demonstrated the relationships both across the story narratives, the interviews and the observations made of both teaching and interview contexts in an attempt to integrate the discourses and form some coherence.

Accomplishing general versus specific research tasks

In a small in-depth study of this type there is acceptance that the data generated is specific to the context. The interpretations generated had local implications via the stories but it is also possible to draw more general assumptions about the learning disability discourse arising from the literature review and overview of the policy contexts.

Resonating with readers

In a study of this type the reader will originate from two standpoints, one of an informed position engaged in the learning disability discourse, and secondly the uniformed position with limited insider knowledge of the learning disability discourse and its implications. It is the responsibility of the researcher to present the interpretation in a style illustrated by the data and with a clarity which encourages the reader to investigate the stories, extracts and observations as demonstrated (Denzin

and Lincoln, 1998). This study although illustrated with examples and interpretations also explained the meaning attributed to the main discourse found to be most prevalent in learning disability constructions.

Summary

This section has attempted to provide an evaluation of this study as adhering to the quality, transparency, honesty and trustworthiness expected of a good qualitative study. The framework used has provided a guide on which to discuss the facets of this study through design application and writing up. The next section considers the chapter as whole

Conclusion

This chapter has outlined and discussed the features which made this study unique I have explored the drives, both theoretical and methodological which formed the basis of this study. In outlining this chapter I aimed to show how I considered my journey from original research aims influenced by my ontological position which views reality as socially constructed through to the collection and analysis of areas of the social world which constructs learning disability in particular ways.

I have discussed the influences which enabled me to embark upon a study of this kind and I have explained that the principal focus of investigation is language, in particular the narratives of learning disability professionals communicating through stories about their experiences with learning disabilities clients. The next chapter will continue to reveal more about the learning disability social world expressed through

the four dominant discourses; medical, professional, political and inclusion/exclusion which have shaped the nature of the learning disability construction.

Chapter Three

Mapping the discursive landscape

Overview

In the previous two chapters I have outlined the established knowledge which has informed my thinking about the construction of learning disability within the discourses drawn upon by learning disability teachers. I also concentrated upon the methods I employed to investigate the learning disability constructions in lecturer stories based upon this knowledge. This next chapter continues the journey to uncover and interpret some of these learning disability constructions. The start of this journey begins with a forward to the analysis and interpretation of the stories told by teachers. This relates to my overall research aim *To investigate the social construction of learning disability by teachers in the stories they tell to their students within teaching narratives* and also more particularly to two of my objectives: *To explore the use of discourse in learning disability constructions within teachers stories* and *To identify any links between the teachers' learning disability constructions and the learning disability discourse.*

Introduction

This study was concerned with dominant discourses which act upon and influence the construction of learning disability by teachers and are manifested in the stories they tell. It is therefore important to identify the discourses their origins and the discursive practices which appear to contribute to the learning disability constructions in

teachers' stories (Willig, 2004). Although, separated into four it is acknowledged that many of the wider discourses influence and correspond to each other in the social world and, as such, do not form discrete categories acting in isolation (Potter and Wetherell, 2004). However the four discourses identified do have individual characteristics which can usefully assist the interpretations and analyses of the learning disability constructions in this study.

The four discourses arise from my literature review as common themes and also during my initial and progressive engagement with the data through open coding. I analysed the four discourses to be the most commonly used when learning disability is constructed in the stories told by teachers in this study. These discourses will be presented and discussed in four sections.

The four discourses

I now draw attention to the dominant discourses originating in the many debates which arose from works as varied as that of Parsons' (1951) attention to the 'sick roles' which has informed medicalised constructions, Goffman's (1963) seminal work highlighting the difference in interactions between 'normal' and 'abnormal' people, and the 1990's disability movement challenging established medical sociology (Barnes, 2005a). These have contributed to the way the relationships between professional and client are constructed and the language used. These theoretical ideas have affected and have influenced this study in a number of ways. The language of practitioners working in the learning disability field constructs learning disability in a medicalised way, and professionals are both affected by and affect this discourse. (Barnes, 2005a). It is therefore important to concentrate upon the dominant discourses

which have arisen and influenced learning disability theory and have driven health and social care policy and education and training.

Arising from my interaction with the literature and analysis the first and main discourse drawn upon in the construction of the stories is one of medicalised care for people with learning disabilities. This arises from the histories of institutionalisation, views about physical impairments, genetics and medical diagnoses. Oliver (1990, p. 50-51) suggests that the domination of professions over disabled people (in particular the medical professions) has been achieved in three ways.

> …the first suggests that this dominance has been achieved because of the superiority of medical knowledge (based on science) over other forms of knowledge; the second suggests that power was achieved because the medical profession was well organised and able to gain dominant positions within the new bureaucracies rising as part of the rationalisation of society; third emphasises the interconnections between the medical profession and the capitalist ruling class. (Oliver, 1990, p.51).

The teachers in my study drew heavily upon language and imagery which reflects the way people with learning disabilities have been, and are still, constructed as medically ill and in need of special care and confinement.

The second major discourse influencing the stories in this study originates in professional language of control, power and knowledge of learning disability nurses charged with the role of caring for people with learning disabilities. This discourse enabled teachers to construct stories based upon their expertise and knowledge which is relatively unchallenged in the current critical health and social climate (Barnes, 1996; Race, 2002). A part of this discourse reflects the affective concerns of learning disability nurses and is based on the fear, blame and otherness which has effected

some of the care practices which learning disability nurses contributed to in the past (Goodley, 2000; Ryan and Thomas,1995)**.**

The third, discourse constructs learning disability in terms of equality or inequality of opportunity, social protection and corresponds to the many paternal views of learning disability care (Wolfensberger, 1972) and I call this the political discourse. Fourth and finally the inclusion/exclusion discourse draws upon society's alienation and description of people considered different. This discourse facilitates learning disability constructions in lecturer stories through the language of folk lore and literary representation.

These discourses that emerged from my engagement with both the literature and the data collected are interspersed and appear within the constructions. As these four discourses figured strongly in the analysis of the stories and the interpretation of the learning disability constructions I considered it appropriate to locate them as a dominant feature within this chapter and to refer to their location and influence to meet my research aims and objectives. As Willig (2004) reminds;

> …from a Foucauldian point of view, discourses facilitate and limit, enable and constrain what can be said, by whom, where and when… (Willig, 2004. p.107)

This study drew heavily upon the view that discourse interacts with and effects the ways in which learning disability constructions are formed and utilised by teachers in their classroom interactions with students.

Summary

This section has introduced the ideas that four discourses could be identified specifically as contributors to the social construction of learning disability in this

study. These main and powerful discourses are attributed with informing the learning disability discourse drawn upon by the teachers in this study and also the general literature which they contribute in part to. The next sections will outline my view of the four discourses which I was drawn to in the open coding of the stories of interviews and in my field observation notes.

The Medicalised discourse

This section draws together the foundation of the medicalised discourse arising from the literature as applied specifically to learning disability.

Origins of the discourse

It is important to remember that the medicalised discourse constructs ordinary citizens (formed on the basis of the power and knowledge of professionals) as ill or as sick patients without agency and without the ability to contribute to their own destiny (Davis, 1997). This has been experienced by some citizens more than others including people with learning disabilities (Paterson and Hughes, 2000). The assistance of powerful decision makers (like doctors) that society ordinarily respects, believes, but tends not to challenge, has led to some restrictive regimes in health care to which little or no objection was made (Goffman, 1961). The surveillance and actions by agencies such as medicine, together with law and religion, further promotes and legitimises this throughout general communities. Foucault argues that

> …doctors, chaplains, psychiatrists, psychologists, educationalists; by their very presence…, they sing the praises that the law needs: they reassure it that the body and the pain are not ultimate objects of its punitive action (Foucault, 1991. p. 11**).**

For people with learning disabilities these agencies have perpetuated the ideas that it is acceptable to examine, experiment and dominate those who are outside the ordinary and who can not or will not voice an objection. As a result people with learning disabilities have been paraded, photographed, researched and categorized in terms of everything from their height, eye colour, and finger print design to their eye width and mouth depth (Barnes et al,1999; Bogden, 1990). This type of observation as described by Foucault (1991) produces a degree of visibility in which people with learning disabilities are judged against the typical norms of human form and behaviour. Often called a medical judgement or diagnosis this visibility reduces people with learning disabilities as something outside of the norm, judged by those with power to label difference and abnormality. This is commented upon similarly by Foucault.

> ..a general process has led judges to judge something other than crimes; they have been led to their sentences to do something other than judge; and the power of judging has been transferred in part, to other authorities than judges of the offence. (Foucault, 1991. p 22).

The dominant discourse promoted by world wide authorities such as The World Health Organisation (WHO, 1980) tends to link ability for action hierarchically by linking the function of a person (or ability to work) to the achievement of positive health and well being. The closer the individuals are to perfect health the more productive a nation will become (Parsons, 1951). Therefore, the less able a person is to work the more sick (less useful) he/she is constructed. The discourse differs in the constructions of perfect health, with some definitions deeming it as the absence of disease, injury or impairment, while other variations see these as distinct categories on which to judge or measure adverse health states (Wasserman, 2001). This discourse constructs people with learning disabilities within a biomedical classification such as mild, moderate severe or profound and is the basis on which diagnoses of learning

disability are made by doctors and other health professionals. This section has highlighted the existence of a medicalising discourse, which exerts pressure and control upon people with learning disabilities through a series of socially constructed positions, roles and images which society has been ready to accept and adopt.

Norms and normality

According to Goffman (1963) we live in a world of norms and we tend to measure our selves in western society, against what is socially ranked as closest to the socially accepted norm i.e. weight, desirability, bodily dimensions and cognitive abilities (Asch and Fine 1997; Aylott, 1999; Davis, 1997; Oliver1990; Priestley, 2003). We are ranked in terms of our education, of our work and our health by others and ourselves (French and Swain, 2005). The medical professional and others professional groups allied to them are founded on a set of principles which seeks to reinstate us to a form of homeostasis closest to the healthy norm (Paterson and Hughes, 2000). Theories of the medicalisation of western societies have driven critiques of the power and dominance of the professions over groups of people including disabled people (Foucault, 1991). Davis (1994; 2005) provided a personal and analytic account of the failings in the relationships between professionals and the people they construct as their client using language. His criticisms reflect some of the common problems associated by disabled people on becoming dependant upon a set of care professionals. For Oliver (1990 p.51-2), this set of problems typifies the rise of science and the increase of medicalised knowledge which has dominated the classification and control of populations.

There is an argument that the scientific conventions providing the medical classifications of learning disability are rooted in the way science is rationalised. Carey (2003) suggests that the rise of political discourse such as right wing eugenics perpetuated the view that only medical science has anything useful to say about learning disability. The eugenic agenda centralised upon the need to control the prevalence of any inferior quality in society and the medicalised approach to science provided the platform to identify such people through classification. Thus, human populations were controlled by those with the power to research and identify deviance and difference (Foucault, 1972; Goffman, 1963). This study drew upon the ideas of Foucault's work which have challenged the traditions of science and knowledge, and also the ideas that have drawn attention to the close relationships between the medical denomination of science and the restrictive regimes in healthcare (Smart, 2002).

The successful medicalisation process of some groups and not others is a phenomenon which Oliver (1990) calls medical imperialism with the profession winning battles both to define and to treat. According to Oliver (1990) and Finkelstein (1994) the initial rise of the medicalising process was attributed to the need to establish hospital based medicine in the attempt to classify, control and remedy people's ability to work in a developing industrialised community. As a result, the wider social processes were affected by the control and promotion of those able to work versus those unable to work and the medical dominance began (Barnes, 1990). However, this discourse has continued to promote and attempt dominance. In a modern society less affected by the need for physical abilities to earn a living and be useful, challenges to the power

vested in medical process have begun (Barnes and Mercer, 2003; Oliver and Barnes, 1998).

Some of the stories in this study constructed learning disability in direct relation to a socially accepted norm. The very language used to describe 'normality' sends shielded messages that something is wrong with people with learning disabilities. Rooted in the recent histories of psychology and (even earlier) in the origins of western medicine, people with learning disabilities have been assessed and classified in an attempt to represent them as less than normal according to Parmeter (2001). Such classifications have taken the form of functional measurements based upon tasks, everyday functions and the ability to perform these under test. The resulting assessments have proved useful to the medical and policy makers in deciding which people have a learning disability and whom should receive or nor receive a specialised service (Gillman, 2005).

The IQ (Intelligence Quotient) has shaped the medicalised discourse that constructs people with learning disabilities both past and present by enabling differentiations to be made between those of the statistically average IQ or normal (above 70), and those below that range and abnormal (below 70). The standard distribution of intelligence was also supported and reinforced in the discourses of medical professionals and was reported upon by the discredited studies of Cyril Burt (1958) (looking at the inheritance of ability using identical twins as control tests). The concept of norm implies that the majority of the population are and should be part of a norm, which strongly suggests that the majority fall under the arch of the standard bell-shaped curve. This curve is the graph illustrating deviations in any populations in comparison

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to a statistical average and any bell curve will have extremities at either end of the scale (Davis, 1997). Such deviations have served to inform medical discourses that disability and impairment fall outside of the norm (at the bottom end of the curve) and are therefore deviant.

Dualities

According to Bauman (1989), social problems are constructed around ideas of dualities (e.g. health/ill health, us/them, security/risk, able/disable). These dualities provide a platform on which to categorise ourselves alongside others. In general people with learning disabilities are constructed by the medical discourse as either receivers, or potential receivers, of treatment..

The medical discourse constructs people with learning disabilities using language which describes the sick, ill and needing treatment, by referring to 'patients' or 'clients' and their ability to function as 'independent versus dependent' or 'danger to others versus vulnerable'(Campbell and Oliver, 1996; Chappell, 1992). People with learning disabilities are seen within the discourse as in need of specialist care prescribed by a trained professional and therefore not capable of functioning without this support or until they have undergone rehabilitation or training. Terms such as training programmes, care plans and drug treatments commonly describe systematic regimes which people with learning disabilities had to undergo in order to leave the hospital and to live in less segregated locales (Campbell and Oliver, 1996).

Sick to be cared for or cured, or client with rights?

It has been argued that the power inequalities between patient and therapist/ doctor/ nurse favour the professional over the person with a learning disability who is likened to a child or a two dimensional character without the rights of an adult to determine his/her destiny. As Davis (2005) comments,

> Becoming disabled brings us into odd relationships with people. One that most of us are familiar with is the doctor- patient relationship. When we are in it, we play the role, the sick role. We're expected to play it whether we're sick or not. Most of us know that it's in our best interests to play it we've never been taught the lines, but we soon catch on to what we're supposed to say. (Davis, 2005. p 203)

Many groups such as those with learning disabilities do not fit the model of 'sick-to-be-cured' and are constructed by professionals as clients in receipt of services in much the same mode as a paying customer. Originating in the consumer culture introduced to health and social authorities by the conservative governments of the 1990's (DOH, 1991) and hence the docile body of the past was replaced with a consuming body (Hughes, 2002). In this construction, the professional offers the services and the client is expected to take up the service and a degree of customer rights are then entitled (as in any other consumer relationship). As a paying customer and member of society one has consumer rights, the right to refuse or return and the right for refund. As clients of a service such rights are difficult to promote. Davis (2005) continues to criticise the discursive relationships between those in receipt of services (clients) and those giving and controlling (professionals) the care by commenting upon the apparent imbalances of rights, responsibilities and accountabilities.

Central to the many debates professionals have between themselves is the need for medical model led care for people with learning disabilities, which seeks to cure, remedy or alleviate the problems encountered by having a learning disability. These

debates and other forms of medical scientific knowledge have affected the ways in which both professionals discuss people with learning disabilities and also the way others are persuaded to act towards those with a learning disability in general society (Edgerton, 1967; Oliver, 1990). Examples of medical advances which have led to initiatives in new knowledge and skills can influence attitudes and decision making about the quality of life of a disabled person in many ways. A useful example of corrective surgery developments to change the facial characteristics of children with Down syndrome raises the arguments of medicine's ability to normalise appearances without clinical purpose (Aylott, 1999). These debates increase the likelihood that learning disability is constructed as a medical problem that can be managed or alleviated or cured.

Separate oppressions

Often the medicalised discourse constructs adults with learning disabilities as yielding to a misleading set of single and separate oppressions which enhance the person's experience of being disabled.

> Disability- the restriction imposed on top of our impairments by the way our society is organised- is a form of social oppression to which all disabled people are subject. The disabled population is not however a homogeneous one. It consists of people with a wide variety of impairments and is undercut by a number of forms of structural disadvantage (Sheldon, 2005. p.69).

Oppressions often quoted are '*they are a problem because they are black'*, 'they have *woman's problems'* and it's all '*a problem because they are disabled'* (Barnes and Mercer, 2003; Begum, 1992). Often it is argued that the circumstances are complex and related to the person's simultaneous experiences of life with others and it is the medicalised discourse which constructs them as a series of problems in order to categorise and simplify the issues they experience.

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The housing offered to people with learning disabilities in the past was termed a hospital, not a hotel, or hostel thus confirming many of the medicalised constructions of learning disability. Alternatively, In more recent times people with learning disabilities live in 'homes' or are tenants of a housing association or care services The areas lived in by people with learning disabilities within the hospital become wards and units and not termed homes, flats or residences. The constructions based on the past reduced people with learning disabilities to a homogenous status shared by others with learning disabilities (and not as individual homeowners or tenants). Many similar patterns of care have been seen in the past throughout the United Kingdom and abroad (Goodley, 2000).

Summary

This section has outlined the functions and form of the medicalising discourse which influences the ways in which people with learning disabilities are viewed and discussed by others. In turn the services and philosophies of care offered by society are informed by this powerful discourse. The next section continues to explore the professionalising discourse and its additional effects upon the professional language.

The professionalising discourse

Professionals occupy influential positions in our society. Their knowledge and skills are valued and often go unquestioned. This next section offers an analysis of the power and the influence of the professionalising discourse in learning disability care.

<u>Origins of the discourse</u>

Influenced by the language of medicine, and a history rooted in the affects of professional and expert power (Foucault, 1972), the professional discourse of learning disability in this study uses a language of expert opinion based upon power. Abberley (2005) comments upon professionals as agents of the state welfare institution, as acting within a top down system which makes them behave and act in a particular way towards those that are objects of their actions. Social processes and politics have developed the ways in which learning disability professionals have become agents of power, through their involvement in the practices of the state (as employees) and citizens of a society which devalues difference and stigmatises people with learning disabilities (Oliver and Barnes, 1998).

It is commented that learning disability constructions (often medically denominated) directly affect the workforce in learning disability care settings via the language and power bases of the organisation or agency, and that this is acted out by professionals seeking their identity and status within it (Chappell, 1992). In learning disability services, changing public agendas have led to an emphasis in care priorities often channelled as economic cuts or measures.

<u>Theorising the professional</u>

The word professional is synonymous with decision making, intervention and power (Finkelstein, 2005). Traditionally, society constructs a client/patient as the object and subject of treatment by a professional and this construction typifies a relationship in which the professional is the expert and the patient is in-expert or novice (Gillman, 2005).

The relationship between client and professional has been commented upon by disabled people and critical observers and it is charged with reinforcing the marginalised positions patients are forced into by professionals (Finkelstein, 2005). One of the criticism is that professional status is sought after and offers high rewards and the sanction to exert control and influence across a variety of social and political settings (Gergen, 2001).The professional relationship prevalent within learning disability health care is that of client and nurse, with the learning disability nurses forming a large proportion (Mitchell, 2002).

The General versus learning disability nursing discourse

The learning disability nurse discourse has evolved differently to the general nursing discourse in a number of ways. The profession of nursing progressed from its roots in the early part of the twentieth century and culminated in the creation of the National Health Service after the Second World War (Mitchell, 2000b). The various types of nursing (mental health, adult child and learning disability) share a common discourse influenced by the medicalised need to categorise, label and control (Mitchell, 2000a). Mitchell (2000b) also comments that the workforce of general nursing was traditionally made up of white middle class woman following an ideology of curing the sick. He further comments that, alternatively, the learning disability workforce has drawn upon a significant population of working class men and women from socialist and union backgrounds who were not working to cure people with learning disabilities, but to provide a better quality of social and health conditions in which they could live. It appears that this ethic struggles to fit in with the larger and more powerful position occupied by general/adult nurses and many in the general nurses

population have some difficulty understanding the role of the learning disability nurse.

Status of the nurse

The professionalising discourse is evident in the way nurses, educated and trained to work with people with learning disabilities, preserve their professional identity. Learning disability. nurses are educated in the theories of humanistic psychology, and sociology among others, and are highly trained in the skills of assessment, and evaluation of human behaviour which is viewed outside of the norm. Learning disability nursing has a history rooted in the institutionalised care of people with learning disabilities influenced by harsh and often cruel care regimes (Ryan and Thomas, 1995). The learning disability nurse profession has fought hard to rid its reputation of these legacies and to establish an improved credibility and higher status amongst other health care groups (Mitchell, 2003).

Abberley (2005) suggests that the behaviours of many health care professionals are affected by their employing service's requirement to provide evidence of successes. For the learning disability nurse evidence of success (or reaffirming of status) is through demonstrating their role in enabling people with learning disabilities to become camouflaged and blend into a society which finds them distasteful or unpleasant (Race 2002). For many learning disability nurses, philosophies of 'ordinary living' originating in the values and goals of normalisation govern the way they design and implement the care they deliver to clients. As such, learning disability nurses are often caught between the priorities of the medicalised discourse which encourages the promotion of good health and curative practices and the more

humanistic drives of promoting self actualisation through opportunity and social engagement (Race, 2002). The professionalizing discourse ascribes the lead role, in implementing so called 'normalisation principles' professed to enable people with learning disabilities to live like others in general society, to those in powerful positions such as nurses (Gilbert, 2005b).

Although influenced by national and global changes in the way disability is discussed, the professionalising discourse of learning disability nursing constructs people with learning disabilities as different from themselves and requiring their specialised help. The learning disability nurse as the expert with specialist knowledge and skills is ascribed the role of decision maker and is expected to fulfil that role by deciding upon courses of action that will enable a person with a learning disability to live a life of quality and without hardship or suffering. This requirement is often deemed to be life long with many nurses working with individuals over long periods without exit plans (Malin et al, 2000).

Unlike other health care professionals learning disability nurses often work to goals not immediately recognisable as traditional health care (for example to assist a person to cope with social situations, which they find stressful and unfamiliar). The professional learning disability nurse will be expected to support and to control people who behave outside of the norms of society. In this example the nurse, although the expert, has little control over the outcome and can only measure their professional successes in terms of the avoidance of difficult situations or public complaints about the person with a learning disability. As a result many learning disability professionals continue to work with people with learning disabilities in areas such as re-housing,

behaviour management and social skills training, that other professionals groups overlook or do not recognise as health care (Gilbert, 2005b).

Language and Terminology

The professionalising discourse generally is not inclusive to those affected by societal discrimination in the language and resorts to complicated terminology requiring a detailed knowledge of the theory (Chappell, 1992; Goodley, 2000). Commonly people with learning disabilities are constructed as unequal and without fully shaped adult form. Informally, first names replace formal reference to any title or status (in an uncommonly informal/unconventional way), and are often childlike e.g. 'Jimmy' not 'James' or 'Mr Smith' or 'boy' not 'man' or 'gentlemen' (Ryan and Thomas, 1995)

The descriptions of a person's impairments are often linked to a generalised use of medicalising acronyms such as 'CP' to mean 'cerebral palsy' or 'Srv' to indicate 'social role valorisation' (a form of normalisation theory), and 'PCP' to mean 'person centred planning' (an inclusive process designed to develop devalued lifestyles). These codes act as indicators of professional affiliation and are used between professional groups at times when communication sharing is a necessary requirement in, for example, case review meetings (Marks, 1993). It is also suggested by Marks that although the professional discourse is informed by the discourses of reflection, emancipation and human rights the privileged position of the professional expert (white, middle class etc) underscores much of the language use. Nursing appears to construct people with learning disabilities in familiar sophisticated professional terms when it is clear the person they describe is in receipt of learning disability services (Davis, 2005). There is less ease with using professional terms when the status of the

individual is undetermined and or when the diagnosis of learning disability is uncertain.

Identities in learning disability nursing

It appears that the professionalising discourse also has a powerful impact upon the ways in which learning disability nurses see their own individual and collective identities. Within the wider professional health care discussions, the learning disability nurse often sits to one side aware that the experiences they share with each other are not shared by other nurses and health care workers. Mitchell (2000a) highlights the stigmatisation of learning disability nursing by other health care professions and links this with the parallel stigma experienced by people with learning disabilities. He likens the marginalisation of people with learning disabilities in society and the stigmas they face from being misunderstood, to the similar devaluation of learning disability nurses amongst the larger population of medicalised professionals groups.

> The manner in which a person is devalued will affect the way in which that person behaves. In short, people live up to the expectations placed upon them. In this context, learning disability nurses have been devalued by the centre of nursing because of their work with deviant groups and because of their inability to fit in with Nursing's central work, (Mitchell, 2000a. p. 81)

Learning disability nurses attempting to share professional discourses with other more medicalised professions can be misunderstood and as a result may often feel unvalued and lacking in self worth leading to a negative identity and a de-motivated professional (Mitchell, 2002a).

