Problems, problems: You are such a problem!

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Abstract

A learning disability discourse has developed over time and is driven by social policy and professional power. Landmark legislation such as the Disability Discrimination Act 1995 has promoted public accessibility for disabled and disenfranchised people. The social construction of difference and disability contributes to the ways people with learning disability are seen and described by others. Many professionals tell stories about their experiences of working with people who are learning disabled. Some stories construct the people with learning disabilities as heroic and tragic, but most construct them as problems to be solved. This qualitative study demonstrates that learning disability constructions in practice-based stories are not merely postcards from the past but indicators of the present and are a demonstration of the issues facing learning disability nurses. I argue that there are tensions in the way learning disability is constructed and ultimately communicated by learning disability nurses.

Keywords intellectual disability; learning disability; learning disability nursing; qualitative; social construction; stories

Introduction: raising some questions about the social construction of learning disability

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 about one's own experience. 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.

Positioning 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 manifested as discourses of health and social care. These dominant discourses are demonstrated in the language originating in the UK government's commentaries in *Valuing People* (Department of Health, 2001), *Valuing People Now* (Department of Health, 2008), *The Same As You?* (Scottish Executive, 2000), *Fulfilling Promises* (Welsh Assembly, 2002) and *Equal Lives* (DHSS, 2005). These have been at the heart of the Labour government's wider agendas of change to health and social welfare (Burton and Kagan, 2006). Central to these changes have been the said need to promote more social inclusion and independence for people with learning disabilities, thus achieving a greater social harmony amongst UK citizens.

What effect this has upon the social constructions of learning disability demonstrated through the language of professionals and in particular of learning disability nurses is difficult to ascertain. The vested interests of traditional professional power based upon science and medical knowledge have been challenged by discourses of inclusion and empowerment and do not always sit comfortably with notions of equality and power sharing between nurses and their clients. I would argue that the powerful position of learning disability nurses is within a medicalized discourse and is supported in this by the current social policy (if it continues). However, the alternative position for learning disability nurses to adopt is to challenge the privileges of power and increased social capital denied to their clients and to promote a power sharing approach. However, this creates a dichotomy and a tension between learning disability nursing, social policy and traditional medicalized discourse which I will further explore in this article.

The related study

This article draws upon the conclusions of a qualitative study. The study utilized a variety of qualitative research approaches to analyse a selection of stories (together with interviews and related classroom observations) about learning disability nurse practice told by five learning disability nurse teachers to nursing students in the classroom. I aimed:

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

The resulting study utilized an investigative style based upon theories of discourse (Foucault, 1991) and discourse analysis (Potter and Wetherell,

2004) to uncover the complexities of the way learning disability is socially constructed. This was achieved by highlighting the dominant discourse in the stories and the influence this has upon the language of healthcare and professional power. A selection of the stories, interviews and teaching session extracts told by teachers to their classrooms of students are used in this article to illustrate what I view as the power of the medicalized discourse in the social construction of learning disability.

Methodology

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 nurses. The questions posed aimed to uncover some of the complexities of a social world constructed by a powerful group. Foucault (1991) reminds us that the discursive practices of language used by powerful groups serve to protect and promote their own interests.

Study design: a series of stages

In this study the first priorities were based upon the interest in collecting teachers' stories as they are told to students in the classroom, and therefore this formed the central focus. The design was intended to be flexible enough to utilize any themes from initial analysis of the first collected stories from 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.

Figure 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.

Data collection: the samples

Sample size, sample shape and the 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.

