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Goble, Colin

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Title: An Exploration of the Discourse of Health in Learning Disability Nursing Textbooks in the Post 'Continuing the Commitment' Era

Colin Goble

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Summary:

The aim of is study was to conduct an exploration of the emergent discourse of health in learning disability nursing textbooks in the era after the publication of 'Continuing the Commitment' (Doh 1995). The method used is an adaptation of discourse analysis involving three distinct stages – 'description'; 'interpretation'; and 'explanation'. The data analysed consists of five chapters focussing specifically on 'health', in four learning disability nursing textbooks published between 1997 and 2003.

The first stage of 'description' involved description of the textbooks in which the texts are situated, and of the texts themselves, and the identification of common themes across the texts. Three main themes emerged:-

1) The identification of a holistic and humanistic model of health as the most appropriate in relation to people with learning disabilities.
2) The problematisation of health as an issue of the vulnerability of people with learning disabilities to the development of health problems.
3) The problematisation of the standard of generic healthcare services in understanding and meeting the health needs of people with learning disabilities.

Stage two of analysis involved identifying 'interpretative repertoires' in the texts, exploring in particular how these are used to construct the 'facticity'of the themes identified in stage one.

The third stage of analysis focused on exploring the relationship between the emergence of the discourse of health and ideological and policy developments in the UK welfare state.

In conclusion the analysis is discussed in relation to critical theories of the caring professions. It is argued that the emergent discourse of health represents part of an attempt to reconstruct the role and identity of learning disability nursing in response to material and structural pressures, whilst struggling to maintain congruence with the ideals of the profession. The need to resist the 're-pathologisation' of learning disability by 'biologisation' of learning disability itself is highlighted, and the need to develop a dialogue with people with learning disabilities about their health and healthcare needs is advanced as one among the strategies needed to avoid this.

Declarations and Statements:

1) This work has not previously been accepted in substance for any other degree, and is not being concurrently submitted in candidature for any other degree.

2) This thesis is the result of my own investigations except where otherwise stated, and all other sources are acknowledged by explicit references and a reference list and bibliography that is appended.

3) I give my consent for my thesis to be available for photocopying and for inter-library loans after expiry of a bar on access approved by the University of Wales, Swansea.

Contents:

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Chapter 1

An Introduction to the Study

Introduction:

Learning disability nursing is a profession under pressure. Few health care professions have, over the last two to three decades, experienced such dramatic changes, either in the physical settings in which its practitioners are employed, or the role and identity they are expected to assume. It has been noted by Turnball (2004) that the fact that the profession has managed to survive at all is something of a tribute to the flexibility, commitment and ingenuity of its members. Much of the professions' survival strategy has not been formally planned or organised, but has been developed as a reactive, and frequently defensive, response to a radically changing ideological and organisational environment. In the mid 1990s, however, as community care reforms in the UK became formalised in the wake of the *NHS and Community Care Act* (DoH 1990), the situation came to a head, and the leadership of the profession became more formally engaged in the task of reconstructing the role of the profession in earnest. The main vehicle for this reconstruction was the *Continuing the Commitment Project* (DoH 1995).

Although precipitated by structural changes in the welfare state which shall be examined in the course of this study, the reconstruction of the role of the learning disability nursing profession undertaken in *Continuing the Commitment* was also shaped by a significant shift in the conceptualisation of the phenomenon currently officially described as 'learning disability'. This has manifested itself in the form of a 'discursive shift' which, in recent decades, in all but a few firmly 'bio-reductionist' branches of the medical profession, such as genetics for example, has led to the widespread demise of the perception of learning disability as a form of pathology, and its reconstruction as an issue of social devaluation and exclusion.

For a profession such as learning disability nursing, with its origins in a 19th century mental asylum system dominated by the emergent psychiatric profession, this reconceptualisation could have been fatal, apparently removing the ontological basis for its existence. The situation was, however, as we shall later see, considerably more complex, and by the time the policy impetus for community care had taken hold across the political spectrum by the late1970s, some leading theorists and educationalists in the learning disability nursing profession were already engaged in trying to reshape the role and identity of the profession in line with the radical 'normalisation' philosophies emerging from Scandinavia and North America, and which centred on the concept of deinstitutionalisation (Nirje 1970, Wolfensberger 1972).

For a while in the 1980s optimism reigned as learning disability nurses took up key roles in running and managing the pioneering new community based services being set up around the country by the National Health Service (NHS). That optimism ebbed seriously in the 1990s, however, as the provisions of the *NHS and Community Care Act* (DoH 1990) took hold, giving local authority governed Social Service departments the lead purchasing role in a newly established 'quasi-market' in community care (Baggott, 1994). Services for people with learning disabilities were largely relocated under 'social', rather than 'health' care provision, with ownership and management frequently switched to the private and voluntary sector rather that the NHS. The position of learning disability nursing came into serious jeopardy as care managers, no longer beholden, and sometimes antipathetic to the NHS, began to question the need for employing 'nurses' in providing social care to a client group who were no longer perceived to be sick.