As suggested earlier, the learning disability nursing profession has inherited the legacies of societies past neglect and dehumanisation of people with learning disabilities. Many nurses practising today in positions of professional influence and working alongside people with learning disabilities have witnessed similar institutional care practices to those which shocked the nation in the 1970's and 1980's. The present disability discourses have been developed and influenced by those on the receiving end of harsh services (themselves disabled) handed out by agents of state provision which was sanctioned by a lack of public opinion (Barnes, 2005a). Disability activists and academics have proved the strongest influence in the introduction of disability studies and the disability debate or 'turn to impairment' into the mainstream.

Some argue however that the disability debate has missed out the areas particular to people with learning disabilities resulting in a narrow view of impairment residing in the sociology of the body originating in physical disability (Goodley, 2001). The present disability discourse often fails to acknowledge the many efforts of learning disability workers and nurses to promote liberating health care practices for people with learning disabilities (Mitchell, 2000a) preferring to construct learning disability workers as contributors to oppressive state sanctioned regimes which inhibit the liberation of people with learning disabilities.

A shameful past

The identity of those entering learning disability nursing is influenced by the wider professionalising discourses, with many candidates wanting to acquire the power and status nurse professionalism is ascribed by general society. The terms 'qualified' and

'nurse' carry the elements of status and social position to which groups aspiring to professionalism look to (Dingwall et al, 1988). The medicalising discourse so heavily influential in nursing of the sick has a tendency to alienate as not qualified (and devalue) those who do not appear to have the same technical skills to care and cure. As a result both the medicalising discourses and the professionalising discourses operating in the nursing fields have not accepted that the skills of learning disability nurses equate with their own highly technically and medically influenced qualities (Alaszewski et al, 2001; Mitchell, 2000a; 2002).

It is argued that the training and education given to health workers develop individuals in various ways and embrace the professional identity of separate professions (Benner, 1984). The professionalising discourse promotes the idea that the ability to perform as an expert nurse is grounded in the context that the nurse is experienced in (Hargreaves and Lane, 2001). Learning disability nurse education curricula have developed in the last 30 or so years to embrace a holistic view of learning disability often considered unique to the health care profession (Coyle and Northway, 1999; Northway and Jenkins, 2003). This view of a health professional is not commonly held in general society, where the medicalising discourse sees nurses performing recognisable nursing tasks wearing uniforms and working in hospitals (Salvage, 1985).

The learning disability nursing professions has changed dramatically in the last 30 years since de-institutionalisation and has become more visible to general society as people have moved out of hidden hospitals into every day streets and houses. Many of the changes in the learning disability professions have resulted from changes in public

wide opinions originating in the outrage of some political exposure or scandal, and some have been led by theory driven changes such as the ethnographic revelations of Goffman's 'total institutions' or Wolfensberger's 'normalisation principles'. However, the reminders of past care for people with learning disabilities are still around in the literature, and many more people with learning disabilities have now recently narrated their experiences to confirm this (Brigham, et al, 2000).

The wider professional discourses of guilt and shame in the learning disability profession constructs people with learning disability as passive recipients of care (French and Swain, 2001). Nurses working today often recall their experiences using language of the time gone by, calling people 'patients' 'high grades'' low grades' and 'residents'. These terms are typically excused as 'what we used then' but are dismissed as un-useful by today's modern professionals (Orme, 2003).

Fearful of appearing active contributors to the regimes of power and institutional control learning disability nurses access the discourses of denial (of any real involvement) and projection (other people were in control) in an attempt to distance themselves from the events described (Mitchell, 2000a). Stories which draw upon this discourse may typically accuse 'others' or 'them' in power as the reasons for the continued situation. The meaning individuals attach to an event (biographic) can often be affected by the wider (demographic) picture painted by the history (Hollway and Jefferson, 2002), and this may be the case in learning disability nursing. Therefore to some extent the shameful history of learning disability care, although a product of many socio-political factors becomes the history of learning disability nursing on

which current learning disability nurses base their constructions of learning disability (Mitchell and Snyder, 2001).

Summary

This section has uncovered some of the influences upon the professionalising discourse of learning disability nurses from both the past (history of learning disability nursing) and also current policy and health care practice. The next section will extend the discussion to explore the political domains of the learning disability discourse which tends to problematise learning disability care.

The Political discourse

The learning disability discourse has entered the political agenda on many levels. Changing emphasis upon social and health care for people with learning disabilities has led to a changed language, 'patients' and 'inmates' have become 'clients' and 'service users'. This section discusses the changing impact of the political discourse upon the construction of learning disability .

Origins of the political in learning disability

Although not always an obvious problem the housing, care and human rights of people with learning disabilities has never taken the political centre stage. The major political arguments have been forged upon deinstitutionalised versus community provision. Malin et al (2000) argues that the relationship between the policy and the ideology of community care for people deemed in need has remained vague since the NHS Act 1946. Over the decades social changes such as employment patterns, national and world economic family demography, and improved communications and

media amongst others have influenced the political discourse surrounding health and social care provision for people with learning disabilities. Public interest in the world of learning disability has been often prompted by public exposure to sensational details about harsh living conditions or the extra-ordinary feats of individuals with learning disabilities to battle with their lives based upon tragedy and adversity (Malin et al, 2000; Race, 1995). The general literature considers that the political discourse of health care and residential provision and of personal citizenship has impacted strongly upon the ways learning disability workers deliver services to people with learning disabilities.

The legacy of ideal living

The political discourse affecting learning disability provision reached a new height in the 1980's with the advent of normalisation which introduced terminology based on an ideology of radical change at both a personal and social level for learning disability workers (Brown and Smith, 1992). The movement originating in North America became a set of standards on which learning disability services could be measured to ensure that people with learning disabilities achieved a valued status within their local communities (Tyne, 1994)

Although the interest from senior policy makers in normalisation was brief, for many the positive result of the uptake of the principles was that large institutions closed and many people with learning disabilities were re-housed in local community settings (Malin et al, 2000). The wider picture of social and economic crisis in the Britain during early the 1970's drove political decisions aimed at reducing the financial burden imposed by large institutions (Malin et al, 2000). The political forces became

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increasingly occupied in justifying and quantifying the need for health services resulting in never seen before evaluations and assessments (Malin et al, 2000). The changes also introduced a set of discursive practices used by learning disability workers to evaluate and to measure the appropriateness of service provision against the values ascribed by normalisation.

Additionally in the 1980's an awareness of the power of language and discourse drew attention to the meaning attributed to the stigmatising labels and terminology of professionals in practice (Goffman, 1961; Ryan and Thomas, 1995). The discourse emanating from normalisation introduced terms such as 'community participation' and 'community presence' 'community integration' used to construct set ideal ways of living for people with learning disabilities (O'Brien and Lyle, 1987). In my experience as an learning disability nurse, those not in favour of these technologies and using other more original terms were often named and shamed as renegades or 'old fashioned' and 'institutionalised' (Chappell, 1992).

Changing agendas in learning disability

In the intervening years since the large scale UK de-institutionalised programs of the 1980's and 1990's the political discourse affecting learning disability provisions has slowly lost its own priorities and has embraced the priorities of the general social and health care agenda of subsequent governments (Bates and Davis, 2004). State provision of services for people as 'patients' of a health service has been replaced by 'clients' of a variety of service providers (Priestley, 2005). Rooted in the change are the values and attitudes subscribed to by the general public and as sanctioned by normalisation/political discourse. This has led to the construction of people (in

particular people with learning disabilities and mental illness) as potential advocates for themselves and as consumers of services.

The health professional dominance in decision making has been replaced by partnerships and alliances which include service user and service provider representation (Malin et al, 2000). The political discourse in learning disability has been slow to develop a place for people with learning disabilities to voice their own position. The professional or carer's influence has changed to include those paid and unpaid or 'care-workers' 'professionals' and 'volunteers' and 'advocates'. Ideologically, O'Brien (1994) predicted that the advocate would be a powerful ally to the promotion of more inclusive services which adhered to the arising political priorities of citizenship and personal responsibility. However, in learning disability the political discourse still tends to construct people with learning disabilities without a voice, advocated or otherwise, amidst a landscape of self advocacy and human rights for others in society (Simons, 1992). Advocacy for people with learning disabilities began as an independently funded exercise (from various sources both private and charity) with a constitutional commitment to ensuring that people with learning disabilities were independently represented. However, as result of 'Best value' exercises aimed at quality evaluation advocacy is now funded by statutory monies bodies and has lost much of its earlier independent power (Beresford, 2005).

The discourse in learning disability services however still struggles to include and not to exclude those to whom it provides services. Instead it often resorts to what Tyne (1994) described as a compromise in which normalisation, citizenship and the voices of the disability movement all challenge as the three priorities in service ideology.

Politically correct language and approaches encompassing any of the three priorities have often resulted in an imposition of inappropriate services. One example could be given of a learning disability service incorporation of a normalisation principle to live a valued lifestyle like other residents in the neighbourhood, which then leads to lack of personal liberty because support staff shortages will not allow individual visits to the local community pub. On one hand, the political discourse encourages freedoms to use local facilities (arising from the pressure to include all society members), but on the other hand it limits liberties, because the service constructs people with learning disabilities to be highly visible, stigmatised (informed by normalisation), and in need of protection (in the form of a paid person drawn from a scarce resource) from the public gaze (Chappell, 1992; Walmsley, 1994, 1997). As this example demonstrates, changing priorities (service ideology, finance and political pressures) influence the constructions of people with learning disabilities. The stories which draw upon the political discourse are often ascribing to one or other of the three priorities when constructing the person with learning disabilities. On occasions (as will shown in the next chapter) in the educational encounter of the classroom the teachers in this study appear challenged by these priorities and they appear as changeable within the one story which reflects the level of complexity on which the constructions of learning disability reside.

Summary

In this section I have attempted to outline the subtle effects the changing political agendas have upon the ways in which learning disability is discussed and the language used. In particular I have outlined the legacy of normalisation and ordinary living principles and their impact upon the direction of the learning disability discourse. The

next section extends this discussion into the arena of human rights and the inclusion versus exclusion discourse which is intended to affect all citizens.

The exclusion/inclusion discourse

A culture of a society consists of the values and beliefs based upon the norms of the tradition that society holds dear and that to become a member of the society one must learn or be socialised into the cultural rules and assumptions. (Giddens, 1989). The relationship between culture and society has attracted much debate from such as Weber, Marx and Durkheim. The study of a society's views and behaviours towards its fellow citizens can be underpinned by an analysis of the political ideologies and resulting social policies which lead to the ways in which some oppressed people and their situations are viewed. This following section concludes the four discourses and outlines some of the more generalised cultural assumptions expressed in everyday discourses about everyday living.

Origins of 'community' in Community Care for people with learning disabilities.

The exclusion/inclusion discourse in this study draws upon the language of those considered by general society to be part or not part of the community of likeminded and similarly equipped members of society, or in other words 'in the community'. The term 'living in the community' has become a recognised term for an ideal life unlike the life experienced in a care institution. It is assumed that all citizens given the choice will want to live in an inclusive community (Nirje,1985).

However the social rules governing membership of communities can give rise to practices which exclude. As members and initiated in the rules and acceptable patterns

of behaviour those on the inside of the community are wary and or are even ignorant of anyone who is non compliant to their rules and patterns. This leads to exclusion (Social Exclusion Unit, 1998).

The exclusion/inclusion discourse in this study constructs learning disability as in danger of remaining outside the inclusion zone and on the margins of the inclusive community which embraces and accommodates its members. The dualities of inclusion and exclusion can be problematic. The questions I posed in examining this discourse are; is it possible to have inclusion without first being excluded? And do we mean inclusion is the absence of exclusion? As a result, I treated the debate simply as linked to inclusion/exclusion. The discussion already alluded to concerns the construction of people with learning disabilities from a variety of settings some living as members of society experiencing some degree of marginalisation and lack of services, and others living outside society with an array of services but absent from social life.

The move to the 'community' for people with learning disabilities is used both as a euphemism for a physical move from an institution to a setting more acceptable by others in society. Moving to the community is also a social shift for those who already live in the vicinity who are forced to accept or not the proximity of someone who looks or acts different but lives next door. (Malin et al 2000; Wolfensberger, 1972)

Bates and Davis (2004) comment upon 'social capital' as elements of a society which are considered to be beneficial to society as a whole and worthy of investment. The term is often used with social inclusion as a way to illustrate and to encourage a

political discourse of change and improvement in the way society treats excluded groups (Bates and Davis, 2004). People with learning disabilities have a history of exclusion because of they are constructed as unable to contribute to the economic development of society (Finkelstein, 1980). As a result people with learning disabilities are constructed as outsiders, uninitiated and vulnerable becoming victims of injustices inflicted by an unjust society.

Recently the government White paper 'Valuing People' (DoH, 2001) introduced strategies to modernise the ways in which people with learning disabilities are provided for by public services. This most recent drive is the culmination of many years of debate and struggle by learning disability champions such as Wolf Wolfensberger (1972) John O'Brien and Connie Lyle (1987), and the other advocates for social improvements for people with learning disabilities. The exclusion/inclusion discourse emanates from these and the struggles of other marginalised groups to enter the mainstream political consciousness (Bates and Davis, 2004).

Changing meaning of inclusion

It is already argued that the force aiming to achieve full integration for people with learning disabilities thus eliminating the need for exclusive practices such as specialist nurses, hospitals and services was normalisation. However, the relationship between normalisation and human rights and citizenship is complex and has changed over time (Chappell, 1992). Originally, inclusion into the community was a social policy of eliminating the exclusion of people with learning disabilities resulting in the mass movement of people with learning disabilities from hospitals to smaller community places. It was easy to see the successes and failures (Malin et al, 2000). The discourse

which developed heralded the benefits of inclusive community living over excluded hospital life. This ideal world was promoted as a setting in which better quality of life for people with learning disabilities would follow their surveillance and ultimately their subordination (McIntosh, 2002)

More recently issues which concern more general society have entered the discourse of inclusion/exclusion including the race equality, education and citizenship. The values on which society base judgements about inclusion/exclusion are considered in mainstream politics and have informed the general debates about access to public buildings, education and health and social services for all people.

Language of the community

The language use by those using learning disability services and those providing learning disability services differs and is an indication of the differing discourses. Those using learning disability services may construct themselves as like everyone else using a service with the same rights and rules of entry. Alternatively service providers often see people with learning disabilities using their services as somehow homogenic with a special set of needs only catered for by special skills and provisions (Beresford, 2005). As a result those in the general public who are neither learning disability service providers nor learning disability service users remain outside the discourse unaware of some terminology or its application. Constructs drawing upon the inclusive/exclusive discourse use both professionally exclusive and everyday language in an attempt to enable the listener to link the many complexities of the learning disability picture to everyday experience.

Stereotypical images

How society views people differently can be analysed from a variety of angles. One way is by looking at ways that myths, folk lore and representations influence how learning disability is viewed and constructed by those doing the caring (and have a relationship) and by also those who do not (general public). There is a recognised view that imagery in popular genres such as film, literature and media influences the construction of disability (Bogdan and Biklen, 1977; Hevey, 1992; Wates, 2005; Zola, 1991). Historically, non disabled people have represented disabled people in ways that have reinforced the social and cultural divisions between them. People with learning disabilities are often constructed by everyday discursive language in varying degrees of being either; frightening or frightened, over sexed or non-sexual, holy-innocent or subversive, and humorous or tragic (Campbell and Oliver, 1996; Corker, 1996; Linton, 1998). To this extent people with learning disabilities always appear abnormal to the degree of the stereotype.

Professionals working with people with learning disabilities are identified with a particular insider knowledge and power which can refute or affirm these stereotypes (Gillman, 2005). learning disability nurses feel they are uniquely positioned to work with people with learning disabilities and construct themselves as experts in the social and health care fields (Mathews, 2006), Stories which draw upon this inclusive/exclusive discourse present people with learning disabilities as understandably misunderstood people. The discourse reinforces the idea that learning disability remains outside of the public's direct consciousness because only specialised education and training can equip suitable workers who understand the intricacies of learning disability work.

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Summary

This section has identified that the general discourse which influences the rights of society members to live valued lives is not extended to all people with learning disabilities. I have highlighted how the origins of 'community' in community care for people with learning disabilities and stereotypical images together with the language of the community have influenced the discourse. This section has also highlighted the changing meaning of inclusion/ exclusion over time and identified the possible impact upon learning disability and corresponding discourses.

Conclusion

This chapter has highlighted the four main discourses identified as important to the construction of learning disability in the stories analysed in this study. The interpretation which now follows will elaborate further upon the ideas presented above and will be developed as and when they arise in the analysis of each story. The uncovering of the discourses and their influences upon the learning disability constructions will now continue in chapters four and five. The construction of learning disability is complex and is influenced by a number of forces acted upon in various ways by the learning disability teachers in this study. I considered it important to unpick these intricacies with care and to pay attention to the possibilities of this study for further development in learning disability nurse education. With this in mind, the next two chapters interpret the stories and present a useful analysis of the affects of the discourses upon the learning disability constructs.

Chapter 4

You are such a problem!

Learning disability as a case which should be managed

Overview

The previous chapter provided the overview of the four main discourses analysed in this study. As discussed in chapter 3, the aim of my study were, *To investigate the social construction of learning disability by teachers in the stories they tell to their students within teaching narratives*. This next chapter aims to present an interpretation of how the construct *a case to be managed* appears in the stories and what I will identify as the discursive modes that the teachers utilised in telling the stories to students. It also was the intention to in part meet one of my research objectives *To identify any links between the teachers' learning disability constructions and the learning disability discourse*.

This chapter and the subsequent chapter will now discuss my interpretations of the way in which the construct *'cases to be managed'* appeared across the stories told by individual teachers. I noted how dominant discourses locate the context, the language, and arising narratives in which the stories are told in the teaching sessions involving both teachers and students. The analysis revealed some common assumptions expressed in the stories, reinforced by field notes, observations and interviews with teachers.

The follow sections explain how the learning disability story was constructed intricately in language and imagery. The initial focus will be upon the stories which appear to be problematising learning disability by accentuating the dominant discourses of health and social care in recent years. This provides a forum to discuss the themes of learning disability as problems to be sorted out or alleviated which emerged strongly in the initial coding and investigation conducted across the stories collected. Secondly, the three discursive modes of learning disability construction will be demonstrated which can be located to different degrees in the teacher stories. The location of these modes formed a major part of the analysis and interpretations that follow each story in this chapter and the subsequent chapter. The modes (highlighted as one two or three) are presented together with a background and context to the story assisted by literature and other field notes interview data and observations which provide an interpretation of the social construction of learning disability .

Introduction

This chapter examines my interpretations of the construction of learning disability as *cases to be managed* in stories told by Sheila, Kit, Mike, Jacky and Charles. It deals with relevant stories told by each teacher. The aim was to explore the social constructions of people with learning disabilities using the particular language and discursive practices of the identified discourses. The extracts used are from interviews with the teachers, teaching narrative transcripts, observation notes and particular stories extracted from the teaching narrative transcripts which appeared as a whole or in-part. It was also useful to consider how the various discourses have affected the constructions and relate these to the context of the stories within the teaching narratives and details provided by teachers in interviews. By drawing upon the various

ways of viewing the constructions I formed an interpretation of learning disability construction in the classroom. The next section will begin the quest to reveal the nature of the construct *case to be managed* which formed the most dominant learning disability construct across the learning disability stories.

Learning disability as a case

This construct appeared commonly in the stories in this study. Given that the teachers were all qualified nurses trained some time ago to work with people facing problematic lives it is unsurprising that learning disability is often constructed in this way. However, interestingly the construct of learning disability can reveal some of the variations in the ways stories told in the classroom are used to a lesser or greater extent to refute or to strengthen the discourses most strongly identified with learning disability care.

Learning disability as a subject:

The medicalising discourse draws upon language which constructs the subjects of action or treatment as different and 'other' to themselves or normal/well people (Oliver, 1990). This pathologising enables professionals to distance themselves and to withdraw from the people with learning disabilities they worked with. The stories in this study often began with an introduction to learning disability as a case not a person.

> **Charles**: … I actually nursed someone… (Charles, story 3)
> **Jacky**: …I actually worked with an individual… (Jacky, story 1)
> **Jacky**: …I did used to work with somebody… (Jacky, story 5)
> **Kit:** …I remember a young lady who I worked with… (Kit, story 3)

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Jacky:… An' when I were at (*an learning disability   Unit)* we had a young gentleman …(Jacky, story 2)

The interpretation suggested that this signifies the construction of learning disability as case to be managed and enables the teacher to draw upon the relevant discourses when they are telling a story about learning disability as an object.

Ill and in need

People with learning disabilities are commonly described using language attributed to a specific classification or diagnosis (Gillman et al, 2000). One typology often drawn upon, is that of a set of inherited conditions causing the person to act in an anti social or unsafe way and different from others in general, thus requiring the support of willing or paid helpers. The medicalising discourse constructs such individuals in terms of a mission or project to be returned to normal or cured of sickness (Davis, 2005). This story by Charles begins to illustrate a constructed view of learning disability which is a project needing a manager.

> **Charles**: an', I actually nursed somebody … ehhm … in (*LD unit)* who had Klinfelters disease an' they did have a lot of mental health issues. Certainly … if you met them you wouldn't think that they had a learning disability, so it was really mild in … his case. You know? … but , the breast development an' the under development … of the testis caused problems for him an' his gender identity, and he was cross dressin' for a while. 'Cause he wasn't sure about what his true gender identity was.
> (Charles, story 3. complete).

Charles constructs learning disability as someone extraordinary, different and freakish. The story conveys a physical image of a man different from others and unable to cope independently in society because of his inherent problems. This man is

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an expression of the way learning disability is objectified and singled out by professional groups as a case or a problem and so assigned to the workload of a professional or team. Mike similarly constructs learning disability as an object in his story.

> **Mike**: I'm goin' back to my … ehh, my days on a … sort of … secure unit if you like? We had a … woman on there who came to us and she had every possession. When I say possession, she possessed everything. She had … tape recorders, CD players, televisions. Stuff … cuddly toys, microwaves … photographs, picture frames, chairs, tables … and a hampers. Ehhm, she even had an air rifle. She had bikes, different … couple of bikes. And that … an' an, … she basically brought everything with her. And at first, we had to store all this stuff in a storeroom somewhere else. So she were on our unit and the storeroom was elsewhere. And this storeroom was like … just jam-packed. Top to bottom, full of her … belongings. Right? An' … we set up a programme for her, so that … you know? once a day she could go and check on these belongings. Because … what she thought was that people … were stealing her stuff all the time. Right? So … once a day we would take her. And the idea were, an' … we basically, the whole day was spent battling with her, over what time we were going to get these things. Who would go with … who'd taken her stuff? D'you know what I mean? An' … an' it was the entire focus of her day. So basically, we ran into lots of problems. So … we did what's called a paradox Right? Now, the paradox in this case was … rather than just having this programme, for once a day, we basically brought all her possessions into the place, so that she could go into the … whenever she wanted. Yeah? See we were … the original mind thought well … "she'll be in there all the time, she'd be creating all sorts of problems". But actually, once she knew they were there, and she could go in when she wanted, this fear actually stopped. (Mike, story 3, complete)

The woman in Mike's story (3) is constructed as abnormal due to her behaviour and actions. The use of the following words to describe the nature of her stay *'…secure*

unit' and *'...battling with her'* and *'...she'd be creating all sorts of problems'* tends to suggest that this woman was not like other people. The medicalising discourse constructs those already in receipt of learning disability services as in need of specialist care and therefore views certain actions as predictable in a person with learning disabilities (Goodley, 2001). As a woman with a learning disability, she is embodied in a context which sits outside of the norm. She is visiting a service specifically for people like herself learning disabled, who are constructed as sharing common problems in every day coping or functioning. Contemporary constructions of people with learning disabilities by the medicalising discourse position the person as a paradox and links causality to learning disability (Indeed Mike goes on to say in the story that her problems were solved whilst visiting the special unit by applying a paradoxical technique). By constructing people in terms of their deficits the discourse fails to accept fully other psychological issues such as how the environmental conditions affect a person's actions and the importance of emotional attachments (Goodley, 2001).

The woman in the story is represented as possessive and childlike in her choice of possessions and her insistence on bringing all her belongings with her to the unit.

> '…When I say possession, she possessed everything. She had … tape recorders, CD players, televisions. Stuff … cuddly toys, microwaves … photographs, picture frames, chairs, tables … and a hampers. Ehhm, she even had an air rifle. She had bikes, different … couple of bikes. And that … an' an, … she basically brought everything with her…' (Mike, story 3, extract)

She is also constructed with self determination also. *'Now, the paradox in this case was ... rather than just having this programme, for once a day, we basically brought all her possessions into the place'*(Mike 3). This self determination is constructed as a

problem to be managed but the paradox is the constructed image given in the story strengthens her childlike adherence to comforts and possessions. Even though she is placed in a strange environment where it is not uncommon for adults to feel the need for comfort and support from possessions the medicalising discourse continues to construct this as abnormal and her actions as symbol of a woman with a learning disability and inability to cope. It appears that individualised views within the medicalising discourse ignores or plays little attention to the possibility that people's (those with a learning disability) behaviour can be a rational and understandable reaction to their environment (Clegg, 1993). People without a pre-diagnosed learning disability are allowed the freedoms to act out of the norm, for example, responses to extreme stresses of life may be expectedly exhibited by a non disabled person as anger and frustration, but a person with a learning disability is labelled as challenging when displayed the same (Goodley, 2001)

Many professionals working in their capacity to advise and prescribe treatment for people with learning disabilities who are constructed as 'problems' and who 'challenge services' draw upon the language of behaviourism. Terms such as *antecedents, behaviour, consequence* and *rewards* and *reinforcement* commonly reinforce the medicalised views which pathologise any person with a learning disability who reacts outside of the norm as problems to be solved using the correct process and method (Clegg, 1993). The constructions of people with learning disabilities as uneducable, unsocial and dysfunctional have been challenged in recent years by the ideologies of social role and social inclusion in normalisation. Additionally, the methods by which people with learning disabilities are moved from one stigmatised place to a less stigmatised socially integrated place is often indebted

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to the success of professional interventions. Although there is a change in the relationships between people with learning disabilities and those who assist their care some scepticism exists as to the extent to which the medicalising discourse accommodates any exchange of power between professional and client (Finkelstein and Stuart, 1996; French and Swain, 2001)

Summary

The construct 'case to be managed' appears strongly in the stories told by the teachers in this study. This section has introduced the construct assisted by the illustrations of story examples. The following section will continue to develop my analysis and interpretation of the cases and problems to be managed and will introduce the idea that the teachers are drawing upon differing modes of discourse devices to construct learning disability in this way.