Using teachers. 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- generalizable and too small to be representative (Silverman, 2000). This study was designed from the original collection to the data analysis to

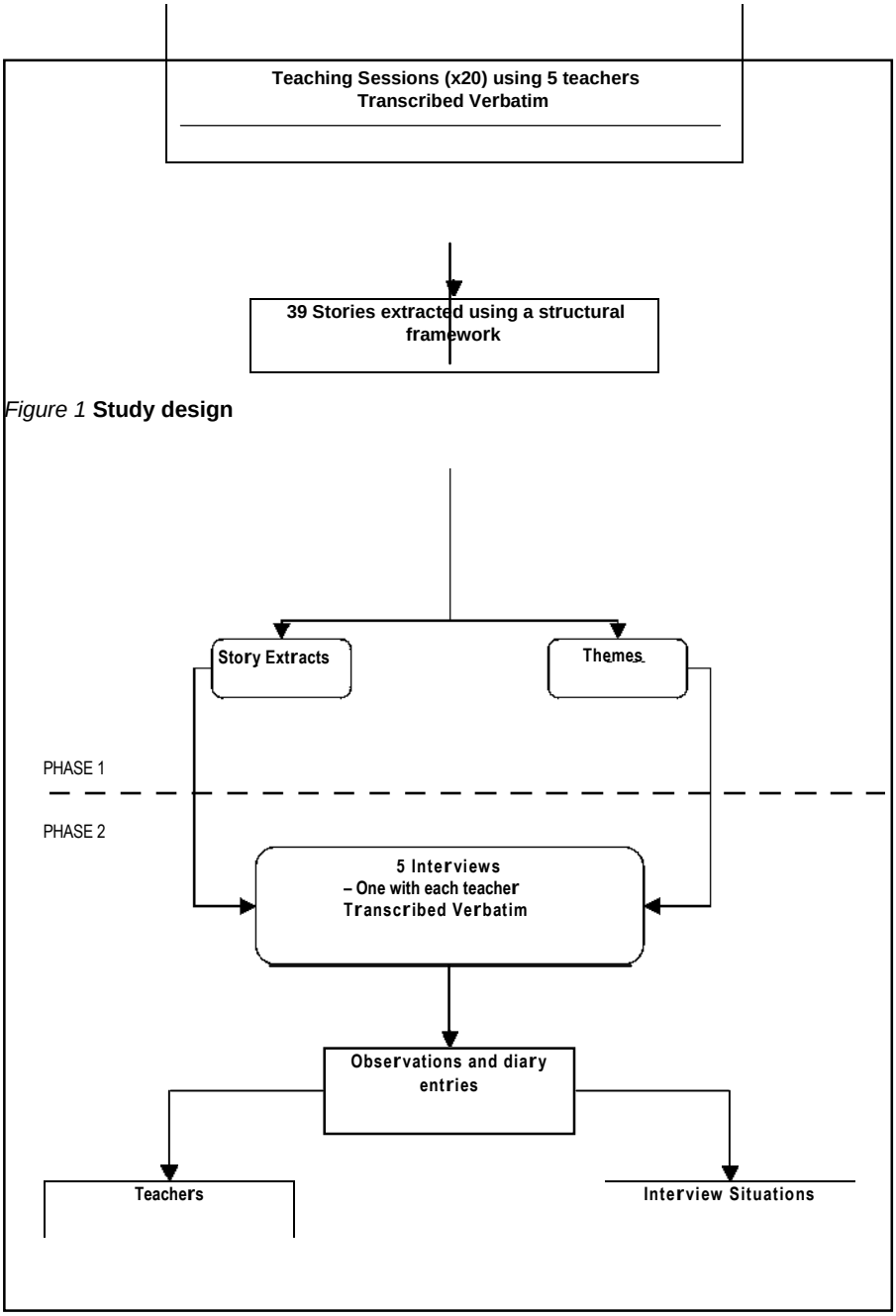

Figure 1 **Study design**

collect meaningful and rich data from the teachers' sample. Table 1 explains the types of data collected.

Table 1 **Data collection**

Types of data	*Method of collection*	*Amount collected*
Data type 1 Learning disability teacher lectures given to learning disability nursing students (classes range from 1 to 4 hours)	Audiotaped 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
Data type 3 Interview between the teacher and the researcher	Audiotaped and transcribed	1 interview with each teacher, total 5
Data type 4 Researcher observation upon interviews	Written observations	1 set of notes for each interview, total 5

Analysis

This study generated data in many forms; teaching session transcripts, extracted stories, teaching session 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 classroom encounters with students.