The main strategy of the professions' leadership in response to this situation appeared, for a while, to be to attempt to engineer a merger of learning disability nursing with social work, and a number of joint training programmes emerged (Thompson and Mathias, 1998). The strict division between 'health' and 'social' care instigated by the *NHS & Community Care Act* (DoH 1990) had become too institutionally entrenched to allow this strategy to come fully to fruition however, and graduates from these programmes found themselves having to choose between one identity or the other on completion of their training (Parry and Renouf, 2003). A serious rethink by the leadership of the profession at this time led then to a further change of strategy, with the emphasis shifting to a firmer identification with the wider nursing profession, and the emergence in the learning disability nursing literature of an emphasis on 'health' as the area in which the professions' unique and specialist contribution to the field is to be found (Moulster and Turnball 2004). This emphasis emerged, as we will see, as the central theme of *Continuing the Commitment*, a document which, emanating as it did from within the Department of Health, carried a strong official sanction.

In discussing recent developments in learning disability nursing Moulster and Turnball (2004) pose the question of whether the emergence of the focus on health in the professions' literature in the 1990s arose out of political expediency as the leadership of the profession sought to reposition its role in the new health and social care market place, or whether it represented a renewed attempt to focus the work of the profession on responding to real health needs of people with learning disabilities? Having raised the question they do not actually attempt to answer it in their discussion. This question is of particular interest to me however, because of the way it relates to challenges raised by disabled people themselves, particularly in the form of the 'social model of disability', about the role of caring professions in the lives of disabled people. I will now outline the nature of this challenge as a precursor to clarifying my main aims in undertaking this study

The Challenge from the Social Model of Disability:

For much of the 20th century the idea that disability was a purely bio-medical phenomenon, equivalent in most respects to disease, and thus in need of similar programmes of eradication and treatment, went unquestioned. This kind of perspective tended to view the caring professions uncritically as part of a natural and rational response to social problems; a view exemplified in Marshalls' (1962) vision of professions as a form of 'institutionalised altruism'. The caring professions came under intense critique, however, from the 1960s and 70s onwards, from analysts who viewed them from more radical ideological perspectives. Johnson (1972), for example, argued from a Marxist theoretical perspective, that the caring professions are primarily institutional agents of social control, whose work renders their clients helpless by assuming over them the power of expertise, based on the acquisition of specialist knowledge. Expert professions are seen from this perspective as gaining legal sanction from the state to represent and reflect dominant class interests and ideologies. From a similar perspective Larson (1977) emphasised the 'privileges' of professions, arguing that they are occupational groups who have managed to gain dominance over particular areas of social concern, such as health.

These critical perspectives raised and emphasised the idea of professions as privileged groups engaged in ideologically and politically, rather than rationally motivated projects; a theme taken up and elaborated by theorists of the social model of disability. Although there are variations, the central tenet of the social model perspective is the idea that the caring professions function in an essentially 'parasitic' way, constructing bodies of knowledge and expertise based, not on the lived experience of disabled people, but on authoritative discourses derived predominantly from a bio-medical conceptualisation of disability (e.g. Davies, 1993. French and Swain 2001).

Some early interest in the perspectives of disabled people about their own lives had emerged from the interactionist school of sociology in the 1960s, including Goffman's study of 'stigma', which looked at the impact of disability and disfigurement on the life experience and identity of affected individuals (Goffman 1968), and Edgerton's (1967) work on the lived experience of people with 'mental retardation' (sic) moving out from institutional care and into mainstream society in the USA. Although this work led to the emergence of new perspectives on the lived experience of disability, and sometimes challenged the nature of professional perception and practice, it did not fundamentally challenge the medical definition of what the phenomenon of disability actually was. The growth of the independent living movement among physically disabled people in the 1970s and 1980s did lead to such a challenge, however, and a redefinition of disability that was first formally articulated in the UK by the Union of the Physically Impaired against Segregation (UPIAS, 1976). The UPIAS definition replaced the term 'disability' with 'impairment' to describe the actual functional limitation experienced by an individual, whilst the use of the term 'disability' was altered to describe the limitations imposed on people with impairments by a society which fails to recognise, and/or organise itself to meet their needs. Disability becomes, according to this definition, a category of social oppression akin to that associated with gender and race (Oliver, 1996).