Modes of discourse in a case to be managed

This section introduces the ideas originating in my interpretations that teachers are accessing learning disability construction by utilising language devices in various modes. I will begin by explaining these modes and will illustrate this with examples from the stories and other data.

Dynamics and Devices

The discursive dynamics of the stories in this study have enabled me to notice that learning disability constructions appear to be utilised in various modes by the teachers in a number of ways. In this next story, told by Sheila, the complexities of discursive modes drawn upon by the teachers to construct learning disability , unfold.

> **Sheila:**…Because I believed … when I first went up to work at (*local mental handicap hospital*), that I was gonna … be terri … ah … that … I couldn't cope with it, that I was gonna be attacked. That it was a frightenin' place to work. And … the … and … that the people that lived up there … were nothin' better than … really animals that walked upright. An' I've gotta be honest, that's how I felt. I was terrified. I don't believe that now….
> (Sheila, story 7, complete)

Sheila situates her story (7) within her wider teaching narrative about the things she witnessed as a nurse working in a hospital for people with learning disabilities. In her story (7) Sheila makes comparisons between learning disability and animals and demons.

In the mode of perpetuating the discourse her use of these terms enables her to explain how the she views people with learning disabilities as occupiers of a particular image in the minds of the non medical public. As a knowing member of the nursing community, Sheila has evidence that shows people with learning disabilities to be very much like others in society. This is in direct contrast to the images constructed by the medicalised language of the past which described people with learning disabilities as idiots, imbeciles or morons. This evidence has been acquired by Sheila over her years as a nurse but was not her first impression. She also has evidence which could assist the stereotypes that people with learning disabilities can be odd, unpredictable and animal like. This likens her convictions as a teacher to portray people with learning disabilities positively appears to drive which evidence she conveys in her constructions *'…An' I've gotta be honest, that's how I felt. I was terrified. I don't believe that now……'*. It is interesting to note the absence of any

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positive construction of learning disability in this story. This next extract from Sheila's teaching narrative aims to set the scene for the story she tells.

> **Sheila:** '…why is it interesting' for me then, the history? Is it just because it's reminiscence, as you get older you know, you can remember things in the past better than you can yesterday. You know, in the far past than the near past, or …. (*student talk*)…I think so yeah. I think that's one of the reasons. I think it does help inform … your belief systems as well.   I think … what's uncomfortable about it … is … an' there are certain practices that I've … witnessed. Or even maybe been party to that I would never tell you about, because they make me feel so uncomfortable…' (Sheila, teaching narrative, extract).

This extract from Sheila's teaching narrative demonstrates her unease with the practices of the past, but her desire to tell stories about them. Sheila is presenting students with a picture of the past shaped from what she views as her 'real' experiences of learning disability care as a nurse. In one mode Sheila is freely associating her experiences with some unease *"..what's uncomfortable about it … is…"* and therefore one can begin to question what purpose the revelation is serving? However given that this study aimed to explore the discourses used by teachers to construct learning disability is it fair to consider if she is reiterating some lesson she learnt from the experience and sees this as an educational tool? There is also a consideration that although Sheila is constructing learning disability she is also constructed as an learning disability nurse by the discourses of medicalised health care. Alternatively is she reinforcing or refuting the medicalising discourse as a device to enable students to develop a critical awareness? or is Sheila benefiting directly from the practice of telling the stories and reinforcing her image or identity? These questions raised some important challenges for this study.

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<u>Uncovering the modes</u>

The above questions gave rise to the suggestion of various modes in which the learning disability construct is operating within the teaching narrative and the stories collected. These three modes of discursive interpretation can be described as (mode One) perpetuating the discourse, (mode Two) refuting the discourse, and (mode Three) using the discourse at a personal level. These modes can be considered or traced to the three theoretical issues of; Firstly, the origins and power of discourse (Foucault, 1972) including the ways in which continuity is maintained through a adherence to the language and formations of the established discourses; Secondly, using criticality as an educational tool (Mezirow, 1990) through the ideas that learning and knowledge and thirdly, accessing the functionality of discourse and personal identity (Potter and Wetherell, 1996; Rose, 1990). These modes enable me to begin to build an analysis of the stories in the forms they are told in this research and I will be drawing upon these and other explanations in subsequent interpretations. These are particularly important to this study as they enable me to explore some of the constructive discursive practices which the teachers use to construct learning disability based in some of the dominant discourses of the learning disability story.

The three discursive modes operate differently for Charles as he tells his story about his work as an learning disability nurse and with a young woman in particular.

> **Charles**: Meningitis yeah can lead to learning disability. 'Cause that's like … again, when, … when I was workin' up in Scotland, I worked in a large institution up in Scotland. And … there was somebody on there who was a twin. And … the other … her other twin … didn't get meningitis. Obviously. So … she used to come in, an' again, I don't mean this to sound sexist in any way, but when she came in, you know sort of like … all the … all the male

staff used to make her cups of tea an' they used to sit her down an' stuff like that, that you get a picture of what she was like. But her twin, who had meningitis, had a learning disability, she was in long stay institution, I mean … it was really good to see the difference. I don't mean the word 'good' in that it was good that it had happened to her. But it was good to see the difference. She was in a long stay institution, she was on Largactol, which meant that when she went out in the sunlight it caused ehhm … brown patches on her skin an' stuff like that. Ehhm … other medication that she had also caused her to have … ehhm … facial …develop facial body hair. You know? an' to look at the two side by side, it was quite something to see. An'; in terms of the difference between somebody who has a learning disability, it … you … you know …it's … it's quite profound, an' it really affected me to see that. What could happen if somebody had a learning disability, through something like meningitis. An' the way that her life course went compared to her sister. You know? her sister had a … a job in a bank. She always came in an' she was smartly dressed. She was drivin' around, an' yet her twin sister was in … a long stay institution in Scotland, it was … it was … quite amazing really. (Charles, story 1, complete)

This story is situated within a time frame some twenty years ago and is historically specific when many (but not all) people with learning disabilities were housed in large institutions outside of social communities. The prevailing discourse of the time (which Charles struggles to justify) would have constructed people with learning disabilities as unusual and strange, needing specialist help and housing away from their locale. Charles draws upon a professionalising discourse which reaffirms (mode One) the need for the nurse working within the institutions of the time and provides a basis for his teaching narrative about the role of the learning disability nurse.

In the context of the discursive modes in this study, this construction of learning disability utilises the discourse as an in-human characteristic which can or can not be

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solved/ treated by medical intervention. This is not a new idea put forward. Charles is reiterating and confirming what he considers to be a commonly held view that people with learning disability are in-human and defective but also needy and ill treated.

In a different mode, the interpretations suggest that the constructions of learning disability in Charles' story also enable him to position himself as a nurse with sympathetic feelings towards his clients. He is able to see the bigger picture for the woman in the institution who compared to her sister without a disability is unfortunate and ill fated. By positioning oneself (as Charles does) *'...it's quite profound, an' it really affected me to see that...'* outside of the medicalised discourse it is possible to refute (mode Two) and contest its dominance. The interpretation suggests that, this device asserts Charles' on a personal discursive level (mode Three) with himself as expert with knowledge of how things were (then) and are done (now), but also as a progressive and enlightened teacher who knows how things should be done.

Summary

The modes of discursive practice in the stories have been introduced in this section. These modes form an integral part of my analysis and have assisted the interpretation and understanding of the constructions. These three modes feature strongly in my interpretation of the stories and analysis of the discourses accessed by teachers telling their stories in the classroom.

The next section considers that learning disability is not only constructed as problem or case but also an object which requires action or remedy. The modes of discursive device (One, Two and Three) will be highlighted alongside the analysis of the stories.

Learning disability as a case/problem to be managed

As an objectified case the problem or person with learning disabilities is constructed as requiring a problem solver or case manager requiring technology and skill (Gilbert, 2003). In this next section, I will outline the role of the learning disability nurse as problem solver as constructed in the stories told by teachers in this study.

This story (2) by Kit is situated in the teaching narrative which is focused upon the potential professional liabilities of learning disability nursing practice. In this story (2) Kit is drawing upon the medicalised view that people with learning disabilities can pose challenges to the personal safety of those caring for them.

> **Kit**: Certainly when .. when I trained, ehhm … the … thinkin' the … lookin' through the procedure manual, and … the within the procedure manual it said ehh … if … "If the patient becomes violent" ehhm "then you must …" ehhh "roll them in their blankets with the minimum force necessary". Now that's quite creative because it was very difficult to find a blanket. Somebody get me a blanket. Just seemed an' absolute … I think it was crazy at the time,
> (Kit. story 2, complete)

The medicalisation of health care characterised by increased bureaucracy and regulation has been a feature of learning disability provision in the UK in the last 50 or so years. This feature was first highlighted in learning disability institutions when centralised control of care was located in one hospital site (Brechin et al, 2000; Ryan and Thomas, 1995). Kit's story refers to a time when encounters involving problems with people with learning disabilities often resulted in violent episodes and were dealt with by physical restraint. Kit suggests that the policy was inappropriate not because she disagrees with physical restraint, but because of the inadequacy of resources

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'...because it was very difficult to find a blanket...' and thus she uses the story to refute (mode Two) the legitimacy of past policies used to prescribe care for people with learning disabilities. The analysis suggests that Kit constructs learning disability as a problem to be managed in an attempt to draw attention to the need to refute (mode Two) the medicalised discourse which constructs those cared for as potentially perpetrators of unacceptable behaviour and action.

Kit is teaching students about the importance of keeping up to date about the correct and legal practice of nursing. The story is used to illustrate an example of a policy which was out of date. The following extract from the teaching narrative aims to contextualise the story.

> **Kit:** particularly if … if someone's got hurt because of one practice ehhm … an' so … if … if your … practice is not in keeping with what is currently seen as being safe practice, then you could be deemed as being negligent…
> (Kit, teaching narrative).

As a problem to be managed, people with learning disabilities in this construction are a potential hazard to be guarded against by those without learning disabilities who are employed to care (Brechin et al, 2000). The story provides fuel to a commonly held view in health care bureaucracy that policies and procedures are necessary to safeguard both those employed to care and those cared for (Finkelstein, 2005). Although, she reaffirms this view in her story that a policy about restraint is reasonable and constructs people with learning disabilities as potentially violent, the interpretation suggests that she also refutes (mode Two) the medicalised discourse

which views all people with learning disabilities as all the same. She also explains this further in her interview when asked about the story.

> **Kit**: And I mean that was an example of we had a written procedure but no one operated it ....because it was inoperable, you couldn't actually use the procedure…..but therefore if you don't question procedures and have useable procedures then you can…it leaves you wide open to all sorts..
> (Kit, interview, extract)

The professionalising discourse provides Kit with the language of what Foucauldian analysts call the process of 'governmentality' (Fairclough, 1992; Gilbert at al, 2003). This is a relationship between knowledge and power and ensures that professional authority is maintained by enforcing particular standards upon the conduct of the said professionals. The professional discourse both constructs people with learning disabilities without power, but also constructs the learning disability nurse with power. The social construction of the learning disability nurse is dependant upon the construction of learning disabled people (Mitchell, 2000a)**.**

Kit accesses the professional discourse which constructs learning disability as a probable case to be managed by suitable standards of professional conduct, but in this example the standards or governmentality of the procedures were questionable. The discourse which constructs learning disability in Kit's story is used by her to refute (mode Two) the dominance of the medical model over learning disability practice. She also seeks to reaffirm (mode One) the professional discourse which positions the learning disability nurse with the necessary skills to help people overcome the problems caused by the over domination of medicalised practices.

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<u>Procedures at work</u>

In this next story told by Kit the client with a learning disability is absent and without a name. Kit constructs the person with a learning disability as an example of a typical problem to be managed through the application of a procedure. The construction sits within a professional discourse often written down in a language based upon legal protection of both parties involved.

Kit is uncomfortable with elements of the procedure she has contributed to in the past and the construction of nameless clients as quoted directly from the manual *'...If the patient becomes violent...'*. Kit chooses not to illustrate any particular example in her story and communicates this dissonance also by adding that *'...... I think it was crazy at the time...'* further adding her disapproval of what she views may have been unethical practices.

The story is told at a point in the teaching session when Kit is explaining the dilemmas of being a professional. Kit's discomfort at the part she played in some of these past activities is an her example of an attempt to provide a picture for the students. She teaches by accessing the world of learning disability care based upon her memories of what it was like for her. She struggles with these realities and with the stories she uses are as she explained in her interview *'...a way of justifying your expertise as well....saying to students. Well yer.. I've done that. I've been there...'* (Kit interview extract)

It is interesting to note that Kit indicates that she is attempting to enable students to learn from her own experiences and that these constructions are her method for

strengthening the learning process "*So If you are using a story to or if you are using a reminiscence to strengthen a point, that that actually does strengthen the point.. ..and it helps them to remember..*" (Kit, interview, extract). The construction of learning disability without name or form serves to weaken the parts played by Kit in some of the horrors of the past. She is compelled to provide evidence of this for the students and to justify her position as teacher. Kit is probably recalling anxiety provoking events of dealing with clients with learning disabilities who were violent or disturbed when she was expected to react within a tightly regulated way. By splitting the regimes for dealing with people with learning disabilities (procedure manual) from the realities of the experiences of people with learning disabilities Kit defends her position as a nurse for people with learning disabilities (Hollway and Jefferson, 2002).

In this next story (2) told by Sheila, she discusses people with learning disabilities in terms of their behaviour towards her as their nurse/carer. The complexity is evident in Sheila's (2) constructions when she is sure that the man in her charge has a learning disability but is unsure of the correct way to act towards him given the principles of social justice.

> **Sheila**:…What ehh … my … speciality is … community. When I was a community nurse in (*local town*) ..was actually I tended to have the … adult males with ehh … mental heal … mental health problems. An' a lot of them had maybe police records or criminal ehh … you, know, were involved in criminal activities. So I came across these … sort of conflicts. You know … on a … almost daily basis. But it would be interestin' to sort of maybe have a case … review. You know? Sort of … without mentionin' names I've a couple of the cases I had … an' the problems there. Because … up … up until then, I haven't really looked at this … sort of … your rights, my rights. An' if they … if … if … everybody's got the same rights … then why should the law

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be different for one section of society than the other? Because I can remember a judge when I stood up, as a representative an' … I stood up an' said "Send him down". "That my recommendation is … that you send them down". But … we normally release them into your care". "Don't want it. Not gonna sign it….' (Sheila, story 2, extract)

It is useful to interpret the construction of learning disability in this story (2) told by Sheila in terms of the stereotypes which she portrays of the adult aggressive male from whom the public needs or may need protection. This kind of image of people with learning disabilities represented as over strong, without moral control and as dangerous has proliferated the fears of the public through a strong medicalised discourse which advocates the control and pathologising of their behaviour (Oliver, 1990).

Sheila's constructions are based upon how she saw their reliance upon her skills as a nurse. In context, this construction is revisiting the influences of normalisation principles upon the ways that people with learning disabilities are managed as a series of problems either self determined (biologically intrinsic) or alternatively unknowing (ill and in need of care). These two positions construct learning disability differently and pose different dilemmas to learning disability carers. Sheila appears to be reaffirming (mode One) the former position in her story and refuting the idea (mode Two) that people with learning disabilities don't know what they are doing wrong.

Wolfensberger (1972) strongly advocated for all people with learning disabilities to lead more valued lives and be afforded the same dignity of risk as all other people in society. In doing so Wolfensberger directly condemned the practices of protecting people with learning disabilities from making mistakes and accepting the

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consequences. The professional discourse which legitimises learning disability nursing has been highly influenced by the cautionary tales of Wolfensberger and has often acted to refute the ideas that people with learning disabilities are always innocent of wrong doing or without responsibility for their actions. The interpretations suggest that Sheila is contributing to this construction and is attempting to guide the students through the complexities of learning disability nursing which tends to sit between the arguments originating in the two positions.

The demonstration of these stories has assisted by the interpretation of the construct problem to be managed. As an object learning disability can be solved or not. As individuals, a person with learning disabilities can not be elevated or cured and therefore the medicalising discourse struggles to provide a consistent and feasible answer to the learning disability problem. The stories in this study demonstrated some of these struggles and my interpretations revealed some of the strategies employed by teachers to explain their role.

Cases are Strange and different

By constructing learning disability as the other side of life unseen by many, teachers maintain an element of mystery and wonder about the world of learning disability care. The stories told revealed a world of unusual and colourful events to which the student may soon be inducted. This construct reaffirms many of the powerful and dominant discourses which act upon the unconscious and represent the ways in which learning disability is viewed.

In this story Kit draws upon the medicalising discourse which sees difference as a problem and that the remedy is to act accordingly with the professional skill acquired and used successfully by learning disability nurses. Story (3) constructs people with learning disabilities as normally inarticulate and in need of care. As an object, learning disability in this story becomes something undesirable, challenging and problematic. The lady is a problem to those around because she reacts strongly to the radio.

> **Kit**: I remember a young lady who I worked with… young lady she had a learning disability, and she had a lot of thought blocks, she could communicate verbally quite well but she would have a lot of thought blocks, and she actually blamed Tony Blackburn, because Tony Blackburn was on the radio on a morning and she used to get really frustrated, 'Tony Blackburn keeps stealing my thoughts' or words to that effect, I don't think those were the words that she used but it was on those lines we all had to turn the radio off because that used to make her more angry than the thought blocking would. (Kit, story 3, complete)

The medicalising discourse sees behaviour outside of the norm as in need of specialist help. Kit's learning disability construction draws a picture of a woman upset by two mediums, her own thoughts and those she hears on the radio. As a person with a learning disability she is not expected by those around her to understand the difference and they seek to alleviate her upset by turning off the one medium they can control, the radio *'...we all had to turn the radio off because that used to make her more angry than the thought blocking would…'*.

Kit draws upon the discursive level which though sympathetic to the woman's needs also reaffirms (mode One) the medicalised discourses which promote being different

as strange and unpredictable. Kit also recalls her past and reflects the elements of learning disability practice which she accepts may have changed. In her interview she alludes to the changes in learning disability practice she has noticed but also the similarities.

> **Su-** How do you think learning disability nursing has changed over that period of time? For the better for the worse?
>
> **Kit-** Gosh am I to answer that in a sentence? Ha Ha. Gosh I don't think there is any.. well there must be some certain similarities in learning disability nursing? I think the main for me the biggest change has been… that learning disability nurses now have a more defined identity than they have when I trained and I that I think that they have a very clear philosophy.. and they are very clearly grounded in learning disability studies..…and I think also learning disability practice is much more clearly defined even though it is quite broad..…and I think that's the biggest change. But there are probably more differences than similarities to be honest...I think the motives perhaps of people who work with people with learning disabilities is still the same.. ..but I think the actual practice and the philosophy bases are very different. very different. (Kit, interview extract)

Kit also draws upon a personal level of discourse (mode Three). Her identity as a learning disability nurse is not challenged by the passage of time although things have changed '...*that learning disability nurses now have a more defined identity than they have when I trained…*' Kit constructs her learning disability story as a reflection that her knowledge and skills are still relevant even though as she suggests herself '...*there are probably more differences than similarities to be honest…*' philosophies have changed since she was a nurse in practice.

The assumptions that people with learning disability need specialist care are widely communicated by the discourses which promote powerful and dependant creating relationships between professionals and their clients (Foucault, 1972). The existence of powerful imagery reinforces the social constructions of people with learning disability as an oppressed and socially marginalised group. This victim status affords them a debt from society and they will need care (Wolfensberger, 1998, 2000). Compared to others in society people with learning disabilities are ill fated. Fate has affected the start in life of many people with learning disabilities. It is easy to compare the lives of people with learning disabilities with our own more fortunate lives. Society can not be trusted to embrace people with learning disabilities into the community. People with learning disabilities are not fully part of society.

Charles alludes to forms of this imagery in his story about a woman with a learning disability from his professional past.

> **Charles**: Anyway a story. When I was nursing up in *(region)* it was one of the one of the profound things that I did when I was doing my nursing it's one of the things that really stuck in my mind ehm, that there was a set of twins and one of them got meningitis and I worked in a long stay hospital in *(region)* Ahm at that time it was a 50 bedded unit and it was just bordering on the kids so, I've got to be really careful how I say this, but the twin sister who came in who didn't have meningitis, was somebody you know like the matrix effect when a woman walks by all the guys used to stop have a cup of tea and stuff and she came to see her sister. But her sister had got meningitis she had learning disability she was on Largactol, so she had like the side effects of Largactol? If you go out in sunlight you get patches on the skin, erm because of other medication she had facial hair growth and stuff like that too …so the

contrast when you saw them sitting together was really quite profound and its one of the things that always stick in my mind about the effects of learning disabilities, you know? just something as, it's not simple I know, but somebody getting meningitis and the other person not getting it. You know? just to see the contrast in the person's lives. One's ended up in a long stay hospital and the other's got a really nice car and a nice job and enjoying all those kind of benefits ?? It quite affected me. It's a favourite story.

(Charles, story 11, complete)

In this construction of learning disability, Charles (11) as a man, navigates between the medicalised discourses which idealise the perfect form (or normative woman) and the general male dominated discourses which value attractiveness and desirability in a stereotypical way represented in the media and popular culture. Both discourses represent women as child like and as victims (Morris, 1991; Wendell, 1997). The two women in the story although alike (genetically as twin sisters) produce different effects upon the men they pass by. It is suggested in this story (Charles 11) that the woman with a learning disability is far less attractive than her sister. She is indeed considered unattractive by those around her whilst her sister causes men to stop and stare at her beauty.

Charles: You know? just to see the contrast in the person's lives. One's ended up in a long stay hospital and the others got a really nice car and a nice job and enjoying all those kind of benefits (Charles, story 11, extract)

Gender discourses

Women are often constructed by the medicalised discourses dominated by men in terms of their abilities to perform the roles ascribed by society as care-giver, nurturer, wife/lover and mother (Wendell, 1997). Disabled women such as the twin who caught

meningitis in Charles' story (11) struggle to fulfil these aspirations and are often constructed as un-attractive, un-sexual, and passively dependant (Morris, 1991).

Charles utilises discourse primarily to reaffirm (mode One) the political discourse which condemns institutional care. In attempting to provide a vivid picture of an un-just life Charles is encouraging (mode One) the justification of the normalisation principle which advocates valuing all people regardless of disability on the same level. Charles is also perpetuating (mode One) the medicalised discourse which sees woman as objects of desire and attraction to men. He reaffirms this view in his story and in the learning disability construction.

The medical discourse although challenged by such feminist critiques has still largely continued to construct learning disabled women negatively and without the necessary personal agency or power to determine how and why they receive treatment or care. Often women with learning disabilities miss out on the necessary health treatments associated with reproduction and sexual health through mis-conceptions that they could not and would not reach sexually maturity and therefore not be sexually active to justify healthcare. Where women with learning disabilities are constructed with sexuality it is often as a deviant behaviour warranting intervention and regulation (Tremain, 2000).

In her short story about another woman, Jacky (1) paints a vivid picture of a person completely without physical or cognitive ability to influence her world.

> **Jacky**: I actually worked with an' individual … a lady … at *(local hospital)*. And ehh … this posture here, where everything was fixed like that. She were

actually … fixed in that position an' she was like a board … she literally was flat in that position. An' had to be lifted flat into an' laid flat. It was *so* severe that … she'd no … major movement at all. (Jacky, story 1, complete)

As a recurrent theme in the construction of the impaired body specifically by caring professionals and more generally by society is of a lack of bodily function and control. The medicalised discourse constructs people with permanent physically disabilities like this woman as a series of treatment decisions based upon the likelihood that the person will not improve how they function compared to normative predications for them as an adult (Priestley, 2003). These predictions based upon the assumptions that adults perform a socially useful role in society through work and economic generation reinforces the biomedical discourses which view the body as asocial and biologically determined and therefore in-repairable. As "..like a board…" the woman is flat and without human form. This construction represents her as a stereotype *vegetable* or *cabbage* with all the imagery used in animated cartoons to illustrate an unfortunate incident when a character is rendered incapable but alive, squashed by a heavy or fast moving object (Mitchell and Snyder, 2001). In this present state, the woman in the story (Jacky, 1) is not expected to create a place for herself in the world, she is without personal agency and is afforded a dependant position in the minds of her carers.

The analysis of the discursive modes drawn upon by Jacky suggests that she is drawing upon the dominant medicalising discourse which constructs impairment as weak, tragic and irreparable. The personhood of the individual is questionable but not questioned by Jacky. She reinforces (mode One) the medicalised view that people with learning disabilities (and especially those also with physically disabilities) are

discussed in terms of their impairments and not their personal impact upon others. The woman is constructed without a name or personal place in Jacky's story.