The analysis that followed involved the coding and recoding of extracted stories, interview transcripts and field notes/observations (Ely et al., 2001; Morse et al., 2001).Table 2 indicates how the dominant four discourses (medical, professional, political, inclusion/exclusion), which I initially identified in both the literature and the narratives within the teaching sessions, stories and interviews, relate to the following three common learning disability constructions:

- cases to be managed
- strange but different
- victim of professional dominance.

The information in Table 2 gives an overall picture of the complexities of the discourses, themes and constructs which contributed to the identified learning disability discourse as expressed in the stories within this study. I would argue that these complexities contribute to the ways in which their learning disability practice is discussed by learning disability nurses.

Table 2 **Story themes, learning disability constructs, and dominant discourses**

Themes in the stories	*Related constructs*	*Common discourses*
Problems to be sorted out	Cases to be managed	Medicalizing Professionalizing Inclusion/exclusion
LD as special knowledge	Strange but different	Professionalizing
Unknowing and vulnerable	Cases to be managed	Medicalizing Professionalizing Political
Controlled lives	Cases to be managed	Medicalizing Professionalizing Political
The end justifies the means	Strange but different	Professionalizing Inclusion/exclusion Political
Ill and in need of care	Cases to be managed	Medicalizing
The more disabled, the more visible	Victim of professional dominance	Professionalizing Inclusion/exclusion
Everyone is a person	Strange but different	Political
It's a shame, it's a tragedy	Case to be managed	Medicalizing
LD is ugly	Victim of professional dominance Cases to be managed	Medicalizing
Strange is not OK	Victim of professional dominance	Medicalizing
New labels, same person	Victim of professional dominance	Political
LD is misunderstood by society	Strange but different	Political Inclusion/exclusion
Two dimensional: lacks colour, shape and form	Cases to be managed	Medicalizing Professionalizing
Abnormal and at mercy of parents	Cases to be managed	Medicalizing Professionalizing

Findings

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 was 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 the discourses are separated into four groups in this study, 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 common discourses identified (see Table 2) do have individual characteristics which usefully assisted the interpretations and analyses of the learning disability constructions in this study.

1 medicalizing discourse
2 professionalizing discourse
3 political discourse
4 inclusion/exclusion.

The medicalized discourse and the social construction 'cases to be managed'

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 *medicalized care* for people with learning disabilities. It is the main preoccupation for this article as it formed the most dominant influence upon the stories in the featured study. This arises from the histories of institutionalization, views about physical impairments, genetics and medical diagnoses. The nurse teachers featured in the study drew heavily upon language and imagery which reflect the way people with a learning disability have been, and are still, constructed as medically ill and in need of special care and confinement. This relates to the three learning disability constructions (see above) which I identified as important indicators in the stories and subsequent interviews. The main learning disability construction discussed in this article is *cases to be managed*.

The medicalized learning disability story

The narratives of former hospital/institution residents have provided images of the medicalized routines carried out by learning disability workers and nurses (Brigham et al., 2000). The constructions made the individuals appear as vulnerable and controlled and 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 social constructions used by learning disability nurse teachers who are themselves learning disability nurses and who believe they are the best placed group to offer care and support for people with learning disabilities.

Central to the many debates between learning disability professionals concerns the application of care for people with learning disabilities based on the medical model, 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 both the way in which professionals discuss people with learning disabilities and the way others are persuaded to act towards them in general society (Edgerton, 1967; Oliver, 1990).

Story examples

Two stories told in the classroom by two nurse teachers, Stella and Jade, illustrate the power of the medicalizing discourses in the construction of learning disability as problems/cases in need of professional help. In Table 2 it can be seen that the story examples drew upon various combinations of the four common discourses, and many themes were highlighted after the analysis. In particular I draw upon two stories and information from supporting teacher interviews and teaching sessions which construct people with learning disabilities as powerless victims or problems to sorted out.