Early articulations of the social model of disability in the UK drew heavily from a Marxist 'social materialist' perspective, explaining disability as a structural phenomena within industrialised societies (e.g. Oliver, 1990 and 1993). Subsequently, what Priestly (1998) identified as a 'social/idealist' paradigm has become more influential, emphasising cultural as well as material factors. From this perspective disability is identified as a 'social construct', shaped by particular cultural and historical contexts. Analysis in this paradigm typically focuses on 'cultural representations' of disability and disabled people in texts and images, such as Wolfensberger's (1972) 'images' of 'mentally retarded people', which he used to underpin his theory of social devaluation; a significant conceptual platform of his version of 'normalisation' philosophy. More latterly Shakespeare (1994) and Ingstad and Reynolds-Whyte (1995) have used a similar form of analysis to illustrate how disability can be seen as a product of specific cultural conditions, and is thus a culturally relative category. Ingstad and Reynolds-Whyte argue that disability is produced, and reproduced, in discursive form in different cultures; a theme developed also by Corker and French (1999), who have used poststructuralist and postmodernist theoretical frameworks to explore disability as a social construct.

These forms of analysis have all served to undermine the assumption implicit in the medical perspective that disability is an individual, and necessarily tragic phenomena, intrinsic to the individuals who 'suffer' from it. Instead, they articulate a socialised, collective and political identity for disabled people from which to challenge structures and practices which are conceptualised as sources of oppression (Oliver, 1996). Chief among the targets of this analysis have been health, social care and educational professionals who, it is argued, have assumed power and control over the lives of disabled people in various ways. These professions, it is argued, have created bodies of knowledge and expertise that carry strong assumptions of deficit, tragedy, abnormality and pathology in their construction of disability. Their practice, it is claimed, reflects this, with disabled people frequently deprived of control and influence over what happens to them, whilst their entire lives are held up for scrutiny as they are objectified and dehumanised in their reduction to the status of 'cases' (Gillman, et al. 1997).

This is a similar argument to that put forward by McKnight (1978) who argued that the caring professions frequently 'disable' their client groups by assuming the mantle of 'expert'; an identity that assumes both the right and the capacity to describe, define and diagnose their client's problems, and the solutions to them. Whilst arguing, like Johnson (1972), that the caring professions play an important role in controlling their client groups on behalf of the state, McKnight asserts that such practices are not purely an expression of materially based 'class' domination and power however. Rather, via the medium of language, they are advanced as an authoritative expression of idealistic belief on the part of professions that they are working in the best interests of their client group. McKnight does not actually use the term 'discourse' to describe this process, but there are strong parallels in his argument with the emphasis of Foucault (1977) on the relationship between language and power, and their linkage in linguistic forms which shape perceptions of social reality.

The disability movement in the UK, and elsewhere, has used this type of analysis to organise politically to press for legislative change to defend and extend the rights of disabled people, including the right to have their views and perspectives listened to in health and social care services (Drake, 1999). This is a trend which, whilst not as yet resulting in the redefinition of disability along social model lines in national government policy, nonetheless appears to be gaining influence at the highest political level; an example being the priority given to the development of advocacy for people with learning disabilities in the *Valuing People* (2001) White Paper. The clear implication of such trends is that only those professions who open a dialogue, and demonstrate a sense of solidarity with, disabled people, including people with learning disabilities, are likely to survive and thrive in the future welfare state. It is for this reason, it can be argued, that the emergence of the discourse of health in learning disability nursing literature in recent years is significant, for here we can see a profession attempting to redefine its role and identity in response to both material and ideological pressures, and the question of how this response has been shaped and influenced is important in helping us to understand the way the profession has, and will continue, to develop.

These are some of the factors that have influenced my decision to undertake this study. Over the past decade I have, sometimes as an observer, sometimes as a participant, witnessed the emergence of a new ‘discourse of health’ in the literature associated with the learning disability nursing profession; particularly those textbooks aimed at the new generation of learning disability nursing students. Having myself been part of a generation of learning disability nursing students educated in a radical curriculum influenced by the philosophy of ‘normalisation’, and the insights and techniques of behavioural and humanistic psychology, and which also sought to shake off what was characterised as the oppressive legacy the of 'medical model' of care, I have found myself questioning the emergence of a discourse that is at once both fascinating and disconcerting. Are we witnessing a re-emergence of the pathologisation of learning disability that could lead us back into an oppressive 'medicalised' mode of professional practice and response – repeating old mistakes, and making some new ones? Or are we seeing a new and potentially emancipatory emphasis on the health of a group of people whose physical and psychological well-being have often been treated with a near abusive disdain? It is to explore such possibilities that I have decided to undertake the following analysis of the emergent discourse of health in learning disability nursing textbooks. My broad aim is to explore the nature, form and underlying reasons for the emergence of the discourse of health, and to consider the implications for the construction of the current and future role and identity of the learning disability nursing profession; particularly in relation to the critiques referred to above. I will now give a brief overview of how I propose to undertake this analysis with an outline of the chapters that will follow.