The interpretation views that the affirmation of the medicalising effects of physical difference are Jacky's attempts to remind students about the harsh effect and realities of learning disability She illustrates this by utilising this discursive practice. Jacky believes that her story can help to construct the realities of learning disability .

> **Jacky**: I think that they respond positively to practice examples because its things in the real world and then they can relate to things that they might have seen. They might not be able to explain it but they can relate to other experiences that they have and I also think it helps give you credibility in terms of your teaching practice and them believing in what you are saying so I do think that they are response positively to it. (Jacky, interview extract)

The medicalising discourse is not only limited to the language of the physically impaired body but also constructs people with learning disabilities acting or behaving in ways which are maladapted to general social life and require adjustments or modification. Largely these constructions view the way a person with a learning disability behaves within/embodied or endemic to having a learning disability. Goodley (2001) argues that through the embodiment of impairments professions such as psychologists and psychiatrists attribute behaviour outside of the considered norm to be directly linked to the persons initial medically diagnosed impairment and as such be pathologised. This discourse influenced by histories such as the rise of therapies and treatments in the fields of psychoanalysis and behaviourism constructs unusual or extraordinary behaviour as tolerated in some circumstances and not others. Common

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anti-social behaviours become challenging or dangerous when exhibited by a person with a learning disability.

Cases are dependant: you need help

The medicalising discourse is said to create dependence in two ways (Oliver, 1990). Firstly, the person with a learning disability becomes a *client, patient, service user* who needs the services of trained individuals to successfully navigate through life, and secondly the professional needs clients and patients to justify salary and work patterns and standard of living. Sheila illustrates deinstitutionalisation.

> **Sheila**: And … a lot of the clients … were patients in *(local learning disability hospital)* The first ones that went out … I remember a lady goin' out … went out kicking' an' screaming', she didn't want to leave … her boyfriend was still up at … *(local learning disability hospital)* Alright … she was sixty odd, but her an' this bloke … had been friends … boyfriend an' girlfriend for forty years. An' he wasn't allowed to visit her because they'd be on their own an' unsupervised down there. She did … even know how to cook. She didn't know how to get to a fish an' chip shop. It was round the corner. So this is how much preparation went into it. She could talk so therefore should find out. But that was the reality … of what was goin' on. It quickly altered. It very quickly altered. But there were bad experiences like that that happened. An' I mean … remember these are … these are actually experiences I've been … ehh... akin … you know, sort of … privy to. They're not things that are just written up in books. These are actual things that happened within this locale. (Sheila, story 3, complete).

The woman in Sheila's story has a strong will which is demonstrated by her actions. Interestingly, the story recalls a woman moving out from an institution into a local community town who clearly does not want to go. She is constructed as unfortunate and at the will of others more powerful who make decisions about her life. Sheila

constructs the woman as mistreated and misled during her transition from long stay institution to a home of her own outside. The interpretation suggests that Sheila draws upon discursive devices which construct learning disability by refuting (mode Two) the dominance of medicalised control and also by reaffirming (mode One) that people with learning disabilities do need help. Sheila refutes (mode Two) the ideas of the institutional era that considered people with learning disabilities as unworthy members of the community, her story constructs learning disability in a discursive mode that serves to convince students that there is need to remember the bad old days.

Sheila:… people only ever see the negative – you know, so I don't know, part of my role I see as sort of drawing out their understanding. I can't make them understand, I can't give them that, they've you know, the penny has got to drop in their own minds as it were. (Sheila, interview extract)

The concepts of choice and empowerment are new to the medicalising vocabulary which use the terms; acting in 'best interests' of clients and demonstrating paternal caring services in learning disability care (Oliver, 1990; Chappell, 1992). Sheila is attempting to draw attention to this fact through her construction of this woman with a learning disability without a choice or without an empowering network. In this story the woman although described as "*kicking an screaming*", would have not moved out displaying such behaviour. The professional decision makers deciding who should move from hospitals first often make assessments based upon individual ability to merge into society quickly and often those who were considered most functionally able residents of the hospital (Chappell, 1992). As a result, the construction of people with learning disabilities was dependant upon their abilities to function and live 'valued lives' within a community of non disabled people living ordinary lives.

In this story Jacky also constructs learning disability as a case needing some attention and suggests that the behaviour of the individual was unusual enough to require some action.

> **Jacky**: I did used to work with somebody at (*LD unit)* who used to be totally obsessed with coffee and would try and would actually eat coffee from the jar, quite bizarre. Had to hide the coffee away. (Jacky, story 5, complete).

This unusual sight of a person eating coffee provides Jacky with a construction of learning disability which is needy, unsafe and requires help. The story concludes with the remedy '…*had to hide the coffee away…*' The story illustrates the picture Jacky constructs of a person not capable of living without outside support and protection and that the support has to be specialised and skilful.

Importantly the medicalising discourse enables Jacky to utilise language devices which make the young man out of the ordinary '*bizarre*' and '*obsessed*' and the professionalising discourse legitimises Jacky's presence to observe him doing these strange things '…*I did used to work with somebody at (LD unit)…*'.

This is an example of a person with a learning disability acting in way which is viewed as challenging to the services providing care to him or her. The scale of the undesirability in the action considered by those powerful enough to be caring for someone in professional position will determine the extent of the challenging label attributed to the person with a learning disability (Davis, 1997). Again the medicalising discourse refers to normalcy as a basis to first judge and then to categorise (Foucault, 1991). The circumstances of this person's actions tend to be

considered in much the same way as a criminal, and are judged according to what a reasonable person might do in that circumstance. Socially constructed as challenging by carers the person in the story (5) is considered highly abnormal for eating raw coffee from a jar.

On interpretation, Jacky is reinforcing and strengthening the dominance (mode One) of the medicalising discourses which constructs people with learning disabilities as strange, different and sometimes comical. My analysis suggest that this discursive devices which constructs learning disability so negatively serves also to reinforce (mode One) the necessity of learning disability nurses within the lives of people with learning disabilities.

Summary

This section has highlighted the construction of learning disability as something other than normal. As a case, learning disability can be viewed in this way objectively and dispassionately by those charged with responsibility to deal with it. My interpretations reveal the power of the medicalising discourse in the teacher's stories and the ability to construct learning disability as a problem based upon socially constructed assumptions about appearance and behaviour difference. The next section expands the discussion to the role of the learning disability nurse.

Managing care is the job of a learning disability nurse

Learning disability nurses form the major professionally qualified group charged with working with people with learning disabilities who have identified problems. The learning disability nurse views his/her skills as making an important contribution to

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the lives of people with learning disabilities. This section identifies the stories that construct learning disability as problems to be helped by nursing skills and knowledge.

The importance of the learning disability nurse

In this next story (8) Mike constructs learning disability as a problem potentially exacerbated by the absence of specialist supervision during a visit home.

> **Mike:** I once remember someone who were in our long-term care in another unit that I used to work on. Went home for the weekends to their parents. And … basically, they gave her more epilepsy tablets than she should have had which meant that she ran out. Yeah? So then they started giving her paracetomol instead. Yeah? Which has no effects in epilepsy whatsoever. So of course when she came back she'd been fitting all weekend. Yeah?
> (Mike, story 8, complete).

Mike draws upon a story which is often familiar to those in learning disability care areas. Commonly people with learning disabilities who lived in long term residential care occasionally visit the homes of their parents (often elderly) for the weekend. Mike utilises this well known story to illustrate the powerful and important role learning disability nurses play in promoting good health for people with learning disabilities. On interpretation the story told by Mike constructs the person with a learning disability anonymously *'…'I once remember someone…'* and as a case to be managed this person was inappropriately cared for in the unit, but in appropriately cared for at the home of her parents *'…So of course when she came back she'd been fitting all weekend…'*. Mike refutes (mode Two) the discourses which condemn institutional care for being inappropriate for people with learning disabilities in this

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instance. He also reaffirms (mode One) that the problems lie in the person with a learning disability which can not be managed without the surveillance of the learning disability nurse (Foucault, 1991). Mike particularly sees the processes of nursing as a means to enabling the identification of problems to be solved by professional skill and expertise.

> **Mike**:…you have a beginning an middle and an goal where you want to get to, so that might illustrate telling students something like, when you set out perhaps doing care for somebody you have a starting point and a goal where you need to be…'(Mike, interview extract).

A useful interpretation suggests that Mike draws upon learning disability constructions as a means for justifying the part played in the past by himself (mode Three) and other learning disability nurses. These justifications assist his constructions of problems and cases in the form of people with learning disabilities whom he has 'sorted out' or resolved in the past by drawing upon medicalising processes of outcome management and risk assessments.

In this next story by Jacky (2), learning disability is constructed with both the medical and professional discourses acting powerfully. In Jacky's learning disability construction the problem resides not in the physically impaired functioning of the young man, but in the relationships he has with those deemed to know better than him. *'... He really didn't want to put them on…'*

> **Jacky** : An' when I were at (*an learning disability Unit)* … we had a young gentleman … who came from school and ehhm … at school, through the Statementing process… an' the Education Act … children with cerebral palsy do tend to get a lot of input from physiotherapist an' occupational therapist an' speech therapist … because it …they've got a … ehhm … there's a *legal*

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responsibility to do so. An' you'd have these hand splints … which stretched out all his fingers and his wrists. And that … when … when he went to school, they used to make him put them on … he's, you know, used to cajole him into puttin' on them on. An' it was a very slow process because … it were quite painful for him. So … gently stretch out his hands an' his wrist an' put the splints on to maintain … a good alignment. An' I came to do me at ****… an' he didn't have these ehh … occupational therapy inside there. Physiotherapist, teachers, sisters who'd caj … cajoling' every day … over many years in the same school. He really didn't want to put them on. He used to cry at his mum an' use emotional blackmail to … ehhm … deter … her from puttin' … puttin' them on him. An' in some ways we would say wouldn't ya really, they had a *choice* about whether he'd wish to do that. He did use to cry, but then we used to try … to stretch them out … one where you got to the day care unit … you're not … there were odd occasions when he were that determined that they weren't gonna do it, that they couldn't. An' it were a slow, gradual process, in which he really opted out of it an' chose not to. An' his hands were really … quickly deteriorating' an' contracted in. An' now they're very set in position. (Jacky, story 2, complete).

In story 2 Jacky recalls working with a young man during her time as an learning disability nurse. The man is a client of hers and is directly affected by the care decisions she makes, however, he is constructed as a determined person making his mind up to refuse the treatment she and her colleagues see as necessary. In the story the man is not empowered in his rights over his body, and as a person with a learning disability, he is seen as unable to make the correct choice.

The professionals in the story are constructed as powerful by the medicalising discourse which recognises him as once childlike without articulate rights and paradoxically, more latterly as an emerging adult saying no to painful treatment. learning disability is constructed in this story as a damaged body and mind which

needs repairing or maintaining by specialists and specialised equipment. In this story the young man is constructed without the abilities to fully understand what is done to his body. As a child he is not expected to understand but as an adult with a learning disability understanding becomes a threat to the professional power to give treatment and becomes a problem to be managed.

Children in society are commonly excluded from decisions about their bodies and the medicalising discourse constructs children without full legal capacity to consent to treatment (Priestley, 2003). Adults in society are generally ascribed a constructed social status of independence and productive legal rights. Children with disabilities are commonly constructed as biological failure's by comparing their abilities to reach standardised child development milestones. Many children with learning disabilities have been subjected to painful treatments aimed to get them to 'walk-normally' 'talk-normally' or attain a physical appearance considered more closer to the norm than their own (Aylott, 1999; Westcott and Cross, 1996). The results are that children with learning disabilities are forced to undergo treatments deemed essential to compete with normal childhood miles stones until they reach adult hood when the obligations quickly disappear. Adult welfare services construct their clients differently to child services.

The young man is not praised for his self determination but suffers for not allowing learning disability professionals to make him better by continuing his treatment and managing his care appropriately. Jacky reaffirms (mode One) him as case which she could have managed better if he had not refused to participate. The medicalising discourse assists the construction through the use of medicalised terms and operations

'*statementing process*' and '*good alignment*' and the professional discourse alludes to the power of Jacky as the learning disability nurse who knows better '*…but then we used to try … to stretch them out…*'. A useful interpretation suggests that the two discourses drawn upon by Jacky both serve the purpose of reinforcing the role of the learning disability nurse to care for this young man.

The construction suggests that the young man could not take control of his life as he did not know what the outcome would be. The learning disability nurse with specialist skills and past experience alternatively could have foreseen the outcome and avoided the physical damage.

<u>Learning disability nurses are better suited than other professionals to meeting the needs of people with learning disability</u>

Mike sees the learning disability nursing profession to which he belongs as the best qualified to support people with learning disabilities. In professing this he is also negotiating his own identity, who he is, what he does, and why. (Connelly and Clandinin, 1999). Mike's place on what Connelly and Clandinin (2000) call *the professional knowledge landscape* is constructed in relation to his experiences and the recalling of them in the context of the teaching narrative with the students.

> **Mike:**… Ermm In terms of moving on I think obviously there's a couple of things, is the nature of where they are cared for has moved so the actual ethos of .. has moved away from particularly care to actually living, but in that I also think we have lost some things…because those aspects those actual structures are making sure people were cared for can actually be missing sometimes, and some people can actually be almost restricted by the freedom…That might sound strange but ermm they are given that much freedom that they don't

know what to do with it so it actually becomes restrictive rather than where you have structures where you are actually moving people, doing things with people, progressing them, ermm its actually more progressive, what we've got to find is what the right balance is between where the freedoms restrictive and where the outside influence is oppressive. (Mike, interview, extract).

Although philosophies of care in learning disability services have changed Mike still sees that there is a role for a learning disability nurse to care for people with learning disabilities. His constructions of learning disability as a problem tends to strengthen his claims that the needs of people have not changed and that maybe the learning disability nurse had it right all along but amidst societal misconceptions about learning disability *'...has moved away from particularly care to actually living...'*. In story (9) Mike represents his convictions that only learning disability nurses can accurately interpret the lives of people with learning disabilities.

> **Mike:**… I used to work in an area and I worked with these kids, when I was a student and they'd come and the school was saying all these things about these kids and I used to think well that's absolute nonsense, these kids, it doesn't relate and then you'd go to the school and they would be doing all of these things, but they wouldn't believe what they were capable of in this other setting, do you know what I mean…(Mike, story 9, complete)

The analysis of the learning disability constructions locates the medicalised discourse which constructs anyone with a learning disability without any potential, as central to an argument that other professionals do not always understand the needs of people with (and in particular children with learning disabilities). Mike's construction of learning disability in this story is of being misunderstood stigmatised and different (Goffman, 1963).

Mike refutes and disagrees (modes One and Two) with the medical discourses that construct people with learning disabilities uneducable but knows that this is not a view shared by others. He uses the established medicalised discourse to develop himself (mode Three) as an enlightened professional capable of changing the way learning disability is viewed through his liberal ideas to difference. In his construction of learning disability Mike is also drawing upon the medicalised discourse on a personal level (mode Three). He is the learning disability nurse who is enlightened by the achievements of the children with learning disabilities who out perform at their school above his expectations. The story serves to both justify his own good enough performance as a nurse and those of the children with potential to learn.

This is demonstrated in his story (9) when he proclaims his surprise on discovery that the children really could do all the things claimed by the school staff '*I used to think well that's absolute nonsense* these kids*, it doesn't relate and then you'd go to the school and they would be doing all of these things'*. My analysis suggests that Mike's constructions of learning disability are utilised by him to refute the medicalised stereotypes that other professionals reinforce about learning disability whilst some learning disability nurses struggle to overturn. It is possible that Mike is attempting to idealise the good enough learning disability nurse (Allan, 2001), and although heavily influenced by the medicalised discourse he struggles to uphold a positive approach to the care of people with learning disabilities.

Summary

This section has drawn attention to the value of the learning disability nurse placed by the teachers in this study. Although past care is reflected negatively upon in the

learning disability constructions the learning disability nurse is generally promoted well and with pride in the stories. The next section draws together ideas that the past history of learning disability care has influenced the present care situation.

It was real in the past

This section discusses the ideas that history seems to be important to the teachers and they utilise constructions of historic and 'real' events in various modes. Both the medicalising discourse and the professionalising discourse are active in these stories.

Horrors of the past

On reading Sheila's story (7) it is easy to assume she is adopting an overly descriptive stance claiming a knowledgeable position of learning disability care and of the horrors of past care regimes. Following deeper interpretation her commitment is revealed to encourage students to think critically about the lives of people with learning disabilities.

> **Sheila:**…Because I believed … when I first went up to work at (a *local mental handicap hospital*), that I was gonna … be terri … ah … that … I couldn't cope with it, that I was gonna be attacked. That it was a frightenin' place to work. And … the … and … that the people that lived up there … were nothin' better than … really animals that walked upright. An' I've gotta be honest, that's how I felt. I was terrified. I don't believe that now….
> (Sheila, story 7, complete)

Story (7) seemly using outdated negative imagery and language appears to be intended to engage the students in an analysis of their own prejudices and constructions. This also takes Sheila on a journey into the past. This assumption that

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learning disability is viewed negatively by most people in society is a feature of learning disability constructions in this study. By justifying her own history of working in a old institution Sheila is revealing the underlying schemas with which she herself makes sense of the world (McLeod, 1997) and in particular the world of learning disability nursing. As Bruner (1986) comments that the key functions of a story is to convey the landscape of consciousnesses of the story teller. By using the medicalising discourse to verify her own position in the history of learning disability Sheila is resourcing the story by which discourse analysts Potter and Wetherell (1996) might suggest is a use of discourse to deny responsibility. Sheila herself reveals much about the first impressions of a new nursing recruit in an unusual and frightening landscape but reveals little about her responsibilities to the people she was to there to work for.

Regrets: I have a few

In this analysis Sheila may have some regrets about her initial beliefs about people with learning disabilities and her reactions towards the experience '… *I was terrified. I don't believe that now…'*, but, has reconciled these as necessary even under the extreme circumstances of the institutional care she witnessed. By refuting (mode Two) the discourse of medicalised institutionalisation Sheila provides a platform on which to paint a picture of her own hardships as a student nurse amidst the bad things that were happening in the hospital. Sheila's construction of learning disability as a *'case to be managed'* by those brave enough (as she was) to stay and continue amidst a chaotic, harsh and frightening environment. She suggests that these bad things were not just happening to the residents but also to her, and her experiences were less than positive leaving her affected too.

Sheila comments further on some of her motives for these constructions in her interview when asked her reasons for telling such stories in the classroom.

> **Sheila:**…But it depends, I think it depends on how you use it. I have actually done a full 2 hour session on one story but it's not just telling a story for 2 hours, it's completely analysing what I have said in the context of how will that help you become a practitioner Why have I told the story, what are we looking at within that. The reason I have told the story is it's a real example, its real to me, you can tell me what you would have done, I will tell you what I have done, what I did do and we can actually critically analyse that because there is always another way it could have been so there is always my story, your story and the right way or my way, your way and the right way…'(Sheila, interview, extract).

Sheila justifies her stories as real '*…it's a real example, it's real to me*'. This engagement with the past event accounted in the story provides Sheila psychoanalytically with what Hollway and Jefferson (2002) term a tension between the emotional reality of the past (remembering the event) and the need to be defensive (providing a distorted view for the audience).

Sheila is expressing the validity of her accounts and her constructions as rational expressions of how she felt when she first encountered people with learning disabilities. On a functional level (mode Three) her feelings towards and reasons for the learning disability constructions are based upon what she views as her reality, what happened to her and what she has learnt. The professionalising discourse which constructs the learning disability nurse in control and superior in knowledge to people with learning disabilities provides a target for the new recruit Sheila to eventually

attain as she learns more about the job and loses her fears *'...I was terrified. I don't believe that now....'.*

In a different mode, the stories can allow Sheila to illustrate her uncertainties about learning disability nursing both in the past and the future and to refute (mode Two) the dominant medicalising discourse that she knows can and will influence learning disability nursing careers. This escape allows her to first recall the development of the role of the learning disability nurse and eventually to subjectify the students own experiences as she suggests in the interview *'...you can tell me what you would have done, I will tell you what I have done..'.* This process of change through the use of a narrative to recall events and similarly affect the future is similarly described by Goncalves (1995).   In this five stage model the therapist (or in this case Sheila/teacher) engages others (client/student) in a process of remembering events, retelling and recalling subjective experience using metaphors with themselves present in ways which empowers and gives power and control. The intended outcome is to reinvent the past in the mind of the client which re-establishes their importance and self esteem.

Sheila is attempting to predict a change in the practice of students as a result of her sharing of what she considers to be a powerful life altering experience of the past. She wants them to know how it feels when confronted by potentially disturbing images of institutional care practices and her stories are ways in which she aims to convey this directly. The professionalising discourse is drawn upon so Sheila can justify the personal changes needed in the individual to become an effective learning disability nurse.

Mike utilised his story of past medicalised regimes in learning disability care (6) drawing upon similar discursive levels which refute (mode Two) the necessity of disempowering practices but also legitimises and affirms (mode One) the need for forms of professional input in the lives of people with learning disabilities.

> **Mike:**…I once saw someone stick chew …I was actually visiting as a tutor to this place. An' … I once saw this bloke. I'd got there just as he'd done it. He'd put, he'd put a piece of chewing gum in an electric socket. Ohhh, it created a riot. Do … d'you know what I mean? Talk about … lettin' everybody know what's the best thing to do to …. to ehhh … spice up your life when you're a bit bored. Yeah? 'Cause all the staff … 'cause it's what I call the 'Oooh ahhh' response. All staff go …"Oooh my God", "Oooh, ahhh, what are we gonna do?". You know? an' everybody's running up and their phoning, quick get the flying squad in, an' all these doctors come in and social workers. And that lad sat there like … "Yes, I've put some chewing gum in the sockets". You know, then everybody's running around then … and then, all of a sudden, everybody else in now … now as if they want to … ehhh … get … get some kind of attention or … you know? have a bit of fun in the … in the day? stick some chewing gum in the … electric socket. Then they have builders coming in and putting little like ehhh … wire mesh boxes around the sockets. The … you know? staff could only undo. And all … crazy, it was.'
> (Mike, story 6, complete)

Similarly Mike constructs learning disability drawing upon the medicalised discourses which view learning disability as a problem to be managed, and the professionalising discourse which strengthens his view that there is a need for learning disability nurses. The need is for nurses to protect the person with a learning disability and others from unwitting harmful acts. Mike reaffirms (mode One) the medicalised discourse which places control outside and away from people with learning disabilities and also asserts the important role of the nurse through the professionalising discourse.

This story based in a traditional institutional setting parodies a person with a learning disability secretly controlling the actions of others *'...Ohhh, it created a riot...'*. Foucault (1984) explores the circulation of power throughout social institutions. He suggests five methodological precautions to identify the flow of power, those targeted, the features and the practices and discourses by which it is proliferated. The construction in Mike's story cites the person with a learning disability as with only a small amount of influence/power upon his day *'...now as if they want to ... ehhh ... get ... get some kind of attention or ... you know? have a bit of fun in the ... in the day...'*. He is invisible to those around him (except to Mike as a visitor noticing him place the gum over the socket) but needs to be more closely supervised. Mike draws upon the medicalised discourse which allows people with learning disabilities to be both unknowing about the world in a child like manner, but also lacking empathy about the dangers to others.

Mike constructs the un-named man as a problem of a busy under-staffed and under resourced service, but not a person seeking to cause serious harm. The learning disability constructions do not particularly praise the efforts of the man to attract attention only ridicules the over reaction so those around him. This therefore further reinforcing (mode One) the discourse which perceives people with learning disabilities to be powerless amidst the care practices which surround them (White et. al. 2003).

The man with a learning disability is a constructed as problem by the fact he is just waiting for an opportunity to cause havoc. *'...Talk about ... lettin' everybody know what's the best thing to do to .... to ehhh ... spice up your life when you're a bit*

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bored…' Mike is reaffirming (mode One) the discourses that people with learning disabilities need specialist care and he can only access an example which illustrates what happens to people like the man in the story when specialist care lapses.

Mike's story (6) further reminds the students/ audience that the man is unable to care for himself at the end to story which concludes with a protective electric socket cover to stop any further attempt at dangerousness. *'…and putting little like ehhh … wire mesh boxes around the sockets. The … you know? staff could only undo…'* This leaves the construction of learning disability helplessly unable to exert the same power and influence again (White et al, 2003).

<u>Nothing really changes</u>

History is a time for Jacky to reiterate the power and importance of the learning disability nurse. Her story reminds her of the course of training she followed and the important skills she developed.

> **Jacky**: Very much when I did my training it was very much focused on advocating for people who couldn't advocate for themselves using your professional skills and abilities to advocate on peoples behalf, okay.
> (Jacky, story 3, complete)

Jacky draws upon the medicalised discourses which construct learning disability as helpless and needy problems to be sorted by a professional with skill. The professionalising discourse in this story is accessed by Jacky to reaffirm (mode One) the need for learning disability nurses in the lives of people with learning disabilities. The construction of learning disability by Jacky is an example of the implicit power vested in professionals (Abberley, 2005). Jacky draws upon a personal discursive

mode (mode Three) which reminds her that the skills she developed on her journey *'...my training it was very much focused...'* to becoming a learning disability nurse are important to the lives of people with learning disabilities.

In personal mode Jacky sees her experiences are positive examples of how things are in reality. She alludes to this in her interview and relates the personalising aspects of the medical and professional discourses she accesses in telling her stories.