The medicalized discourse: you need help

The medicalizing discourse is said to create dependence in two ways (Oliver, 1990). First, the person with a learning disability becomes *a client*, *a patient* and *a service user* who is said to need the services of trained individuals to successfully navigate through life. Second, the professional needs the clients and patients to justify salary, work patterns and standard of living. The following story was told by a learning disability nurse teacher (pseudonym Stella) to a classroom of students. It illustrates the medicalized discourse which categorizes and labels learning disability and has operated as a powerful decision making mechanism in the care of people with learning disability now and in the past.

> Stella: And . . . a lot of the clients . . . were patients in [local learning dis-ability 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 didn't . . . 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. (story used in teaching session)

The woman in Stella's story has a strong will which is demonstrated by her actions: 'I remember a lady goin' out ... went out kicking' an' screaming', she didn't want to leave.' But this will is not acknowledged. She is constructed as unfortunate and at the will of others more powerful who make the decisions about her life. Stella constructs the woman as being misled during her transition from long-stay institution to a home of her own outside.

The discursive practice which constructs learning disability in Stella's story *reaffirms* the dominant discourse which has often viewed people with learning disabilities as different and vulnerable. The woman in this case is different because of her experiences in the learning disability hospital making her dependent and in need of care, and not necessarily because of any biological impairment (Brigham et al., 2000). This difference was enough to present her as a problem to be adequately managed by professionals (learning disability nurses) during her move to the community. By accessing this level of discourse to construct learning disability as a real problem she has experienced, Stella appears to both *challenge* the motive of those organizing the relocation process for the woman and also *reaffirm* the construction of the woman as powerless in the process of the move. We are left wondering if the woman would have preferred to stay in the hospital: would she have become a greater problem? And was her advocate a learning disability nurse? The problems emphasized by Stella are attributed to the woman needing rehousing, but her reason for being in the hospital is unclear. History would suggest that she would have been a social problem within her community (Braddock and Parish, 2001).The present inclusion agenda would not advocate this.

By *refuting* the more general principles of the inclusion/exclusion discourse, in which hospitals for people with learning disabilities are all bad and community living is always preferable, Stella presents an interesting paradox. I would suggest that this is an example of the tensions in promoting the full inclusion of people with learning disability in society and controlling them.

On the one hand the learning disability nurse (represented by Stella) agrees with the view that all people deserve the same chances (inclusion/exclusion discourse). However, on the other hand she also knows from past experience that people with learning disabilities need to be given a different route to self-fulfilment and ultimately social capital (Bates and Davis, 2004) through the professional support of learning disability nurses (professional discourse). The story helps Stella to explain this tension.

Stella hints at her reasons for using this particular story and learning disability constructions in her general teaching during an interview which asked her to discuss in more detail some stories she used in her teaching:

Stella: Right the first one was umh in the very early days of the hospital closures the first client, in those days sorry there were patients, you know, so it's the terminology, they were the first patient ever to go out into their own independent living area umh and it was the hospital, it's strange because the hospital and the management thought it was very successful, everyone that had worked with her, the public and the patient herself were totally miserable and she fought tooth and nail to come back ... 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. and it was totally cruel, totally inhuman and totally political. (interview extract)

The interview refers to the same story as used in the teaching sessions and reiterates the powerlessness of the woman featured. These constructions are based on the medicalized assumptions that did and do problematize people who are different (Oliver, 1 990).

I would argue that Stella's story is an attempt to simplify the complicated interplay between the discourses which pressurize priorities in learning disability care (Shaw, 2009). Therefore the analysis of this learning disability construct provides an insight into some of the challenges that learning disability nurses face as they navigate between the discourses which problematize people with learning disabilities and their role of enabling individuals to make life-changing decisions to live like others in mixed communities.

Women are victims: women with learning disabilities are greater victims

In the following short story told by Jade (pseudonym), the medical discourse constructs the person with a learning disability (as a case to be managed) without shape or form, a shadow of personhood using a

negative or absurd image. This construct describes a person outside the norms of human appearance (Oliver, 1990; Swain et al., 2005).