> **Jacky:** I think that they respond positively to practice examples because its things in the real world and then they can relate to things that they might have seen. They might not be able to explain it but they can relate to other experiences that they have and I also think it helps give you credibility in terms of your teaching practice and them believing in what you are saying so I do think that they are response positively to it. (Jacky, interview, extract).

The encounters she constructs from the past are seen as real by Jacky. The analysis suggests that she is constructing her story *'...its things in the real world...',* based upon what she sees as credible events and that this device helps her students to learn. This device reaffirms (mode One) the medicalising discourse which stresses the need for nurses and also the professionalising discourse which empowers them to take actions.

Kit also sees the power of the past. She recalls a woman whom she constructs by accessing the medical discourse which categorises her as different and requiring help.

> **Kit:** I remember a lady used to call me a terrordemian all the time. Terrordemian was quite obviously quite abusive because she used to say it er in an abusive way but I always quite liked the word terrordemian thought it was amusing (Kit, story 14, complete).

The story is positioned in Kit's teaching narrative at a time when she is reaffirming (mode One) the medicalising discourse which categorises people as mentally ill. This story acts at a personal level which reaffirms (mode One) the claim made by the medicalising discourse that people with learning disabilities are different from other people with problems to be managed.

> **Kit: …**From a learning disability perspective its very very difficult I think its difficult (a) to know whether someone's got delusional ideas or not because delusional ideas do are in keeping with the person's intelligence as in I mean I've know extremely intelligent delusional people who its very difficult to know I suppose you're at the other end of the spectrum really its very difficult to know whether they're delusional or not because you haven't got the same level of understanding of what they're talking about so you don't know that what they're saying isn't true … (Kit, teaching narrative, extract).

The positioning of the story in the teaching narrative serves to help Kit construct learning disability as problems to be managed, and that her 'real' examples illustrate her difficulties with the medicalised discourse which attempts to categorise all people in the same way. By drawing upon the example of a 'real' person she attempts to help the students understand the complexities of learning disability and the medicalising discourses. She further reinforces in her interview

> **Kit**: …if they are linked with a with with ..when they are linked a real.. Supposedly real anecdote then it helps you remember them.
> **Su:** *Does you think it matters that they are real then, does that make a difference? If say they are Harry F 's or they are yours.. ..does that make any difference?*

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Kit: Do you mean if they are real to you I don't know? I think I don't know whether it that matters or not? Certainly if I use them they are real, they are examples...

Su: How does it make you feel when you're saying them? How does it make you feel? What effect does it have on you when you are telling these stories?

Kit: It sort of. I think it takes me back to a past …

(Kit, interview, extract)

Kit constructs 'real' people stories from the past in an attempt to reaffirm (mode One) the professionalising discourse which promotes the learning disability nursing. She also refutes (mode Two) the medicalising discourses which tend to exclude people with learning disabilities on the grounds of being outside of the norm. She reveals that her reality is constructed as real for her only *'...Certainly if I use them they are real, they are examples…'*.Her tensions indicate a tendency to construct learning disability through mediation between, how it was in the past and how she chooses to recall it afterwards. Thus, it is useful to interpret Kit's story as an indication that the history of the past event (institutional care) is utilised to construct a version of learning disability which is appropriate to the way she now sees learning disability nurses (contemporary care) and the learning disability nursing profession (Hollway and Jefferson, 2002).

Summary

This section has revealed some of the importance placed upon the past for those working in learning disability care. In particular learning disability nurses appear to be aware of their part played by in the development and the eventual decline of institutional care.

Conclusion

This chapter has highlighted the learning disability constructions I identified with 'problems/cases to be managed, and the three discursive modes I interpreted are utilised by the teachers in this study. This construct is most commonly associated with the medicalising and professionalising discourses which the teachers both in one mode agree with and affirm, and in a second mode disagree with and refute. The modes of discursive device used to construct learning disability in the stories confirm this and in addition illustrate that teachers also draw upon a third mode, the ability to identify or position themselves as actors in the past learning disability story.

It appears that elements of these past reflections serve as powerful devices in the abilities of the teachers to construct learning disability in a meaningful and personalised way. I have discussed the three modes on which I interpret the various discourses and those are; firstly the reaffirmation of the power and control vested in the primarily medicalising discourse but also to a lesser degree in the professionalising discourse of learning disability nursing. Secondly, I have acknowledge the abilities of the lecturers to attempt to refute the medicalised discourse which problematises learning disability and labels all people as the same. Thirdly, my interpretation has noted the personal mode of discourse drawn upon by some lecturers when constructing learning disability. This personalising appears to enable the lecturer to establish an identify which is strongly associated with being an learning disability nurse and with the power invested in the professional and the disempowerment of people with learning disabilities as result. These modes will continue to be highlighted (but not specifically as modes One Two or Three) in the

next chapter that continues to present an analysis of the construct of learning disability

as problems to be managed and also as strange and different.

Chapter 5

How it can all go wrong: Cautionary tales

Overview

The teachers in this study depicted life for a person with a learning disability as seen by learning disability nurses. Many of the teachers constructed the recent past for people with learning disabilities by blaming an unjust society and unfeeling bureaucracy. The stories concentrated upon institutional life with a Dickensian tone and focus upon the hardships that the residents of the then mental handicap institutions endured.

Introduction

This chapter aims to continue my journey *To investigate the social construction of learning disability by teachers in the stories they tell to their students*, and in part moves forward on one of my objectives *To identify any links between the teachers' learning disability constructions and the learning disability discourse.* In particular I will also uncover the two other constructs identified in the open coding of the original data these are learning disabled: victims of professional dominance and learning disability: strange and different.

Things can go very wrong

The stories in this study often depict extreme happenings in the lives of people with learning disabilities. The history of learning disability is constructed as a series of failures, failure of the political and social systems and failures of people with learning

disabilities to live like other people. The following explores my interpretations of learning disability care that went wrong.

<u>They all got it wrong</u>

In this next story, Sheila constructs a woman with a learning disability as a problem to be managed that went drastically wrong. Her story reveals the dominant power and inhumanity of the deinstitutionalisation programme which quickly spread across the UK in the 1980's and 90's. This closed down a number of large mental handicap hospitals and discharged long term residents into more 'community based' provision (Richardson, 2005).

This next story by Sheila has appeared in chapter 5 and illustrated learning disability constructions associated with being different and being vulnerable. The following interpretation focuses upon the inhumanity of professionals to being learning disabled to which no one admits.

> **Sheila:**…I remember a lady goin' out … went out kickin' an' screamin', she didn't want to leave … her boyfriend was still up at …*(mental handicap hospital*) Alright … she was sixty odd, but her an' this bloke … had been friends … boyfriend an' girlfriend for forty years. An' he wasn't allowed to visit her because they'd be on their own an' unsupervised down there. She did … even know how to cook. She didn't know how to get to a fish an' chip shop. It was round the corner. So this is how much preparation went into it. She could talk so therefore should find out. But that was the reality … of what was goin' on. It quickly altered. It very quickly altered. But there were bad experiences like that that happened. An' I mean … remember these are … these are actually experiences I've been … ehhh .. akin … you know, sort of

… privy to. They're not things that are just written up in books. These are actual things that happened within this local…' (Sheila, story 3, complete).

The story (3) tells of a woman with a learning disability as a case to be managed in the movement of residents from an learning disability hospital to the local town. She refutes (mode Two) the dominant discourse of the time which is projected as the 'authority' or 'powers that be'. Sheila constructs the woman as someone she knows very well. Although it is assumed that Sheila is part of the 'powers that be' she chooses to stay out of the action. This construction allows Sheila to refute in the strongest terms the actions sanctioned by the discourse of deinstitutionalisation at any cost. Her language suggests that the woman was ill placed in the hospital and could have benefited greatly from living in the outside community but that this was too late for a woman who had grown old living in the institution. The paternalising attitudes of the time are used by Sheila to explain why the woman was denied her rights and how the medicalising discourse had constructed her as able to cope with some aspects of life away from the institution but not others. Words like *'allowed' 'unsupervised'* are used to convey how much control over the woman the central medicalised system had.

Returning to this story (used in earlier interpretations) by Sheila, she draws upon an learning disability construction which explains a more general story of people moving from one excluded community to another. The discourses which have advocated a normal life for people with learning disabilities are often attributed to being highly political and ultimately controversial for those concerned with the human rights of oppressed groups (Gilbert et al. 2003).

As Sheila describes, people moving from hospitalised communities were often transferred to local towns/villages without preparation. Their life skills were highly developed to being a hospital resident in shared facilities of a large commune. The woman in this story is constructed as a person rightful placed in the locale but is wrongly prepared *'...So this is how much preparation went into it...'* The discourses of inclusion presently advocated by modern-day professionals advocate for people with learning disabilities to live supported lives and not unsupported lives (French, 1993; Noble, 2005).

My interpretation suggests that the discursive practice which constructs learning disability in Sheila's story reaffirms the dominant discourse which views people with learning disabilities as different. The woman in this case is different because of her experiences in the hospital and not necessarily because of any biological impairment, but this difference is enough to present as a problem to be managed by learning disability nurses. By accessing this level of discourse to construct learning disability, Sheila poses a question to the general learning disability story, should people with learning disabilities live in the community? By refuting the principle in the general inclusion/exclusion discourse that hospitals for people with learning disabilities were all bad and community living is always preferable Sheila presents her case. The discourses drawn upon by Sheila in the construction of the woman with a learning disability can be further analysed and interpreted as I reflect upon some of her reasons for using her stories

My interpretation suggested that this is again an example of the tensions of promoting the full inclusion of people with learning disabilities in society. On the one hand the

nurse is compelled to agree with the holistic view that all people deserve the same chances, but also they know from experiences in their past that people with learning disabilities need to be given a different route to self fulfilment and ultimately social capital (Bates and Davis, 2004). Sheila gives her reasons for using learning disability constructions in her teaching *'...but very quickly realise that there is nothing mysterious about this...'* as an attempt to simplify what is a complicated navigation between the discourses which pressurise priorities in learning disability care. Therefore the analysis of this learning disability construct provides an insight into some of the challenges that learning disability nurses face when enabling people with learning disabilities to make life decisions and to live like others in mixed communities.

Sheila comments upon the event of the woman moved out from a mental handicap hospital in her interview.

> **Sheila**:…I think she died before she did because of a lack of care because she was an elderly lady anyway and I just thought it was so so cruel. In fact it made a lot of us cry. It was almost like she had literally been wrenched away for no reason other than they needed a test case…' (Sheila, interview, extract).

Sheila continues to construct the woman with a learning disability (both in the story told to students and later in her interview) from what she describes as *'…actual experiences…'*. My interpretation notes that the use of the learning disability construction in her story enables her to rejoin the levels of personal identity which she misses out in the main story. Although she continues her line to refute the main discourse which contributed to the painful experiences of people with learning

disability leaving their homes, she seems to gain some comfort from telling the story to students in her teaching session. Sheila continues in the teaching session to draw upon the lessons learnt from her experiences with this woman by drawing upon her own identity as a good nurse judging how to do the right thing on which she reflects further in my interview.

> **Sheila**:…and it was totally cruel, totally inhuman and totally political. And when you were telling that, emotionally you felt quite involved with that and students …. Yes, and that's another thing I say its not wrong to be emotional, you are in the wrong job if you can't be emotional and be human…' (Sheila, interview extract).

A useful interpretation of this is that the construction of the woman as a problem to be managed provides Sheila with justification for denial of her own involvement in the horrors of the past. She can construct the powerful decision makers as 'them' faceless and nameless but seemly '*cruel* and '*inhuman*'. These struggles with the complexities and constraints of her social circumstances are a feature for Sheila's construction of learning disability and one which she finds difficult to reconcile with telling a story of what happened (Hollway and Jefferson, 2002).

Mike also has a story to tell of a woman living in an institution and at the mercy of the system. However, the learning disability construct in this next story is vulnerable in a different way to the medicalising and professional discourses.

Learning disability: As a challenge

In story (2) Mike draws upon the medicalised language of the learning disability worker to construct a woman with a learning disability who misunderstands the social

rules of the environment she lives and other people work within. The language of the story constructs the woman as *'playing up'* assuming a role of a child towards a parent, or actor to an audience (Mitchell and Snyder, 2001)

> **Mike:**…Yeah. I once remember … this person. And we … on the morning shift, this person had been playing up. Yet when you looked at the staff that were on the morning shift, it was no wonder she'd been playing up. 'Cause basically they were … ehh that set of staff that … are likely to … how can I say … deny her request as opposed to … yeah? Ehhh … go along with them. So they'd have all sorts of problems with her… '.
> (Mike, story 2, extract, part 1).

In this early part 1 of story Mike (2) my interpretations focus upon the competing constructions of learning disability as a case to be managed within a given set of nursing guidelines but also learning disability as an unreliable human condition in which the complexities of relationships also prevail. Mike knows that his experiences of people with learning disabilities are not unique in that people with learning disabilities do run away and/or act aggressively under certain conditions. He also acknowledges that other people around also contribute to this behaviour negatively and positively, *'…Yet when you looked at the staff that were on the morning shift, it was no wonder she'd been playing up…'*. A useful interpretation considers that Mike's construction places the woman with a learning disability without agency or right to reply in a position where all she can do is *'play up'* because so much misunderstanding surrounds her, not even the staff team know how to act towards her.

Workers employed in caring positions often find themselves confronted by people with learning disabilities who display openly aggressive or frightening behaviours but

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are often not educated to deal with their own responses (Bromley and Emerson, 1995). Mike's construction of this woman (and her learning disability) is based upon the knowledge shared by those familiar to learning disability care work that people with learning disabilities normally behave abnormally. The medical discourse is reinforced and strengthened as an appropriate way to discuss individuals who have learning disabilities.

In part II of story (2) Mike continues to construct the woman in his charge as potentially troublesome but also draws upon a different professional discourse that affirms his role and the actions he takes as a result of his role.

> **Mike:**…Now … in the afternoon, or the evening, there was like ehhm … a disco organised, within the service. Which meant that everybody else, in this particular place, was eligible to go to a disco. But this person had been playing up in the morning. Having said that, in the afternoon, she'd been fine. Fine and dandy. Yeah? And … the staff that were working with … with her in the afternoon had a good relationship. So … and … muggins here was in charge. So I had to decide whether because of her behaviour in the morning which I'd not been involved in. Yeah, I'd been … told, you know, that it'd been documented about all these sort of ehh … challenging behaviours if you like. Ehh … I had … I had to think about what her frame of mind is. I had to think about everybody else is going, so everybody else needs to be escorted. Which means, whoever … if this girl doesn't go, somebody's got to stay behind with her. Which some … is implications for that and … and I knew full well, if she didn't go, we're more likely to have … more incidents and behaviours. Yeah? So these were all that, these were the things that I had to take into account. For chance. So there I am. And I've … I knew that the staff I'd got with me were reliable staff. So … we all went. Which were fine and dandy. And we had a great time at this … disco or what ever you want to call it. We all had a good time… (Mike, story 2 extract, part II).

Mike utilises the medicalising discourse which constructs the woman to position him-self as an important element in the decision making process effecting the woman's care and therefore considers himself to be at risk from making a mistake. As the unfortunate and nominated person (which he terms himself as…) *'muggins here was in charge…'* the discourse which constructs the woman as in need is also used by Mike to reinforce the importance of learning disability nurses in making the right choice of team action. Mike's utilitarian approach to the rights of the other people living on the care area to attend a social event (disco) interestingly reinforces the medicalised view of care that the outcome will justify the means taken (Pogge, 1999). The issue of who should attend the disco is dependant upon the behaviour of this woman as the staff can only accompany the whole group of people with learning disabilities. The right decision enables the most happiness for the group members with a learning disability who play by the rules of the care area. Mike constructs the woman as a victim of circumstance and views it unjust that she and others could not attend the disco if the problem originally resided in a bad professional decision. Even if that decision was made by other members of the team before he came to work.

A person with a learning disability: as a victim : Who do we blame?

The learning disability constructions that appeared in this study can appear as victims, optimised by the view of some that learning disability care has a shameful past when people with learning disabilities were not treated fairly (Mitchell, 2000a). Often the past is recent and within the working lives of the story tellers. Recounting the events does appear to provide an opportunity for learning disability lecturers to both reaffirm the goodness in learning disability care and also the damage occurring as a result of bad applications of the same practice ideology.

The interpretation of part III of Mike's story (2) again focuses upon a differing mode of discourse device. Mike draws upon the medicalising discourse which assumes the woman with a learning disability can not help her actions to run away, but he also uses the construction to refute the idea that people with learning disabilities should be treated with little respect or worth.

> **Mike:**…And ehh … on the way back. We'd just about got her to the door. And this girl ran for it. An' I mean ran for it for it …You know ?… but she'd of given … Linford Christie a …. a run for his money. And basically, she were missing for three weeks. Right? So she went missing for three weeks. And she'd eh … she'd got … she had a history of ehhm … arson. Yeah? So I spent three weeks really … ehh … in a bit of state. Yeah? But eventually we found her. And ehh … returned her … back … continued to work on her programme. Right? But … I would have still made the same decision again. D'you know what I meant? But at the end of the day, I could have been saved and stuck to the rules and said "ahh … no". She's got to stay behind because she's been … bad this morning. But that … then I'm sort of punishing her for something that happened earlier. Ehh … that she may have good reason for. And that … the … the problems that she might of caused back in … in the actual service itself would perhaps been even worse. D'you know what I mean? We might have been looking at, sort of violence and aggression all night long. And … an' perhaps, because of that, somebody else might have been … had to not go to the disco. Yeah?... (Mike story 2 extract, part III).

His justifications are based upon the tenet that other factors must have contributed to her unhappiness (and need to escape), one of which could have been a badly judged decision by other nurses which caused her to run away from her care area '…… *then I'm sort of punishing her for something that happened earlier. Ehh … that she may have good reason for…'.* In refuting the construction that nurses always know best and people with learning disabilities are always wrong, he constructs the woman as a

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more active participant in the obviously medicalised regime in which she lives. Mike reveals his thoughts about his story (2) in his interview.

Mike…The notion of the story was ermm the story was basically that I made a decision I regretted and in hindsight I could actually say it was the wrong decision, but at the time based on all the factors available to me…..it was the right decision, and still if I had to go back to the point in time just before..…given all the same factors I would make the same decision. But once I'd got all the information afterwards I wouldn't make the same decision. Ermm…'. (Mike, interview extract).

I suggest that Mike is accessing the two discursive modes in the constructions of the woman to both refute what he considers bad nursing practice and to reaffirm his position as a good nurse. The dualities of nursing practice he considers are determined by the situation and the abilities of a learning disability nurse to react in the most appropriate way and to learn from their actions. Mike sees his role as a teacher to lead by his own example of reflection of the type he communicates in his story.

Mike:…so if I learned lessons from it then I can tell the students what the lessons were for me and maybe there might be some lessons in it for them too, because what I was actually saying was something occurred that was quite dangerous in reality, but even though it occurred and I'd made the wrong decision, because I went through the right procedure afterwards…' (Mike, interview extract).

For Mike, the discourses he draws upon in his story are justification for him to provide students with a version of the ideal learning disability nurse as he wants it to be and wants them to become. My interpretation suggested that Mike refutes the medicalising discourse as an ideal way to view learning disability, whilst also

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reaffirming and constructing the role of the learning disability nurse as the most appropriate and best option available.

Summary

This section has uncovered some of the complexities of learning disability constructed by the teachers in this study. For some teachers, people with learning disabilities are constructed as victims of a corrupt or unjust regime contested by learning disability nurses now but contributed by them in the past. For others learning disability is constructed as making silent victims of people within their own bodies which the medicalising discourse identifies as defective and abnormal. It does appear that the learning disability construct as a problem to managed is sometimes extended to include learning disability as a victim also. The next section continues this discussion and looks at my interpretation of learning disability as a victim of professional dominance.

A person with a learning disability: a victim of professional dominance

This construct is interesting and encompasses the language of the professional and in particular the learning disability nurse influenced by political forces. The assumptions appear to be based upon confirming the dominant discourses of everyday life which labels people with learning disabilities as abnormal, fearful, as undesirable or invisible, forgettable and as two dimensional. Some of these assumptions reflect the changing form learning disability has taken in stereotypical images which have informed public policy, or as Alaszewski, (1988) commented the transformation of from villain to victim.

Alternatively, this construct also refutes the ideas that learning disability should be treated differently and instead draws upon the expert knowledge of normalisation and ordinary living ideas often proclaimed in learning disability nursing (O'Brien and Lyle 1987) in an attempt to promote better egalitarian attitudes in general. Often the learning disability nurse appears in the construct as the champion of normalisation with the ability to see through the medicalising discourse reserved for other less enlightened professional groups.

Women are victims: Women with learning disabilities are greater victims

In the following learning disability construct the medical discourse constructs the person with a learning disability without shape or form leaving only a shadow of personhood often with negative or absurd images describing a person outside of the norms of human behaviour and appearance (Oliver, 1990; Swain et al 2003)

> **Jacky:** I once worked with this girl, she'll be an adolescent now, who used to constantly bang her head and had massive scabs and sores, I often think it's the most difficult thing to work with you know? (Jacky, story 3, complete)

According to Foucault (1991), society can regulate its members by observing and recording their actions and by separating them in to groups. The professionalising discourse of learning disability nursing has been equipped with the mechanisms to regulate people with learning disabilities through a preoccupation with their bodies which have become objects to be examined and recorded.

For the woman in Jacky's (3) story rights to self regulation are not the issue here, as she is without agency or ability. She is afforded a passive role in relation to the more

powerful abilities of those around her (Wendell, 1997). The wider discourses of disabled women's struggles against the oppressions of male dominated societies like the medical profession tend not to enter the discourses of the learning disabled woman for a number of reasons. Firstly, women with learning disabilities struggle to articulate their own experiences and their lives tend to be reported upon by other observers. The observations of life for some women with learning disabilities focus upon their physical vulnerability to exploitation or their inability to control or regulate their own sexual activity. Thus the behaviour of the woman with a learning disability is constructed as a medical problem to be prevented by contraceptive or behaviour regulating medication (Priestley, 2003; Swain at al, 2003).

As a difficult problem to encounter, it is easy to feel the frustration of the woman who needs to bang her head and the horror of those who watch and try to stop her. The political discourse which signals the rights of the woman to a life without pain and suffering is drawn upon by Jacky who is not prepared to fully accept that this woman in pathologised by the medical discourse as ill and incurable. My interpretation suggested that Jacky draws upon the political discourses in her learning disability construction which affirm the entitlements of all people. She also draws upon the exclusion/inclusion discourse which affirms a place outside society for people with learning disabilities, and refutes the medical discourse which constructs the woman who uncommonly bangs her head as not entitled to rights because she is abnormal and disenfranchised.

Summary

In this section, my interpretations are centred upon the ideas that the learning disability construct can assist the learning disability nurse/teacher to position themselves away from the oppressive regimes they encountered as practitioners. This distancing projects the problem caused by learning disability care practice of the pasts upon the powers above and beyond the learning disability nurse. Therefore, it is the pressures of society or attitudes which placed people in institutions and the learning disability nurse could only perform within these parameters, thus, leading to an understandably less than perfect way of life for people with learning disabilities. The next section looks at the learning disability construct as a set of problems to be minimised.

There is a correct way

Risk assessments and management through surveillance (from both external bodies and self regulation) has become a feature of modern health care professional life (Gilbert, 2003) and as such all professionals are obliged to acknowledge this or become vulnerable. This was not the case and in the past when learning disability care incurred less regulation and accountability.

<u>Why do we need protection?</u>

In this construction, Mike relies upon a reaffirming of the medicalising discourse which states that people with learning disabilities are abnormal and have a tendency to act out of the ordinary, but also refutes the discourse which targets people with learning disabilities as evil or destructive. In this next story Mike uses the lessons learnt by a team of carers to advise students about risk assessment.

Mike:…I'll give you an example. I once remember someone who … ehhm … threw a kettle of water, over a carer. And the carer sued … the person in charge … of this place. Sayin' that ehhm … they'd not been informed about this. Yet … that carer had actually done a Risk Management ehhh … assessment. Including a care plan related to … the throwing of … ehhh kettle water and signed it. D'you … d'you know what I mean? So if she were actually ignoring the … the process that she'd been through herself, and then trying to sue …. So, d'you know what I mean? By having that sort of Risk Management policy in place there, that actually protected the service and the manager of the service. Yeah? And the … the carer themselves had actually signed to say they'd been through this. An' understood it and everything. OK?...(Mike, story 1, complete).

Mike constructs learning disability as a problem or case to be managed. For Mike there is a correct way to work as a nurse for people with learning disabilities. He views the learning disability constructions he uses in his stories as ways to illustrate '…*how something should be done…*' and that the task of education is to enable (through discipline) the students to do the right thing at the right time (Foucault, 1991).

Although the teaching session as a whole is instructional about the perils of not assessing risk, there is little mention in the story of the person with a learning disability who threw the kettle. In story (1) Mike problematises the behaviour of the person who threw the kettle as a factor which can contribute to a hazardous environment and reaffirms the idea that there must be something wrong with the person as this is not how one should act. This approach reminds me of the critical transformations Mezirow (2000) outlines as changes in *'habits of mind'* brought about often by a significant event or life change. Therefore Mike's story could be used by him to induce particular changes in the ways the students (those who listen) view

learning disability using devices such as metaphor in his story telling. He attempts to explain this in his interview.

> **Mike:** …One of the points that I have actually made in (*own research)* is that erm…teachers ought to be taught how to deliver metaphor properly...how to structure them?, how to use them? and how to deliver them? as part of teacher training…
>
> *Su: Are you talking about teaching methods?*
>
> **Mike:** …Yes. In order to actually create that sort of visualisation inside so that you can actually start to create thoughts as object in the mind in that sense, do you know what I mean? because if you think the word metaphor actually means, meta means over and above and metaphor comes from the same route of the word as porter which means to carry. Right? so you are carrying something over, so you are carrying something with you, so if the thought is an object you carrying the thought as an object then you are passing that object on through metaphor.'(Mike, interview extract).

It is possible that Mike's learning disability constructions illustrate dramatically possible life events which are constructed as normal in a learning disability setting but would appear abnormal if they happened in an everyday household. Not all households conduct risk assessments before using kettles, but not all household are lived in by people with learning disabilities. Mike's story (1) whilst serving as a device to reaffirm the medicalising discourses which constructs learning disability problematically at the same time also problematises the work of the carer.

My interpretations of this story focused upon the implications made by Mike that problems are inevitable but taking suitable action is important to the welfare of people with learning disabilities in receipt of care services. The dangers of hot kettle water highlighted by Mike originates not only with the person who is likely to throw it but

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also with the *'the carer themselves'* whom Mike sees as educated sufficiently to help avoid un-necessary incidents. For Mike having the knowledge and skills of a learning disability nurse are important factors which affect the way people with learning disabilities are cared for.

This construct assumes that applying the techniques of outcome management to people's lives reduces them to problems to be sorted out, eliminated or normalised. Nursing philosophies have tended to be preoccupied with a reductive approach to manage their time given over to the care of individuals (Draper and Thompson, 2001; Roper, 1996).

Assumptions

Other assumptions include professional talk of problems to be assessed or evaluated leading to the structured reduction of people with learning disabilities down to risks and commodities leaves them as units to be managed and organised. These are typified in the following assumptions. The many physical and psychological problems experienced by people with learning disabilities require medical intervention. These problems often define the nature of the health or social services the person receives. The medicalising of benefit places the person with a learning disability as unable or unfit to work. Although not sick in the acute sense, people with learning disabilities are ascribed the same as those with chronic ill health (Finkelstein, 1991).

Summary

This section has interpreted the stories which construct learning disability as case to be managed through the application of professional skill involving degrees of damage

limitation. Learning disability is often constructed in dramatic ways in these stories and prompts actions from learning disability nurses. The next section continues these themes and extends my discussion to the skills of the learning disability nurse.

Problems managed correctly

The construction of learning disability as a case to be managed draws from the medicalising discourse which sees that there is a correct way for professionals to behave. More recently professionals have become involved with the increasingly dominant professionalising language epitomised by Foucault (1972) as strategies, programmes, or technologies of power and control. Of these three variants, the programmes of care planning in learning disability services has been most obvious (Gilbert, 2003)

This is how to do it

In Mike's story (3) the medicalising discourse is drawn upon to illustrate Mike's certainty that the learning disability nursing skill involved in care planning can help improve the lives of people with learning disabilities.

> **Mike:**…Now … again, I'm goin' back to my … ehh, my days on a … sort of … secure unit if you like? We had a … woman on there who came to us and she had every possession. When I say possession, she possessed everything. She had … tape recorders, CD players, televisions. Stuff … cuddly toys, microwaves … photographs, picture frames, chairs, tables … and a hampers. Ehhm, she even had an air rifle. She had bikes, different … couple of bikes. And that … an' an, … she basically brought everything with her. And at first, we had to store all this stuff in a storeroom somewhere else. So she were on our unit and the storeroom was elsewhere. And this storeroom was like … just jam-packed. Top to bottom, full of her … belongings. Right?

An' … we set up a programme for her, so that … you know? once a day she could go and check on these belongings. Because … what she thought was that people … were stealing her stuff all the time. right? So … once a day we would take her. And the idea were, an' … we basically, the whole day was spent battling with her, over what time we were going to get these things. Who would go with … who'd taken her stuff? D'you, know what I mean?

An' … an' it was the entire focus of her day. So basically, we ran into lots of problems. So … we did what's called a paradox Right? Now, the paradox in this case was … rather than just having this programme, for once a day, we basically brought all her possessions into the place, so that she could go into the … whenever she wanted. Yeah? See we were … the original mind thought well … "she'll be in there all the time, she'd be creating all sorts of problems". But actually, once she knew they were there, and she could go in when she wanted, this fear actually stopped. …'

(Mike, story 3, complete).

The medicalising discourse features strongly in Mike's construction of a woman with a learning disability behaving oddly. As a case to be managed this woman brings a set of problems with her when she comes to stay, including all her personal belongings which are also constructed to be a problem. It is useful in my interpretation to consider the picture painted of the woman with a learning disability. She is considered to be abnormal to a great degree which means she does not currently fit into society's norms of behaviour. Anyone medically admitted to be care for on a *secure unit* is considered to be a danger to themselves or to others. These units are often staffed by nursing and other medically trained personnel including clinical psychology, psychiatry and occupational therapy teams with social workers (Beer et al, 2005).

The construction of learning disability and in particular the woman in Mike's story (3) is one of unsoundness, danger and unpredictability. Mike reaffirms the medical stereotype of people with learning disabilities as ill needing treatment and his story uses medicalised language *'...programme'* and *'...this case'* to position the woman as an in-patient. By constructing the woman in this way Mike draws upon a discursive mode to affirm and recommend the control by skilful and knowing professionals by what Foucault (1991) calls a *'...carceral network'*. Control of the woman is exerted by those with the insider knowledge (signified by the key to the store room in this secure unit), and Mike is communicating this as an important skill for his students to acquire.

Alternatively Mike uses the constructions of the woman with a learning disability in a different mode to refute the idea that learning disability is untreatable or pathological. His resolution resides in the appropriate actions taken by himself and others in the secure unit team. Mike considers that a challenge to the medicalising of the care which restricted the personal belongings of this woman was necessary and necessitated that the woman have access to her possessions at will *'...once she knew they were there, and she could go in when she wanted, this fear actually stopped...'*. By refuting the discourse which places blame with the woman with a learning disability it appears Mike is attempting to enable the students (and himself) to reflect upon their own actions and behaviour towards people with learning disabilities as he shares in a moment of the same teaching session from which the story originates.

> **Mike**:…The first part of Risk Management is? Risk assessments. We're determining here in your assessment, whether there are any factors that are

missing or there … that can have an adverse effect…' (Mike, teaching narrative, extract)

My interpretation suggested that Mike constructs people with learning disabilities as presenting problems when cared for by professionals, but that the complexity of the problem does not reside in the person's disability. Mikes' constructions in story 3 reveal his disagreements '...*So basically, we ran into lots of problems...*' with the medicalised discourse which places people with learning disabilities in situations which provoke their vulnerabilities and provide opportunities for more powerful agents to exercise control.

Commenting about story (3) Mike reasserts that he is using the story in a discursive mode which refutes the established view that learning disability is pathological, but also provides a personal platform on which to explain his own contribution to the medicalised systems of care.

> **Mike:**…And there's a number of things there's one about decision making there's one about challenging behaviour there's all sorts of stories could be brought out of this, there can erm be trust, there can be relationships with patients, service users and staff, there's something about going through proper procedures afterwards, there's something about taking advice from others, there's lots of lessons that can be drawn out of it erm so…'
> (Mike, interview, extract)

A useful interpretation could suggest that the relationship between the person with a learning disability and those who provide care can be constructed is various ways by the person telling the story. Mike is legitimising himself to tell the story in this way by drawing upon a discursive mode which positions him as an authority (and

theoretically the medicalising discourse advocate) in this particular case/story (Potter and Wetherell, 2004). As the woman with a learning disability is not present Mike is able to construct her as the victim of a medicalised system. This construction serves to assist Mike's stated aim to illustrate to the students through the use of an example from which '…*lessons that can be drawn out of it…*' (Mike, interview extract).

Objects and priorities

Mike utilises the professionalising discourse in story (2) when he uses a story/case of a woman with a learning disability to explain the skills of nurses to make decisions based upon the options they are presented with

> **Mike**: Yeah. I once remember … this person. And we … on the morning shift, this person had been playing up. Yet when you looked at the staff that were on the morning shift, it was no wonder she'd been playing up. 'Cause basically they were … ehh that set of staff that … are likely to … how can I say … deny her request as apposed to … yeah? Ehh… go along with them. So they'd have all sorts of problems with her. Now … in the afternoon, or the evening, there was like ehhm … a disco organised, within the service. Which meant that everybody else, in this particular place, was eligible to go to a disco. But this person had been playing up in the morning. Having said that, in the afternoon, she'd been fine. Fine and dandy. Yeah? And … the staff that were working with … with her in the afternoon had a good relationship. So … and … muggins here was in charge. So I had to decide whether because of her behaviour in the morning which I'd not been involved in. Yeah? I'd been … told, you know, that it'd been documented about all these sort of ehh … challenging behaviours if you like. Ehh … I had … I had to think about what here frame of mind is. I had to think about everybody else is going, so everybody else needs to be escorted. Which means, whoever … if this girl doesn't go, somebody's got to stay behind with her. Which some … is implications for that and … and I knew full well, if she didn't go, we're more

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likely to have … more incidents and behaviours. Yeah? So these were all that, these were the things that I had to take into account. For chance. So there I am. And I've … I knew that the staff I'd got with me were reliable staff. So … we all went. Which were fine and dandy. And we had a great time at this … disco. We all had a good time .And ehh … on the way back. We'd just about got her to the door. And this girl ran for it. An' I mean ran for it for it. You know? but she'd of given … Linford Christie a …. a run for his money. And basically, she was missing for three weeks. Right? So she went missing for three weeks. And she'd eh … she'd got … she had a history of ehh … arson. Yeah? So I spent three weeks really … ehh … in a bit of state. Yeah? But eventually we found her. And ehh … returned her … back … continued to work on her programme. Right? But … I would have still made the same decision again. D'you know what I meant? But at the end of the day, I could have been saved and stuck to the rules and said "ahh …no". She's got to stay behind because she's been … bad this morning. But that … then I'm sort of punishing her for something that happened earlier. Ehh … that she may have good reason for. And that … the … the problems that she might of caused back in … in the actual service itself would perhaps been even worse. D'you know what I mean? We might have been looking at, sort of violence and aggression all night long. And … an' perhaps, because of that, somebody else might have been …had to not go to the disco. Yeah?.

(Mike, story 2, complete)

In this story Mike draws upon the medicalising discourse which constructs the woman with a learning disability as a problem to managed '…*she'd been playing u…*'. He also utilises the professionalising discourse '…*I'd been … told, you know, that it'd been documented about all these sort of ehh … challenging behaviours if you like…*', which places the learning disability nurse at the centre of decision making power.

It is useful to place this story in the context in which it appeared in the teaching narrative as whole and this assist my interpretation of the learning disability

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constructions and the discourse Mike utilises. He explains (with the help of the student) his reasons in his teaching session just before telling story 2.

> **Mike** : …Risk Management is not about stopping things. It's actually about creating things. Ventures. Yeah? Sometimes, it is down to takin' a chance. It has implications for you as nurses then in, taking chances. D'you have to do that?
>
> **Student**: You … have to weigh up the consequences.
>
> **Mike** : Go again …?
>
> **Student:** You have to weigh up the consequences.
>
> **Mike**: Yeah I once remember…
>
> (Mike, teaching transcript extract).

My interpretation further developed the ideas that Mike feels are important to learning disability nursing, those of skill and knowledge. Mike draws upon discursive practices in a mode which reaffirms the roles of the nurse as powerful and important and also reaffirms the ideas that people with learning disabilities need to be controlled.

Summary

This section has highlighted the importance learning disability nurses place upon their skills and ability to control the lives of people with learning disabilities. The professionalising discourse produces a domain of language and a set of technologies which enable professionals to modify their actions accordingly and make decisions based on what they see are the needs of their clients. I now proceed to the next section which considers that tensions exist between the discourses which construct learning disability and those which construct the learning disability nurse.

We need to watch you for your own good!

Returning to the necessary surveillance by professionals suggested by Foucault (1991), many stories in this study constructed learning disability as something to be watched. The watching or surveillance is often constructed as *being for their own good* and is not necessarily a watching of curiosity, disbelief or admiration.

Nursing is a risky business

The construction of learning disability in Mike's story (4) continues the theme that people with learning disabilities are powerless and visible and that others are in control and watching. In the following story learning disability is constructed as abnormal and requiring the care of specialist and intuitive care staff who watch over. This story (4) is considered by Mike to be about the topic 'Risk management'.

> **Mike:**… I remember another … story … ehh … that someone told me. They worked in ehhm … sort of a group home, which I've … there were quite a few people in there. About ten or twelve people Ehhm … and they'd previously had locks on all the cupboards for the food. An' 'cause people used to go down and steal food. So what they did were … right, they'd made a decision over-night, no more locked cupboards. Big decision to make. Not … yeah? No more locks on cupboards or fridges or anythin' like that. And ehhm … everybody was terrified. And what happened was … one night, the first night, one of this … one of the guys who regularly stole food, came down, right? Opened the fridge, ate a full bag of frozen peas. Yeah? Then merrily went off back to bed. Never did it again…' (Mike, story 4, complete).

The main assumptions made by this story (4) are that it is quite normal for people with learning disabilities to want to steal anything which appears as food (even dangerous frozen items) *'...An' 'cause people used to go down and steal food...'* and

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that only ingenious and smart care staff can outwit this desire and ensure everyone stays safe. My interpretation suggested that Mike is aware of the reasons why people may steal food which has origins in the institutional living when people with learning disabilities often stole food or ate anything available through lack of health education (not knowing what was or was not food) or even because of hunger (Ryan and Thomas, 1995).

Mike constructs people with learning disabilities as 'unknowing' and the staff team as 'all knowing' and 'all seeing' in a 'panoptical' sense (Foucault, 1991). One theory of power offered by Foucault (1991) concerns the way society governs the behaviour of citizens. Hierarchical observation, according to Foucault (1991), encourages citizens as (objects of observation and discourse) to act in a disciplined manner because of the actual or perceived act of being watched or gazed upon by those with authority to punish. Those being watched are encouraged to act in a normalised way which is described by those with the ability (and therefore the power) to watch and regulate. The apparatus of this observation is further described by Foucault as a central architectural structure or 'Panoptican' from which those being watched are unaware if they are being observed or not but act as if they under constant surveillance just in case.

The surveillance of the people with learning disabilities by their carers is justified by Mike as the means to rid the people with learning disabilities of the need for locked food cupboards in their kitchen. The unlocking of the cupboards is suggested as the liberation of the house residents (although we are not told this by the residents in the story) by their carers who want to give them some freedoms. The changing

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construction of learning disability in the story although focused upon the people who live there in general is explained by describing the actions of one person *'…one of the guys who regularly stole food…'*. As a result of the new regime in the home to leave cupboards unlocked it appears that the man in the story unlike other people with learning disabilities never stole again (or at least not frozen peas).

Mike draws upon the medicalising discourse in a mode that affirms that learning disability is abnormal and that people with learning disabilities are potential problems to carers. Mike also draws upon the political discourse in a mode which refutes the strong medicalised view that people with learning disabilities are pathologised by their disabilities and can not be trusted to care for themselves. Is his story the people who lived in the house proved the staff majority wrong by not stealing when the cupboards were left open *'…Then merrily went off back to bed. Never did it again…'*. Although the attempt to refute the medicalised discourse is weakened by the constructions associated with learning disability as a problem my interpretation suggests that Mike wants the students to understand that people with learning disabilities can learn and adapt to their environment. By refuting the idea that people with learning disabilities are passive receivers of care Mike is advocating that people can care for themselves.

Although Mike draws heavily from the political discourse reserved for the disability movement which challenges the power of professionals over people with disabilities. There are tensions within the role of the learning disability nurse which he begins to reiterate in this interview explanation. Mike wants them to know that learning

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disability nursing and the skills acquired can work for people with learning disabilities.

> **Mike**:…Again there's a few things that came out of this because the guy went and ate the peas and never did it again, it was almost like, 'oh well I can come down here anytime then?…So therefore there's actually no need for me to use stealing behaviour… (Mike, interview extract).

The common care philosophies within learning disability care homes are based on normalisation principles (Wolfensberger, 1972) and have often been charged with assisting progressively thinking care staff to provide a more valued lifestyle for people with learning disabilities. As result the home aims to resemble any other ordinary household and has the same fixtures and fittings one would expect on a domestic house.

In providing evidence that the man who stole food '...*Opened the fridge, ate a full bag of frozen peas. Yeah? Then merrily went off back to bed. Never did it again...*' Mike is justifying the risk-taking actions of the staff team (leaving food cupboards unlocked and risking dangerous eating) and is constructing people with learning disabilities as either worthy experiments or useful collaborators (eating or not eating the food). Either way the person with a learning disability is constructed as unwise '...*merrily went off back to bed...*' and uninformed about the risks of unlimited food eating.

In this next story by Jacky, learning disability is constructed by the medicalising discourse as in need of care through observation.

Jacky: I actually went in and did a really serious complaint in an old persons home where staff had, that where the relatives had actually said this person was in a care home, he had got more serious dementia so they moved him into a care home for people with dementia and he was quite challenging but he had lost weight documented in the care home and then went to the new one and then by the time he entered pre-hospital and he had not received the proper care and they really weren't seeing to his dietary thing, he had lost something like 2 stone in a few weeks and he had got terrible pressure area sores and he was in a terrible state and he got severely dehydrated because nobody was monitoring his fluid intake and he actually died in the end. It was quite sad. These sort of relatives were absolutely totally appalled obviously at this lack of attention. They hadn't really been monitoring his dietary intake or his fluid intake. They had never looked at his communication need and how to deal with his behaviour to get him to eat and drink and nobody had really monitored it so. (Jacky, story 10, complete)

The man in this story is judged as a case needing appropriate management through observation and attention to detail '…*They hadn't really been monitoring his dietary intake or his fluid intake…*' Jacky constructs learning disability as a problem with a number of solutions. The medicalising discourse is utilised in this construction in the language of sickness '*dementia*' '*severely dehydrated*' and '*dietary intake*'. Additionally, the professionalising discourse has a marked impact upon the way the man was treated and the extent to which the treatment was justified as appropriate nursing action '…*and he had not received the proper care…*'. She constructs the problem not in only the person with an a learning disability (although he presents as a sick and ill case to be managed) but in the way those caring for him act '…*They had never looked at his communication need and how to deal with his behaviour to get him to eat and drink and nobody had really monitored it so…*'. Jacky draws upon these discourses in a mode that reaffirms and reinforces the need for the control of the

situation through observation by the nurses. If they had attended to the man's needs correctly instead of incorrectly *'...never looked at his communication need...'* and taken careful observations of his actions *'...totally appalled obviously at this lack of attention...'* he would have improved in health and survived.

Summary

My interpretations suggested that the construction of learning disability by Mike and by Jacky in this section as objects under investigation serves to reinforce the learning disability nurse with the expertise to control and manage the problem of learning disability, but only if they follow the rules. The rules may be typified by a moral conduct superior to that of other groups and unique to the learning disability nursing profession. Doing 'the-right-things' however can mean conflict with the larger systems of control and professionalism. The next section considers that learning disability care has a common goal.

Promoting independence is a job well done

The promotion of full inclusion into society of people with learning disabilities lies at the heart of normalisation philosophies (Wolfensberger, 1972). Although not without criticism (Brown and Smith, 1992; Malin et al. 2000), this tenet forms the main theoretical position for the White paper *Valuing People* (DOH, 2001) and as such affects modern services. One of the gains for people with learning disabilities attributed by the adherence (by service providers) to normalisation principles is of an increased independence leading to greater individual choice and improved social value. Service providers therefore often aim particular activities in pursuit of this goal

for people with learning disabilities (DOH, 2001). This section now considers the ideas constructed that learning disability is wholly a dependency creating situation.

<u>Who is in charge?</u>

Mike's story (5) constructs learning disability quite negatively. The woman with a learning disability is without agency and it is without responsibility for her actions, unlike the student nurse who is held responsible for the events, actions by herself and the woman. My interpretation questions the implications of independence for the woman with a learning disability.

'**Mike:**…Just remember a student who went out with someone, and this person was quite independent, went out all the time, independently. Yeah? Went to college by themselves, Went shopping by themselves and so on. But the student just was invited one … to go. He was stood at the bus stop and this … ehh … this woman belted somebody at the bus stop. Yeah? And the student were put in quite a … tricky situation.

(Student question) :What would you have done if you were in that position?

Ehhm ….You have to ….She had to … apologise to the … the woman. I mean basically, that could have happened if the student weren't there. D'you know what I mean? want to work, the student is there…. That that woman, or whoever she hit, was her fault? she was responsible, she should have….Hmm. Yeah, I mean, luckily, the woman was OK Yeah? Ehhm …but she offered things like that she could complain or who to contact an' …things like that. She apologised. And then they had … they had to come back and go through a big risk incident form, an' there were a big enquiry an' … this that and the other. Yeah?...' (Mike, story 5, complete).

Services for people with learning disabilities are dominated by the medicalising discourse of rehabilitation (Barnes, 1996; Finkelstein and Stuart, 1996; Gillman, 2005). Mike's construction of learning disability draws upon these ideas of

rehabilitating people with learning disabilities from being dependant to independent via a process assisting by contact with learning disability professionals and the services they provide.

For people with learning disabilities, this is realised in the service aims to reduce the independence and independent gap (Noble, 2005) and promote functioning in everyday skills like travel and shopping. Terms such as 'travels independently' or 'manages own money' are commonly used in learning disability services to denote someone who has learned the skills needed and therefore is expected to cope with such outings as travelling to a pre-determined venue by public transport (often college) or to a local shop to buy sweets or other treats.

The woman in this story fulfils this hypothesis '...*Went to college by themselves, Went shopping by themselves and so on...'*. It appeared in my interpretation that Mike is commending the successes of the woman to the skills of her carers. The medicalising discourse provides professionals with opportunities to relinquish their power over people but only when they have improved (Davis, 2005).The improvement constructed by the medicalised discourse is to be more independent, more socially able and reliable. Mike's story constructs the woman as only partially independent and my interpretation suggest that he is drawing upon his professional knowledge as a nurse who knows that the woman will always need support '...*they had to come back and go through a big risk incident form, an' there were a big enquiry an' ... this that and the other...'*

In the construction in story Mike (5) the medicalising discourse suggests that the woman with a learning disability needs some support and care as n order to live her life but those in charge of her care believe she can operate as other people do (independently) at the bus stop and at the college. This view is challenged when it is witnessed that she assaults someone at a bus stop.

Mike accesses discursive modes in his story that reaffirm the medicalising discourse that suggests that people with learning disabilities are flawed. He does not refute the idea that people with learning disabilities are likely to assault others; instead his affirmation is used to suggest to the students that learning disability nurses should be armed with management devices such as risk assessments. The lesson to be learned according to Mike is not how to prevent the woman from harming again but how to assess the likelihood of this happening and what actions should learning disability nurses take. Health and safety legislation is a powerful and persuasive tool in health and social care and motivates accountable professionals to consider ways to achieve compliance (Hasler, 2005).

The assumption in this story is that the woman with a learning disability is generally able to cope '…*quite independent, went out all the time, independent…*' and had earned the trust of her carers who then allowed her out unescorted. The story sits in the teaching narrative amongst discussions about risk taking and risk management of potential events by learning disability nurses, but not by people with learning disabilities.

> **Mike**: '…Also we have to take into account then … what risks there are to others. Yeah? So again, they might abuse others…' (Mike teaching narrative).

My interpretations suggest that Mike is constructing learning disability with uncertain potential in an attempt to demonstrate the powers that nurses wield over services. As agents of power nurses draw upon a web of administrative, professional and informal activities which attempt to direct the ways a person with a learning disability lives his/her life (Gilbert, 2003). The risk management process in this construction is suggested as a chore and unnecessary action, '*…She apologised. And then they had … they had to come back and go through a big risk incident form, an' there were a big enquiry an' … this that and the other...*' (Mike story 5). Mike draws upon the professionalising discourse to sanction the responsibilities of the student nurse as an agent of responsibility. Even as a trainee the student is assumed with greater social responsibility than the woman with a learning disability and it is expected that she will apologise on her behalf.

Summary

Mike's particular use of the medicalising discourse serves to both warn the students about the dangers they face as professionals from unwittingly committing negligent actions and also the dangers people with learning disabilities face from the expectations of others that they can really cope. The next section considers the firm assumptions that learning disability nurses have a positive effect on the lives of people with learning disabilities.

Of course you need learning disability nurses in your life

The relationships between learning disability nurses and those they care for shows in the learning disability constructions of the lecturer's stories. In many of the stories the learning disability nurse is constructed as the best professional to deal with the problems associated with learning disability because they have a historical connection which makes them best placed to understand their unique life needs. This section looks at the view that people with learning disabilities are at risk from other unknowing or less expert professionals.

Good things come from bad

The learning disability construction in Mike's story (7) positions him as an learning disability professional struggling for control. The people with learning disabilities are seen negatively and without the social skills Mike sees as necessary to cope with a day outing. Due to the length of the story it will be split into four parts.