> *Jade*: I actually worked with an' individual . . . a lady ... at [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. (story)

According to Foucault (1991), society can regulate its members by observing and recording their actions and by separating them into 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 Jade's story, rights to self-regulation are not the issue, as she is without agency or ability: 'An' [she] had to be lifted flat into an' laid flat. It was *so* severe.' 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 societies like the medical profession tend not to enter the discourses of the learning disabled woman for a number of reasons. In particular, women with learning disabilities struggle to articulate their own experiences and their lives tend to be reported 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 medicalizing discourse has been known to use language to construct the appearance of the woman with a learning disability as a medical problem to be prevented, sorted out or made normal through surgery or mechanical correction (Priestley, 2003; Swain et al., 2005). As a difficult problem to encounter, it is easy to feel the frustration of the woman (and others) and the horror of those who care for her: 'she literally was flat in that position'. The political discourse which signals the rights of the woman to a life without pain and suffering is drawn upon by Jade who is not prepared to fully accept that this woman is pathologized by the medical discourse as ill and incurable.

In this extract from Jade's teaching session she explains the medicalized view of people with severe physical differences:

> *Jade*: Treatments should minimize the aggravation of symptoms. An' the earlier interventions that are started, the more opportunity is given. . . . for whatever potential there may be for developin' normal activi-ties .. . as the degree .. . for decreasin' abnormal movement patterns.

> Postural difficulties. Has anybody had a placement on [institution]? Or anywhere like that? Come across anybody, with severe . . . cerebral palsy, very fixed positions ... with very rigid positions . .. A lot of severe .. . Frequently, in the past, people would not have, the opportunity to have ... correct handlin' an' positionin'. An' these are the sort of postures that ... that people can develop. (teaching session)

My interpretation suggested that Jade 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 at the same time she *refutes* the medical discourse which constructs the woman who appears twisted, inhuman and not entitled to rights. Once again a learning disability nurse uses a story to explain the paradoxes associated with caring for people with learning disabilities within a medicalized discourse of illness and incurability.

Discussions: revealing the tensions

The five learning disability nurse teachers in this study navigated between the pressures of the past and the present. These pressures have been reviewed in the literature and arise from the reality that learning disability nurses have worked in learning disability institutions which, now considered unsuitable, contributed to the marginalization of people with learning disability (Mitchell, 2003; Mitchell and Smith, 2003).

The constructions of learning disability in the teaching narratives, stories and interviews in this study did not consistently represent learning disability in the ways of general society. In contrast, the teachers attempted to construct people with learning disabilities both positively and negatively but as reliant upon their professional help. The portrayal of people with learning disabilities as pitiful biological accidents or dangerously inhuman (Bogdan, 1990) has assisted the medicalized learning disability constructions in society generally, but enlightened professionals armed with knowledge and skills view this as wrongly held ignorance (Wolfensberger, 1972). The result is the language used in the resulting discourse of learning disability nursing.

This article has attempted to show that there is perhaps a tension between the learning disability constructions expressed by learning disability nurses. This is achieved through the language of problem solving, stories and the celebration of the professional role of learning disability nursing in the care of people with needs. The social constructions of learning disability are of oppression and of need. Alternatively, the theoretical discourse of learning disability nursing, influenced by the Human

Rights Act 1998, present political discourses (Department of Health, 2001, 2008) and philosophies such as normalization (Wolfensberger, 1972) and more recently those of the Royal College of Nursing (2007), draws heavily upon language which aims to promote equality of opportunity for every person regardless of age, gender or race. These competing social constructions paint a picture of a person with learning disability as a rightful citizen with potential and self-worth but with a need to be cared for and controlled.

The learning disability nurse draws upon a strong theoretical base influenced by the ideologies of normalization and humanism and advocates the rights of their clients to lead valued lives (Walmsley, 2001). The stories told by teachers in this study help to illustrate the influence of such theory and of their own experience. The specific learning disability discourse utilized by learning disability nurses expresses some interesting insights, and the interpretations I have outlined can enable learning disability nurses to understand professional positions, the construction of learning disability and their roles within it.

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