> **Mike:**...when I were a student but I were doing my management assessment. And this charge nurse, ehhh … who … was a good friend of mine. Or is … is a good friend. I haven't seen him for a long time. But he used to think that … when students were doing their management … assessments, they were meant to earn it. So … I had to take the six, and I mean the six people with the most severe challenging behaviour. These people had not been out for like years. Right, and so he said you can do your management assessment but you've gotta take these folks out. (Mike, Story 7 part I)

In his attempts to affirm the skills of the learning disability nurse, he draws upon the discourses which problematise people with learning disabilities as behaving in extreme ways. By constructing people with learning disabilities as such and drawing

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upon the devices which strengthen his personal claims he justifies the actions of trained learning disability professionals. He therefore attempts to both reaffirm the role of the nurse through the legitimisation of the medicalised construction of learning disability and also to dispute the challenge that professionally qualified help is not justified. In story (7) Mike illustrates the struggles of the learning disability nursing profession.

The story is positioned in the teaching narrative of risk management and continues a theme of averting risk for learning disability nurses and at the same time trying to promote a degree of social life for people with learning disabilities '...*You have to take into account your environment...So.. therefore if there are risks from the environment, the person can also create risk to the environment...*' (Mike, teaching narrative extract). This complexity forms Mike's justification for the learning disability nurse's work.

The learning disability construction in this story draws upon the medicalised discourse which arouses the expectation that people with learning disabilities will act inappropriately in public and such their behaviour will need modification (Richardson, 2005). Mike constructs his story as an example of his own growth experience as a student nurse. The important feature in his story is that his needs for a successful day were more important than the needs of the people with learning disabilities. Those appearing in his story are constructed as actors in his portrayal of learning and professional development. The people with learning disabilities appear as the colourful actors playing farce to his serious assessment day.

The learning disability construction as potentially disruptive and naïve people adds to the tension Mike feels about his management assessment. The importance of passing the assessment is implied by Mike. He, as a student nurse, would have needed to complete this 'management of care' practical examination observed by a senior nurse colleague for a working shift (7 hours) to pass his nurse training, *'...But he used to think that ... when students were doing their management ... assessments, they were meant to earn it…'*. By earning it Mikes is referring to the management of a situation working with people potentially with the most problems.

Mike's construction of learning disability depersonalises the individuals whom he takes out on a day trip. Commonly, medicalised constructions of people difficult to categorise tend to depersonalise the individuals with a stigma that is deeply discrediting (Goffman, 1997). The learning disability construction featured in this story portrays the men with learning disabilities as anti-social and disruptive.

> **Mike:** …Now we had a number of… incidents…First of all … one of them was … ehhm … this charge nurse himself. There were me, a care assistant, another student, a charge nurse. And we got to Lake Windermere with these six clients. So we broke off into two groups with three people each. Yeah? Sounds like an SAS operation. An' … I … I'd got one lad who really likes beach balls. An' outside this little lock cabinet, this side of the ehhm the lake, one of these … these great big beach balls. So of course, you know, he … he's gone in … an' khhhh … beach balls everywhere. Right so … so we're running round getting these beach balls and that an' … an' then he's trying to get the beach balls off us, and I'm trying to stop him goin' in the * and ehhh for any onlookers, d'you know what I mean, it's just a *.So … that were an incident I had to deal with. Then we'd arranged to meet back at a certain rendezvous point. So … like I say it's like an SAS operate, at a certain rendezvous point…'. (Mike, story 7, part II)

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The six men in Mike's care for the day are viewed as 'guinea pigs' for Mike to practise his management skills upon. Mike's story reveals the practices of power featured in learning disability nursing at this time, when the decision where to go, for how long and which venue were made by the person in charge (Ryan and Thomas, 1995). Mike is invested with this power by those on the nursing team as ' in charge' for the day. His ability to manage difficult situations is proven by the events of the day '…*Now ... we had a number of ... incidents…'*. My interpretation suggested that Mike draws upon discursive modes which reaffirm he knows how it feels to be a learner. He uses the dramas of the day to illustrate the difficulties experienced by student nurses undergoing training. He makes some reference to the use of this as a device in his interview.

> **Mike:**… also it does legitimise you with the students….. in a particular way you can say yes well a similar thing happened to me in a service.
> *Interviewer: How important is that would you say?*
> I think that's very important because they see you as .we're imparting knowledge to them which they have to take on board. If we're not deemed to actually be walking the walk ….. you know? then they can question our right or place to give them that knowledge, whereas if we are walking the walk as well as talking the talk then I think it gives it more credence…'
> (Mike, interview extract).

In the interview Mike clearly talks about legitimising himself *'walking the walk'* as a person eligible and able to teach and advise students how to act towards people with learning disabilities. My analysis suggested that Mike's use of stories in various discursive modes construct learning disability in ways that enable him to illustrate the complexities of learning disability care and the role of learning disability nurses. I suggest that this learning disability construction as a problem to be managed through

military precision enables him to legitimatise his view that learning disability nursing is important and skilful. Although Mike reaffirms the discourse which suggests that people with learning disabilities are problems he also reaffirms the idea of the powerful nurses ability to control the situation and to lead the way! *'...Sounds like an SAS operation...'* As Foucault would suggest this is way to control *docile bodies* (Foucault,1991).

Outside of the hospital or institution both the nurses and their clients are conspicuous, on show, and being observed by the public (Foucault, 1991). People with learning disabilities have been commonly constructed as fools, clowns or freaks attracting the public's side-wise gaze on occasions (Hevey, 1992). The public in this story were observing the spectacle of six men and their carers performing like clowns in a comedy show or drunken youths on a stag night. Neither construction is positive for people with learning disabilities.

> **Mike:** An' when I got there, this charge nurse who was … something like six foot four and built like brick out house, yes? was, absolutely wet through. And so was another lad. And I said to him, "Well, what's happened?" and he said, well, well … this is the polite version. He said he'd been paddling, so this charge nurse had taken … one of the … the lads … paddling in the lake up to his knees. So they both got the …. their trousers and that rolled up. So they're just paddling in … in end of the lake sort of thing. And then they'd come out an' he was … drying himself off, the, the charge nurse. And … this lad had gone back in, but he'd gone back in … up to here. Right? So he's in the lake, now the other student that was with him all the time had been watching this and *. And done absolutely nothing about it. Right? So the charge nurse sees this lad in the lake, you know? So he runs in … to the lake, fully clothed. Drags him out, yeah? And … the lad's wet through, the charge nurse' wet through and he said … he said to this other student, who shall

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remain nameless. He said that "Why didn't you stop him going in?" And he said "Well you were already wet". Right? So there were that. So when we met up he weren't best pleased with me. This is on a … this … I'm being assessed for all this as well, you know?...' (Mike, story 7, part III).

Again reaffirming the medicalising discourses, Mike enrols a hero in his story in the form of the charge nurse *'...So the charge nurse sees this lad in the lake, you know? So he runs in ... to the lake, fully clothed. Drags him out…'.* My analysis considers that Mike is vesting the qualities of the learning disability nurse in the heroic actions of the charge nurse. He constructs people with learning disabilities as devalued and vulnerable saved by the skills of the learning disability nurse. This reaffirms the medical discourses which label people with learning disabilities needing total professional care and legitimises the hierarchy with the learning disability nurse at the top and the person with learning disabilities at the bottom (Foucault, 1991). These discursive modes are utilised by Mike in his quest to illustrate the complexities of becoming a learning disability nurse *'... I'm being assessed for all this as well, you know...'* when people with learning disabilities act so oddly in the public eye.

> **Mike:…**and then, on the way back on the bus, there's these … two lads having a go at each other. One … you know? Pullin' hair an' … an' havin' ….So I decided to separate them. So I moved the lad who were on the edge onto the inside, and moved the other lad across. So the lad, now, has moved onto the inside, next to the window, is not happy. And we're going down the M6 motorway. Bang … the whole window knocked out … onto the motorway. Right? So then … when we got back we had to explain to Polar Ford. This is oh … I mean … the most minor incident that occurred were basically ehhh …Somebody had puked up all at the back of the bus as well, so, we had to take this thing back to Ford that had … somebody that had vomited all over it, and ehhh … somebody that had smashed a window out. The

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window itself didn't actually smash, because they hit it with such force that the rubber seals and everythin' went. It all went as one unit. Yeah? But … so … they were … they were down one window, 'cause we'd had to stop an' phone the motorway police, who'd said there's nothing you can do about it, you're gonna have to leave it. Yeah? An' … so I had to drive along with that. Ehhm … so that was an eventful day. I passed by the way.' (Mike, Story 7, part IV).

In this part of Mike's story the learning disability constructions focus upon the negative and dangerous potential of people with learning disabilities. The medicalising discourse is again drawn upon as Mike agrees with the stereotype that people with learning disabilities will self destruct without intervention. In my interpretation I considered that Mike uses the language associated with children's behaviour when travelling in cars *'…two lads having a go at each other. One … you know? Pullin' hair an' ……Somebody had pucked up all at the back of the bus as well…'* ,to reinforce the idea that supervision by a skilled professional is essential to the well being of the group outing.

He also positions himself personally as central to the well-being of the men travelling on the bus by his assessment of the situation and in his inventions and actions *'…So I moved the lad who were on the edge onto the inside, and moved the other lad across…'*. Although the language used is not technical (Dyer and Keller-Cohen, 2000) Mike constructs the story by drawing upon the professionalising discourse which highlights the behaviours of the men on the bus and reinforces the skill of the learning disability nurse (or student on a management assessment) to decide what is the safest actions to take.

Summary

The teachers in this study drew upon devices in their learning disability constructions which reinforce the need for modern learning disability nurses and attempt to justify an escape into the past to remind the students of the dangers of previous and outdated practices. A useful interpretation could suggest that the stories containing learning disability constructions as a case to be managed are legitimised by the lecturers who now sees the situation for people with learning disabilities so improved (in contrast to the past) that the power and control learning disability nurses is a better alternative. Thus the reflections upon the past actions of learning disability carers as demonstrated in this section provides a platform on which to compare the differences between then and now and to justify the present role of the learning disability nurse. The next section moves on the consider a construct identified in this study, learning disability as different and strange

People with a learning disability are strange and different: should we include in them general society?

The construction of learning disability by professionals has been partially shaped by the contradictions and confusingly arising from the principles of care advocated by normalisation and the priorities of community care and rehabilitation (Moser, 2000). Ideologically, learning disability nurses have promoted the idea that people with learning disabilities should live like other people in society and experience the same benefits, however, these discourses which promote inclusion not exclusion can enhance the contradictions further when people with learning disabilities encouraged to live independent lives are still constructed as different and therefore dependant by learning disability nurses.

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<u>Can you live your life independently?</u>

In this story, Jacky describes the life of a person with a learning disability struggling to meet the aims of independent living like every other young adult, but additionally experiencing the perils of an unjust society. Jacky situates this story in a teaching narrative aiming to explore the role of the learning disability nurse working with families of people with learning disabilities.

Jacky: Okay – in actual fact, this lady, she had a very,… relationships with parents are never easy and how they get into patterns of behaviour like we all do in our lives are not easy and it's a continuous battle, an ongoing tension if you like, umh I worked with this lady, I am getting her to see how her own behaviour actually fed some of their over protectiveness at times and that what she would be doing, she would totally fly off the handle and lose her temper and what she would do she would empower herself but she would do it in such an inappropriate fashion, she would really upset them. She used to get herself into such a state that she would have, you know, a massive row with them but come across in a totally inappropriate way so they never took it seriously and then the next day she would be phoning them up again umh and it was a real trigger for her mental state, she did get really down about it. It was about getting her to try and see – one build her self esteem up in terms of seeing what she could manage and get her parents to realise that she weren't going to do the things exactly as they would do and live her life like they would because she was a different person from a different era, they were very quite elderly umh and to get her to see, she had a thing about, she did have a thing about the Outreach Support. She saw it very much as a very intrusive thing but she had not connected that with a greater independence from her parents so it was about not telling her that that was the way to go but getting her to think in those lines and that took a long time to get her to realise that actually accessing some support from somebody independent would actually support her to deal with the parents as well was a better way forward and it was a lot of struggle to get her to come to terms with the fact and negotiate with her that

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that was one of the avenues that were best open to her and that is what eventually happened but it umh the tension was always there between them and the other piece of work was working on the parents, getting them to see how odd comments she perceived as really really critical and that could send her off on a tangent for weeks sort of getting them to see how disempowering or the impact psychology that had on her for a significant period of time and that it would affect her mental state and again, the thing about being bullied, she was really targeted in that community but she did not want to give up her flat so it was about how that could be managed to allow her to do that and that involved in using vulnerable adults in and community police and her Dad actually posted a camera outside her flat door at one point to try and put them off knocking on her door. They had actually got in her door and stolen things from her a couple of times but she was so innocent she didn't realise that that was what they were there for and that ultimately triggered off her admission because she just deteriorated so badly so it was about negotiating with her where she needed to be but some of her expectations were really unrealistic. It was about trying to get her to see that and then advocating on her behalf to her parents so that they did see the impact on what their behaviour was having on her. (Jacky, story 22, complete)

My interpretation of Jacky's story began with the notions that the construction of the woman with a learning disability is one of a child-like adult without some of the responsibilities of adulthood '…*she was so innocent....*' The parents in the story are constructed as understandably overprotective (as parents usually are) but she ultimately is causing them to act in this way and as such is constructed with some responsibility for her actions '*...her own behaviour actually fed some of their over protectiveness at times...*' My interpretations suggested that the construction of learning disability in this story draws upon the inclusion/exclusion discourse popular in learning disability services and promoted by the political discourses which views people with learning disabilities as like everyone else with rights and responsibilities

(Chappell, 1992). However, Jacky's story also contradicts this view and presents the woman as vulnerable and innocent '…*They had actually got in her door and stolen things from her a couple of times but she was so innocent she didn't realise that that was what they were there for…*'. The woman constructed as strange and different to those around her and the view of learning disability nurses is that she needs support and help.

A useful analysis suggested that the discursive practices which construct learning disability in Jacky's story are reaffirming the political and inclusive discourse which assures the rights of all people to live valued lives in the community without the fear of persecution and violation. Alternatively, the discursive devices and modes assisting the learning disability construction also critique and question the same discourses which view people with learning disabilities as like everyone else, in fact Jacky's story suggests that the woman is very different to her neighbours and needs protection '...*that took a long time to get her to realise that actually accessing some support from somebody independent would actually support her to deal with the parents as well was a better way forward…*'. Jacky appears to be drawing upon the learning disability construction in the story to relate the tensions between the discourses she has experienced as a nurse herself which she also illustrated in her interview.

> **Jacky**: Because I think it really helps to bring the theory alive and bring it into a practice context in order to illustrate that for students so that they can think about things in reality and then the other thing is I always like to think about things in terms of the tensions and things aren't always umh clear cut in practice and I think the best thing to do is to give examples of that to introduce that idea. (Jacky, interview, extract)

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For Jacky the *'...things in reality...'* help her to explain the problems associated with the professional ideologies. The professional discourse of learning disability promotes the rights of people with learning disabilities to be fully included in society however implementing these ideas as a learning disability nurse may cause conflicts. It would appear that the discourses accessed by Jacky in her learning disability constructions reveal that the inclusion/ exclusion debate is not fully realised by learning disability nursing practice which struggles to enable people with learning disabilities full participation.

Is there a problem with normalisation?

The political discourse of normalisation contributes to the ideas that people with learning disabilities should be treated like anyone else in society is a technology based upon the assumption that people with learning disabilities are vulnerable individuals, devalued by the roles ascribed to them by society (Wolfensberger, 1972, 1983). In addition to the medicalising discourse which pathologises learning disability and cites the problem purely with the individual, the political discourse associated with normalisation places the blame with society and the services society sanctioned for people with learning disabilities. In general the discourse most commonly associated with normalisation is political and based upon the individual change of a person with a learning disability (adopting a new social role) or their social circumstances (other local people offering an opportunity to the individual) in order to achieve an improved life experience (Race, 2002). This next story by Sheila illustrates a local reaction.

> **Sheila** : There's a lot of strange people out there. That might have a learning disability that you don't know about. For example … we … we went to a car boot sale in *(local town)* on Saturday. I think I must open myself up for this

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you know? An' this … *idiot* of a woman wanted … a young girl really. Me dog was stuck … me dog's *old*, she's really old an' she's not very well, an' she stood next to me so she'd … walks into the dog. Looks down … an' instead of … goin' round … she tries to carry on walkin' shufflin' me dog … out of the way. I said "Ahh, you know, what are you doin'?" "Oh, I'm sorry, I didn't see her." I said "Yes you did, you just looked at … down, an' then … tried to kick … boot her out of the way. You know? It's … its not very nice." An' she started off on me, an' this bloke came from a stall because he thought I were gonna be smacked an' I thought … you know? all I'd say … asked for … was a bit of respect. An' I got this mouth. I says "Look, I think you're … over-reactin'." You know? "An' I think your aggression is probably because you realise you're in the wrong." "Don't you … preach to me …" you know? Blah, blah, blah. An' I'm sort of thinkin' … "Go home … it's not worth it … go home". But we had to go home we'd only just started, but she insisted on followin' us around. You know? And … I just thought I'd You …what do I do? I mean I … I ….What should I have done? No, she didn't say it, she just did. Yeah. But it's uncomfortable ….It's uncomfortable It was Sunday … eight o'clock ….In mornin'….Come on … it were freezin'. Well car boot sale I said. No. No, car boot sale. Yeah..…..I mean the example The example I'm tryin' to make there is community presence. I think ….I think I've got the right to claim my presence an' to walk round car boot sales …without being verbally abused. Now … as far as I could tell this girl … I mean I … I suspect she did have a mental health problem if nothin' else because she had a very limited vocabulary. Most of the words startin' with 'f' 'c's' or 's'. You know? 'One with a few 'b's. Ye … You know? And … I was … something that she'd just, rubbed off the … bottom of her shoe. But what I've … what I'm try to say is … I feel that I had a right to do that, but I felt I had that denied, because of her behaviour.

(Sheila, story 1, complete).

In this story told by Sheila, learning disability is constructed as a social problem to be managed. The woman although not identified as a person with a learning disability is constructed using the medicalising discourse of problem behaviour *'...as far as I*

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could tell this girl ... I mean I ... I suspect she did have a mental health problem if nothin' else because she had a very limited vocabulary... ', and as misunderstood by general society but understood by professionals. She struggles to explain why she constructs learning disability differently to those around her. The woman Sheila encounters on her social outing is not a client of hers and as such is outside her control.

Sheila both reaffirms the medicalising discourse which constructs people acting outside of the norm as different and '*...The example I'm tryin' to make there is community presence. I think ....I think I've got the right to claim my presence an' to walk round car boot sales ...without being verbally abused...'.* Alternatively, Sheila also refutes the construction of some people as strange and different and therefore to be avoided '*...we'd only just started, but she insisted on followin' us around. You know?...'*which encourages the different treatment of the woman to anyone else in the vicinity.

The development of the relationships between health care professionals and their clients is influenced by many past and present events underpinned by changing power relations (French and Swain, 2001). The medicalising discourse has been present in this development. French and Swain (2001) comment that three structural elements can be analysed in professional power and these can be used to explain how encounters between professionals and people with learning disabilities shape learning disability constructions within the medicalising discourse.

Summary

This section has outlined how the learning disability construct 'strange and different' which is represented by some stories in this study enhances my interpretation of the ways in which the main discourses relate to the discursive modes used by the teachers to construct learning disability . This construct is based upon the more common 'problems to be managed' ideas but appears across fewer stories as an indicator of some of the tensions which my interpretations revealed are inherent in the ways in which the learning disability discourse struggles with the role of the learning disability nurse.

This section has also discussed the ideas attributed by normalisation and the influence these ideas have upon learning disability construction in the stories in this study. The learning disability stories are intended to suggest that adherence to the principles of normalisation will ensure a better deal for people with learning disabilities. However, my interpretations highlighted some of the problems teachers experience when illustrating how they operationalised normalisation in their own practice. The following section concludes this final section of my interpretation

Conclusion

This chapter has demonstrated the construction of learning disability as a case/problem to be managed by professional help and in particular the help from learning disability nurses. The stories told by lecturers in this study provided me with a basis on which to present an analysis of the discursive modes used by lecturers in the construction of learning disability. In this chapter my interpretations have concentrated upon the learning disability constructions which have appeared to

demonstrate lessons to be learnt from past learning disability care. My analysis revealed that that learning disability is not easily a problem to be solved and many mistakes have happened.

The learning disability constructions revealed in many of the stories in this chapter, position the learning disability lecturer as an learning disability nurse personally away from the decision making of the past. The learning disability nurses are typified try to use their skills and knowledge to improve the lives of their clients but this is often undermined by the medicalising discourse which misunderstands the issues. learning disability is constructed as problem for a society that misunderstands it as 'strange and different'. This construct is although accepted by learning disability nurses (and sometimes reinforced) is understood in more depth than in general society and often than other professionals. This celebration of the greater understanding and knowledge of learning disability nurses can bee seen in the discursive modes used by some lecturers in the construction of learning disability. The differing discursive modes used to construct learning disability illustrate the extent to which the learning disability story is shamefully remembered or celebrated as a success.

My interpretations in this chapter revealed the tensions experienced by the learning disability lecturers when constructing people with learning disabilities as problems. The powerful professionalising discourse pressurises the use and affirmation of the language of risk assessment and risk avoidance and places the learning disability nurse in control. In contrast, and in competition, the discourses of social inclusion and humanism (originating in normalisation) inherent in the learning disability nurses role are accessed by the lecturers in an attempt to educate the students about the right and

wrongs of learning disability care. In most cases the construction of learning disability reinforces the important role played by nurses in the in lives of people with learning disabilities and promotes the continued work of the profession.

The next and final chapter considers my overall comments arsing from my quest to explore the learning disability constructions and my overall aim to *investigate the social construction of learning disability by teachers in the stories they tell to their students.*

Chapter six

Final discussions

Overview

The aims of this study were To *investigate the social construction of learning disability by teachers in the stories they tell to their students within teaching narratives.* This investigation took me on a journey emanating from an initial interest in story telling to a preoccupation with the intricacies of learning disability construction as influenced by general and specific discourses of medicalisation, profession knowledge and social policies.

This final chapter aims to summarise the main issues I have discussed and the questions I have raised to form what I consider are the 'key findings' emerging from this research study. My aim is the drawing together of ideas generated initially from the learning disability discourse, driven by the research approach and explored in the interpretation of learning disability constructions.

Generating the learning disability discourse

A learning disability discourse has developed over time and is driven by social policy and professional power. The key themes which have informed how learning disability is discussed both past and present originate in how we as a society view difference. Landmark legalisation sparked by the disability awareness and human rights agendas has promoted public accessibility for disabled and disenfranchised people, but the social construction of difference is still influenced by other factors (Swain et al 2005). Although care contexts for people with learning disabilities have changed over time,

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the discourses of illness and medicalisation continue to inform the language used by non professionals and professionals alike in reference to people with learning disabilities.

In general, there is a promotion of politically correct language intended to promote the tolerance of difference in mainstream society and in particular in professional discourses (Roberts, 1999; Tilley and Pollock, 1999). Theories of personhood and humanism delivered in professional education are intended to encourage post-modern thinking in the way difference is discussed by professional discourses. Culturally available discourses such as inclusion/exclusion of those constructed as different also influence professional discourses. What emerges are tensions in the ways in which aspects of difference such as being learning disabled are communicated by professionals.

Raising some questions about the social construction of learning disability .

In chapter two, I explored the intricacies of social construction and in particular the possibilities of studying the social construction of learning disability by analysing and interpreting the different ways teachers represented learning disability in the classroom narratives. Professionals, like the general population construct their realities from their own experiences and are constructed by the discourses with which they interact (Potter and Wetherell, 2004). One way to relate an experience is to tell a story, however the story can reveal many interesting insights about the conflicts and tensions individuals construct through their representations. These revelations can appear isolated when viewed alone (in one story or narrative), but in relation to the

bigger picture painted of the learning disability discourse they can enable us to understand the pressures of professionalism in learning disability care.

As Foucault (1991) reminds us, the origins of power are deep rooted in social practices and are promoted by society in an attempt to maintain control and social order. Following this argument, this study has demonstrated that learning disability constructions in stories are not merely postcards from the past but are indicators of the present and are a demonstration of the issues facing professional practice In particular learning disability nursing practice.

Many of the stories in this study showed some signs that the learning disability constructions are communicated in an attempt to justify the control of people with learning disabilities by professional others. The stories draw upon the medicalised language which restricts the descriptions of the learning disabled person as anything other than a problem or a case to be managed by a professional and thus affirms the role of the professional to legitimately occupy the caring role.

This justification is most evident when the teacher constructs learning disability drawing upon the medicalised language used specifically in learning disability nursing. By utilising this, teachers fulfil what for them are their stated aims (often stated explicitly within their interviews) to tell the 'real story' of what learning disability care is 'really like. Thus, the teachers are constructing their own version of reality based upon their work experiences, something the students in their audience can not achieve as these experiences can not be repeated. I would suggest that this is an important consideration in educational and training courses for professionals.

Revealing the tensions: A useful process?

The teachers in this study navigate between the pressures of the past and the present. These pressures have been reviewed in the literature and arise from the realities that learning disability nurses have worked in learning disability institutions which now considered unsuitable, contributed to the marginalisation of people with learning disability (Mitchell, 2003). At the time of the rise in institutional care (early 20th century to 1970's) people with learning disability tended to be constructed as a menace or a burden upon society and were marginalised promoting the use of secure and remote housing in institutions, which is Foucault's terms would be considered invisible (Foucault, 1991) . This changed as result of political and social priorities to consider the human rights and human economics of health and social care (Gilbert, 2005a) and the emphasis was placed upon community care and local housing provisions for people with learning disabilities. This led to a change in social construction from invisible and a menace to visible and vulnerable. I would argue that the change in the ways that learning disability is constructed by society has affected the learning disability nurse profession in a number of ways and is demonstrated by the interpretation of stories in this study.

The learning disability story has been widely told historically as a tragic and painful tale (Braddock and Parish, 2001). The narratives of ex residents through their contributions have provided images which made visible the medicalised routines carried out by learning disability workers and nurses and made the individuals appear as vulnerable and controlled with the nurses as tyrannical and powerful. Learning disability nurses however, have a different story to tell which represents people with learning disabilities as less vulnerable and more problematic, thus requiring the

specialist support of well qualified personnel. To this end the power of the story also reveals the socially constructed nature of the identities of the teachers as a learning disability nurse.

The representation of vulnerable people has provided some justifications for providing professional help for what society constructs as 'passive victims of an unjust past'. Professionals carrying out work with vulnerable people can be constructed by society as heroic and 'doers of good' (Brechin et al, 2000) and often do their work unquestioned by non professionals. At other times professional behaviour is demonised in the media as neglectful and institutionalised. Both of these representations helped to construct the view professionals may have of themselves and their role.

The specific learning disability discourse utilised by learning disability nurses expresses some interesting insights and can enable learning disability nurses to understand their present professional positions and the constructions of the learning disability nurse. The learning disability nurse draws upon a strong theoretical base influenced by the ideologies of normalisation and humanism and advocates the rights of their clients to lead valued lives (Walmsley, 2001a). The stories told by teachers illustrate the influence of such theory and of their own experience. These influences are further expressed in the interviews and the field notes of observations when the social constructions of learning disability is legitimised as a problem requiring a problem solver.

The constructions of learning disability in the teaching narratives do not consistently represent learning disability in the ways of general society. In contrast, the teachers attempt to construct people with learning disabilities both positively and negatively but reliant upon their professional help. The portrayal of people with learning disabilities as pitiful biological accidents or dangerously inhuman (Bogdan, 1990) has assisted the learning disability constructions in society generally, but enlightened professionals armed with knowledge and skills view this as wrongly held ignorance (Wolfensberger, 1972). There is therefore a tension between the learning disability constructions promoted by the general discourses of disability and difference and the modified constructions of them promoted by learning disability professionals/nurses.

In addition to this debate about the tensions between the general and more specific construction of learning disability (and learning disability nursing), there is also a debate centring on the differing constructions within the professions of learning disability nursing. The teachers in this study were drawn to the cultural representations of learning disability and the discourses which act powerfully to socially construct learning disability, but they are also compelled by their own experiences of the past.

This study has highlighted the power of the main discourses in the constructions of learning disability. The medicalising, professionalising, political and inclusion/exclusion discourses operate in different ways and lead to changeable learning disability constructions. Within one story a teacher can produce learning disability constructions which convey signals about themselves as confident or doubtful professionals, or supporters of new innovations, and as political cynics or

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optimists. This research has highlighted the different discursive modes which the teachers use to construct learning disability and can help to explain some of the tensions described above.

What can the modes tell us?

Through the interpretation of the learning disability constructions vividly portrayed in the narratives I identified three modes of discursive devices with which the teachers specifically constructed learning disability. The modes are not hierarchical and operate at differing times within a story. The three modes are complexly associated with the most powerful discourses of medicalisation and professionalisation and are most evident when the teacher is remembering a past event which either reinforces or contradicts current learning disability nursing practice.

The medicalised view is right, it justifies our place.

Mode One in this study, was identified as reaffirming the dominance of power in learning disability care. As Foucault (1972) reminds us, the origins of power are deep rooted in social practices and are promoted by society in an attempt to maintain control and social order. The interpretative approach taken in this study and the emphasis upon knowledge and meaning as being social constructed led me originally to consider that learning disability is social constructed and that the realities of the event described were created based upon the tellers use of constructive devices (Potter and Wetherell, 2004).

Many of the stories in this study showed some signs that the learning disability constructions are communicated in an attempt to justify the control of people with

learning disabilities by professional others. By utilising this mode, teachers fulfil what for them are their stated aims (often stated explicitly within their interviews) to tell the 'real story' of what learning disability care is 'really like. The stories drew upon the medicalised language which restricts the descriptions of the learning disabled person as anything other than a problem or a case to be managed by a professional and thus affirms the role of the professional to legitimately occupy the caring role.

You must challenge the system that's why you are here!

Encouraging criticality and a dialogue with the ideas of the past and the present is essentially the role of education (Connelly et al, 1997). If the confirmation of the medicalised view of learning disability relates to the first discursive mode in the construction of learning disability, the second mode I identified refutes the power and encourages a defiance of the general assumptions of the medicalised discourse. Within the same stories the learning disability constructions operate in this second mode and some of the stories use language and discursive devices which encourage a reconsideration of the generalised medical view that learning disability is a powerless and hopeless human condition.

This mode of discursive device operates to deliver the teachers obligation to educate and encourage critical thought in the student listener. The construction of learning disability in stories provided the teacher with an opportunity to pose a set of questions about the systems of learning disability care. In this mode the teacher often constructs learning disability above and beyond the generalised view in society (that people with learning disabilities vulnerable, or a burden) and often in a grandiose way i.e. more

disruptive or comical thus deeming the person with a learning disability to be even more problematic or more passive.

The learning disability construction often places the learning disability nurse or story teller as the advocate of human justice and provides a moral platform similarly to that advocated by normalisation principles of Wolfensberger (1972) to propose a radical change in the ways in which the 'others' in society construct learning disability. The influence of the theory of normalisation is strongly embedded in the stories. As the educated professional in stories of the past, the learning disability nurse constructs, and is constructed by the ideas expressed by society through the medicalised discourse. The challenge posed in the classroom is to refute this old fashioned or outdated medicalised discourse which defined institutional care and to encourage more enlightened thinking in a work force that will need to embrace change.

I was there at the time

The two previous discursive modes I identified as used in the construction of learning disability by the teachers can help explain some of the complexities in the relationships between the powers of the discourses and the tellers of stories. The third mode realises the potential of identity in the stories.

For the teachers in this study, the images captured and reconstructed in the stories represent events in their own lives. The meaning individuals attribute to an event can be affected by the wider historical picture (Hollway and Jefferson 2002). Thus, the learning disability constructions by the teachers positioned themselves as actors in

what they view are temporally situated events (Connelly and Clandinin, 2000) and may be affected by the present discussions in learning disability care.

The stories presented by the teachers in this study related to a past time when learning disability care was a contested practice operating in an unregulated fashion compared to the learning disability nursing practice of today (Mitchell, 2000a). It is interesting that the teachers told the stories and constructed people with learning disabilities as passive recipients of care from themselves. This view of people with learning disabilities as passive and receptive is not a view promoted in health and social care today (Gilbert 2003). Why then did these teachers construct learning disability in this unpopular and unfamiliar fashion?

The data in this study illustrates the complexities of the learning disability construction and in particular the complexity of the socially constructed identity of the teacher as an learning disability nurse. My interpretations placed emphasis upon the discursive mode of personal self which some teachers access in their stories. The personal identity as expressed in the discursive mode of learning disability construction by teachers in this study has revealed some of the characteristics of those torn between competing discourses. The teachers are constructed by fragmented discourses. They are constructed on one hand as experts in their field and with respect and status, but also they are constructed by the discourses attributed to the stigma of a past history of learning disability institutional care. As Polkinghorne (1988) reminds us, the transformation of knowing (experience of learning disability care) into telling (teaching students and telling stories) is a way that the teacher makes some meaning

of the learning disability world and their part played in it, this is possible source of tension for the teachers.

The teachers in this study positioned themselves as participants in events which they contest. The learning disability stories constructed in a personal mode drew upon the medicalising discourses in order to explain the role of themselves as a learning disability nurses in the past. The more political discourses of inclusion/ exclusion promoted by the ideas that everyone in society should treated with value and equal respect informed the view the teachers hold about their role as learning disability nurses.

The teachers appeared to struggle to be themselves in the story and to be equally alongside their clients, the person with a learning disability is positioned as an 'other' or outsider. This struggle is realised most significantly when the stories constructed people with learning disabilities as problems to be managed. As an learning disability nurse the teachers knew what to do and the learning disability constructions drew upon discourses which demonstrated their own professional skills with pride and justification. Alternatively, in the same story the teacher often demonstrated a significant reticence to accept that the medicalisation of learning disability is justified and may positioned themselves as outsiders to the professional decision making of the time and acting only under orders or the direction of others.

Some explanations of the struggles with their constructed personal identity can be found in the stories. The learning disability constructions served to both verify, the lecturers legitimacy to speak from experience about working with people with

learning disabilities and promoted their professional identity and status (Dyer and Keller-Cohen, 2000), and also provided a platform to call back the 'good old days' from their past when life was less complicated and nurses knew their role in the medicalising discourse. The teachers were less comfortable with their role as learning disability nurses now as they reflected back through their stories and began to make some meaning from the way they now construct learning disability through a combination of discursive forces and the pressures to be enlightened educators.

Contributions to the wider picture of learning disability constructions

This study has made a start at understanding the complex nature of the relationship between the construction of learning disability and the pressures of the wider discourses. It appears that for the teachers in this study telling stories about people with learning disabilities produced a tension difficult to hide. These tensions were experienced in many different modes and originated in the medicalisation of professional language and discourses. Research into the narratives and stories used to construct learning disability can promote an awareness of the power of the discourses emanating from professional and from political sources. It is important that future work looks further and wider at the implications for learning disabled people constructed as 'problems to be managed'. This work will enable the professionals to develop language use based upon people with learning disabilities as more equal members of society.

The limitations of this study

This study has its limitations, and it presented an in-depth analysis of the learning disability representations of one group of learning disability nurse teachers in one

university department. Within a greater time frame it would have been interesting to extend this to other similar groups of learning disability nurse teachers in other institutions. This would have provided an extended insight into the social construction of learning disability and it would be an interesting area for further study.

Additionally, this study has relied upon the interpretation of one key researcher (myself) which relied heavily upon my own reflexivity's and energies, it could be argued that this could have bee enriched by a more group approach to analysis as identified by Connelly and Clandinin (2000) in which other learning disability nurses or learning disability nurse teachers engage in interpretations and member checking of the analysis of data. Again this is an interesting area for further research.

Impact of this study upon learning disability nursing

The positioning of learning disability nurses as an important group working with people with learning disabilities is influenced by nurses but controlled by current and dominant policy contexts of health and social care. These dominant discourses are demonstrated in the language originating in the government White Paper 'Valuing people' (DOH, 2001) and the Labour government's wider agendas of change to health and social welfare (Burton and Kagen, 2006). At the heart of this agenda is the said need to promote more 'social inclusion', thus achieving a greater social harmony amongst UK citizens.

'Valuing people' based on the principles of legal and civil rights, independence, choice and inclusion was levied with the heavy responsibility of shaping the services available to people with learning disabilities. The constructed image arising post-

Valuing People is one of a world (encompassed many years earlier by Wolfensberger's principles of normalisation) in which people with learning disabilities can and will make choices in life guided by well meaning support workers and that these choices will enable the person with a learning disability to achieve greater economic influence and contribution. As a result of these and other changing fiscal powers, people with learning disabilities now can potentially achieve economic control through individualised funding or direct payments and ultimately have governance over the agents who offer social and personal care.

What affect this has upon the constructions of learning disability by professionals and in particular upon learning disability nurses is difficult to ascertain. The vested interests of traditional professional power based upon science and medical knowledge has been challenged and does not always sit comfortably with notions of equality and power sharing between nurses and their clients. From the discussions raised in this study, it is evident that the arguments against the domination of professional power based within a medicalised discourse are supported by current social policy (if it continues) seeking to curb the powers of privilege and capital.

Impact of this study upon professional education literature and research

The rising tensions of the learning disability nurse I have identified in this study that are visible in the stories could indicate that there is a need for a different kind of relationship between members of society and professional based upon something other than traditional power and knowledge. This study has raised some important questions about the relationships between the ways in which the vested interests of power and control appear from the past during learning disability nurse education. It

is apparent that the complexities of this story telling by teachers serve more than one purpose and that teachers are drawing upon personal experience to represent their own form of reality for students. However, the realities appear often incongruous with some present modern day discourses of health and social care. Therefore, I would suggest that a greater awareness is needed amongst educators about the potential of stories in education and particularly in professional education courses requiring experienced practitioners to draw upon their experience.

This is a challenge that could affect the nature of the professional teaching of learning disability nurses and the future of the profession as a whole. This is an area for further study.

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Appendix 1 –Colleague letter

Dear Colleague

Thank you for agreeing to assist me in this project.

I am currently collecting information for my doctorate thesis. I am particularly interested in teaching situations where students and teachers interact.

I aim to collect information in two ways:

1. Audio taping and observations of your teaching session with students.

2. An interview consisting of short questions about teaching sessions.

The focus of the information collection is on <u>what</u> is said rather than <u>who</u> speaks and for this reason I will not be using video, but I will be audio taping teaching sessions which will be transcribed to text. The subsequent analysis of the information will be treated confidentially and no names or locations will be used.

My aim is to provide any necessary information, which you require, and to ensure that no disruption is caused to the learning experience. Therefore if require any further information please feel free to contact me on 01484 473367 or e-mail s.a.shaw@hud.ac.uk.

Yours sincerely

Su Shaw

June 2000.

Appendix 2 – Student letter

Dear participants.

Thank you for agreeing to assist me in this project.

I am currently collecting information for my doctorate thesis. I am particularly interested in teaching situations where students and teachers interact.

The focus of the information collection is on <u>what</u> is said rather than <u>who</u> speaks and for this reason I will not be using video, but I will be audio taping teaching sessions which will be transcribed to text. The subsequent analysis of the information will be treated confidentially and no names or locations will be used.

My aim is to provide any necessary information, which you require, and to ensure that no disruption is caused to your learning experience. I will be making the audio transcripts available to you all with time set aside for discussion at a later date. Therefore if require any further information please feel free to contact me on 01484 473367 or e-mail <u>s.a.shaw@hud.ac.uk</u>.

Yours sincerely,

Su Shaw

Appendix 3- Interview schedule

Welcome: time setting.

Reasons for interview:-

"My research is interested in the different ways that personal and practice reflections are used in teaching."

" I don't intend to include any names or reference to places in any of the data so even 2nd hand information will not be named is that Ok?

" Please ask me any questions if you wish to know anything further."

Prompts

" Are you aware of any particular personal or professional reflections
 you use in class with students?"

" Can you remember using this one recently"

" Would you call this a story"

" Do you reuse any stories?"

" What made you decide to use this story/reflection"

" What purpose do you think it serves in the session?"

" How do you think students react to these"

" How do you feel when you use this story or others like it?"

" How do you feel LD nursing has changed over the years"

"How long have you been teaching now and how long were you in learning disability nursing practice before that?

" Have you any other comments about the use of story in teaching?"

Thank you for your time.

Appendix 4- Supplementary Interview schedules

Supplementary Interview Schedule for Charles

Charles Extract 1

"…Meningitis yeah can lead to learning disability. 'Cause that's like … again, when, … when I was workin' up in Scotland, I worked in a large institution up in Scotland. And … there was somebody on there who was a twin. And … the other … her other twin … didn't get meningitis. Obviously. So … she used to come in, an' again, I don't mean this to sound sexist in any way, but when she came in, you know sort of like … all the … all the male staff used to make her cups of tea an' they used to sit her down an' stuff like that, that you get a picture of what she was like. But her twin, who had meningitis, had a learning disability, she was in long stay institution, I mean … it was really good to see the difference. I don't mean the word 'good' in that it was good that it had happened to her. But it was good to see the difference. She was in a long stay institution, she was on Largactol, which meant that when she went out in the sunlight it caused ehhm … brown patches on her skin an' stuff like that. Ehhm … other medication that she had also caused her to have … ehhm … facial … develop facial body hair. You know, an' to look at the two side by side, it was quite something to see. An'; in terms of the difference between somebody who has a learning disability, it … you … you know …it's … it's quite profound, an' it really affected me to see that. What could happen if somebody had a learning disability, through something like meningitis. An' the way that her life course went compared to her sister. You know her sister had a … a job in a bank. She always came in an' she was smartly dressed. She was drivin' around, an' yet her twin sister was in … a long stay institution in Scotland, it was … it was … quite amazing really." (Tape 07/03/02)

Charles Extract 2

"…Yeah, big ears, big noses. Deformed, frightening, yeah. That's very much … the kind of thing … that you associate with Hurler's Syndrome.   An' it may well have been that the Hunch Back of Notre Dame had Hurler's Syndrome … along with … that you get things like mental health problems. Ehhm … you know, if you think about the … the Hunch Back of Notre Dame, not the Disney version, but in like the film version. You know, I think that's very much the characteristics of somebody who has Hurler's Syndrome. An' the mental health problems even that might explain why he's always swingin' from the bells of Notre Dame cathedral, 'cause … * sings an' want to do somethin' like that. Along those lines as well, when … when you look at somethin' like Hurler's syndrome, an' the Hunch Back of Notre Dame an' the association with gargoylism, you can link that into … into this kind of social aspects as well. If you think about that the side of churches, they had people who had who had … gargoylisms, you know, where they named, gargoylism after those things. Then … why are they on churches? This is the point I'm tryin' to make … d'you know why they're on churches?…To frighten   away ….Evil spirits it's meant to be from the church. So … people who go to church will see these an' * what's that for? Or somebody like that will frighten away the evil spirits. So if you come across somebody in the street who has gargoylism, way back in the … the dark ages or whatever ….You're gonna be pretty frightened of this person aren't ya? Because … you've learnt that it frightens … spirits away from churches. You know … so you … you can look at that in social development, with people with learning disabilities, an' some of … the concepts an' ideas we might have now … about the people with learning disabilities, might be related to things like that. As well as just general fear … with people about the evil spirit *. So there's … there's always that wider picture people, keep thinking…"

Supplementary Interview Schedule for Kit

Kit Extract 1

"…original solicitor … well, he's actually retired now, but he … he had quite a lot of anecdotes of whereby people would … ehhh … where people have become injured. I mean one of his was a … a case of a … a gentleman who'd been suffering a lot of ehm … a lot of … physical pain. Sort of abdominal pain, he had loads an' loads of investigations. An' it had gone on for lots of years, an' this … ehhh … physical pain, an' all these ehhm … all these investigations that he'd had, an' then eventually, someone actually …did ehh … an operation, an' found that he'd had … ehh … a piece of tube left in him. Ehhm … he'd actually swallowed, I think he'd swallowed his … his rice tube or somethin'. I can't remember the full day … details of it. Ehhm .. and this had actually been causin' loads of pain, but no one had actually …found that this had happened. An' this was for like … for three or four years that this had gone on an' he had three years to bring his case from … in finding out that this was actually causing his distress.So … it can be quite some … significant time later, that people can bring their case more or less can't it?..."

Kit Extract 2

"…I certainly when .. when I trained, ehhm … the … thinkin' the … lookin' through the procedure manual, and … the within the procedure manual it said ehh … if … "If the patient becomes violent" ehhm "then you must …" ehhh "roll them in their blankets with the minimum force necessary". Now that's … quite creative because it was very difficult to find a blanket.. Somebody get me a blanket. Just seemed an' absolute … I think it was crazy at the time,…"

Supplementary Interview Schedule for Mike

Mike Extract 1

"…Yeah. I once remember … this person. And we … on the morning shift, this person had been playing up. Yet when you looked at the staff that were on the morning shift, it was no wonder she'd been playing up. 'Cause basically they were … ehh that set of staff that … are likely to … how can I say … deny her request as apposed to … yeah? Ehhh … go along with them. So they'd have all sorts of problems with her. Now … in the afternoon, or the evening, there was like ehhm … a disco organised, within the service. Which meant that everybody else, in this particular place, was eligible to go to a disco. But this person had been playing up in the morning. Having said that, in the afternoon, she'd been fine. Fine and dandy. Yeah? And … the staff that were working with … with her in the afternoon had a good relationship. So … and … muggins here was in charge. So I had to decide whether because of her behaviour in the morning which I'd not been involved in. Yeah, I'd been … told, you know, that it'd been documented about all these sort of ehh … challenging behaviours if you like. Ehh … I had … I had to think about what here frame of mind is. I had to think about everybody else is going, so everybody else needs to be escorted. Which means, whoever … if this girl doesn't go, somebody's got to stay behind with her. Which some … is implications for that and … and I knew full well, if she didn't go, we're more likely to have … more incidents and behaviours. Yeah? So these were all that, these were the things that I had to take into account. For chance. So there I am. And I've … I knew that the staff I'd got with me were reliable staff. So … we all went. Which were fine and dandy. And we had a great time at this … disco. We all had a good time.And ehh … on the way back. We'd just about got her to the door. And this girl ran for it. An' I mean ran for it for it. You know … but she'd of given … Linford Christie a …. a run for his money. And basically, she were missing for three weeks. Right? So she went missing for three weeks. And she'd eh … she'd got … she had a history of ehhm … arson. Yeah? So I spent three weeks really … ehh … in a bit of state. Yeah? But eventually we found her. And ehh … returned her … back … continued to work on her

programme. Right? But … I would have still made the same decision again. D'you know what I meant? But at the end of the day, I could have been saved and stuck to the rules and said "ahh … no". She's got to stay behind because she's been … bad this morning. But that … then I'm sort of punishing her for something that happened earlier. Ehh … that she may have good reason for. And that … the … the problems that she might of caused back in … in the actual service itself would perhaps been even worse. D'you know what I mean? We might have been looking at, sort of violence and aggression all night long. And … an' perhaps, because of that, somebody else might have been … had to not go to the disco. Yeah?..."

Mike Extract 2

"…I … I remember another … story … ehh … that someone told me. They worked in ehhm … sort of a group form, which I've … there were quite a few people in there. About ten or twelve people Ehhm … and they'd previously had locks on all the cupboards for the food. An' 'cause people used to go down and steal food. So what they did were … right, they'd made a decision over-night, no more locked cupboards. Big decision to make. Not … yeah? No more locks on cupboards or fridges or anythin' like that. And ehhm … everybody was terrified. And what happened was … one night, the first night, one of this … one of the guys who regularly stole food, came down, right? Opened the fridge, ate a full bag of frozen peas. Yeah? Then merrily went off back to bed. Never did it again. Never bothered. Because it was almost like …well … it … it's here now all the time. So … I don't need to … sort of steal. An' … an' so … the actual … paradox was that the stealing behaviour is actually stopped when they have more access to the … to the food than when the food was locked up…"

Supplementary Interview Schedule for Jacky

Jacky Extract 1

"…I actually worked with an' individual … a lady … at (*learning disability hospital*) And ehh … this posture here, where everything was fixed like that. She were actually … fixed in that position an' she was like a board … she literally was flat in that position. An' had to be lifted flat into an' laid flat. It was *so* severe … that … she'd no … major movement at all…"

Jacky Extract 2

"…An' when I worked at (*practice area*)… we had a young gentleman … who came from school and ehhm … at school, through the Statementing process… an' the Education Act … children … with cerebral palsy do tend to get a lot of input from physiotherapist an' occupational therapist an' speech therapist … because it … they've got a … ehhm … there's a *legal* responsibility to do so. An' you'd have these hand splints … which stretched out all his fingers and his wrists. And that … when … when he went to school, they used to make him put them on … he's, … you know, used to cajole him into puttin' on them on. An' it was a very slow process cause … it were quite painful for him.   So … gently stretch out his hands an' his wrist an' put the splints on to maintain … a good alignment. An' I came to do me at ****… an' he didn't have these ehh … occupational therapy inside there. Physiotherapist, teachers, sisters who'd caj … cajolin' every day … over many years in the same school. He really didn't want to put them on. He used to cry at his mum an' use emotional blackmail to … ehhm … deter … her from puttin' … puttin' them on him. An' in some ways we would say wouldn't ya really, they had a *choice* about whether he'd wish to do that. He did use to cry, but then we used to try … to stretch them out … one where you got to the day care unit … you're not … there were odd occasions when he were that determined that they weren't gonna do it, that they couldn't. An' it were a slow, gradual process, in which he really opted out of it an' chose not to. An'

his hands were really … quickly deterioratin' an' contracted in. An' now they're very set in position…"

Supplementary interview schedule for Sheila

Sheila Extract 1

"…And … a lot of the clients … were patients in (*Learning disability hospital*).The first ones that went out … I remember a lady goin' out … went out kickin' an' screamin', she didn't want to leave … her boyfriend was still up at *…(learning disability hospital)*. Alright … she was sixty odd, but her an' this bloke … had been friends … boyfriend an' girlfriend for forty years. An' he wasn't allowed to visit her because they'd be on their own an' unsupervised down there.She did … even know how to cook. She didn't know how to get to a fish an' chip shop. It was round the corner. So this is how much preparation went into it. She could talk so therefore should find out. But that was the reality … of what was goin' on.It quickly altered. It very quickly altered. But there were bad experiences like that that happened. An' I mean … remember these are … these are actually experiences I've been … ehhh .. akin … you know, sort of … privy to. They're not things that are just written up in books. These are actual things that happened within this local.

Sheila Extract 2

"…Because I believed … when I first went up to work at *(Learning disability hospital*), that I was gonna … be terri … ah … that … I couldn't cope with it, that I was gonna be attacked. That it was a frightenin' place to work. And … the … and … that the people that lived up there … were nothin' better than … really animals that walked upright. An' I've gotta be honest, that's how I felt. I was terrified. I don't believe that now…."