An Outline of the Chapters:

Firstly, in Chapter 2 I will start by providing a brief outline of the history of learning disability nursing up to the publication of the *Continuing the Commitment* (DoH 1995) document. I will describe how the history of the profession has been inter-twined with the response of the state and 'psycho-medical elites' to the phenomenon currently know as 'learning disability'. I will describe the origins of the profession in the 19th century asylums, where the nature of its role was defined by the emerging psychiatric profession, and how the relatively benevolent regimes of the mid nineteenth century gave way to a more punitive and custodial ethos as the eugenic movement gained influence in the late nineteenth and early twentieth centuries. I will subsequently outline how the legacy of this ethos persisted up to and beyond the creation of the NHS in 1949, when the institutions were redesignated as 'hospitals' wherein a medical model of treatment for people with learning disabilities reached its zenith. At this point nurses were functioning as an integral part of this medicalised system; a system that encouraged therapeutic pessimism and created conditions in which institutional abuse was prevalent.

I will go on to describe how the emergence of the influence of behavioural and humanistic psychology, together with normalisation philosophy, transformed nurse training and practice, and how, despite some resistance, learning disability nursing came to optimistically embrace the community care agenda in the name of 'normalisation' philosophy. I will outline the development of community care policy in the UK, and describe how it was implemented according to a 'new right' ideological model, dominated by a culture of tight fiscal control and managerialism that conflicted with the social idealism of normalisation. We will then look at the difficulties faced by the learning disability nursing profession as the effects of *The NHS and Community Care Act 1990* emerged; effects that led the leadership of the profession to attempt to reconstruct its role and identity in the *Continuing the Commitment Project* (DoH 1995). a descriptive outline of which forms the main substance of Chapter 3. This was the point historically where 'health' began to appear as a distinct topic in learning disability nursing textbooks, and it is to these texts that we will then turn to begin our analysis of the nature and form of this newly emergent discourse.

Having outlined the relevant historical and policy background in Chapters 2 and 3, we will focus in Chapter 4 on methodological issues. This discussion will begin with an outline of how my interest in this area of research developed. Here the reader will be provided with relevant aspects of my professional biography which, in keeping with the tenets of an interpretative research paradigm, of which the discourse analytic tradition is one form, will to help clarify the perspective from which my own analytical 'gaze' originates.

I will then go on to outline the broad approach for the analysis of the texts which constitute the data in this study, drawing particularly from the work of Gill (1996), before going on to describe in more detail the method and procedure used; a method that involves an adaptation of a three-stage framework of analysis - 'description', 'interpretation' and 'explanation' – drawn from Fairclough (2001), incorporating aspects of linguistic and rhetorical analysis drawn from Potter (1998).

Having explained the approach I will then, in Chapter 5, begin the process of analysis with a detailed description of the textbooks in which the texts are situated, including details of the editors and publishers, and where the book falls in chronological relation to other editions, an outline of cover notes, and other relevant introductory and explanatory material, such as 'forewords', 'prefaces' and 'introductions' which explicate the aims of the book and its relationship to the education of student learning disability nurses. This description serves to contextualise the texts as data, and helps to locate also their 'action orientation' – that is, how the reader is being 'cued' to interpret the relevant chapter by the wider text - the books - in which they are presented. After describing the books I go on to describe the chapters themselves, outlining firstly their structure, organisation and content so that they can be viewed as a structural 'whole'. Finally, this initial stage of analysis concludes by identifying and outlining the major common themes around which the texts are constructed.

In Chapter 6 we move onto the second stage of analysis, 'interpretation' which will involve exploring how the discourse of health is constructed in these texts. This stage of analysis will focus on exploring the themes identified in stage one, concentrating particularly on linguistic and rhetorical features used to construct what Potter (1998) calls, the 'facticity' of objects and concepts in the discourse. Such features include the 'action orientation' of the text; 'defensive' and 'offensive' rhetorical strategies; management of 'stake' and 'interest'; use of 'detail', 'authoritative corroboration', and 'consensus construction' as described in Chapter 4. To facilitate this process 'key passages' from the texts will be presented. These are passages identified and coded during analytical readings of the texts. Analysis of these passages will be presented in commentaries appended to the relevant passages, which are quoted at length.

In Chapter 7 we will complete the process of analysis by exploring the question of why the discourse of health emerged in this way and at this time. This will involve an exploration of the relationship between the emergence and form of the discourse, and the ideological and policy contexts in which the learning disability nursing profession has found itself functioning during the micro-historical period I have designated the 'post *Continuing the Commitment* era'. Here we will also pick up once again the historical narrative outlined in Chapters 2 and 3, and explore how the texts relate to both structural changes in the welfare state, and policy developments in relation to people with learning disabilities.

To conclude we will, in Chapter 8, discuss the findings of our analysis in relation to critical theories relating to the role and identity of the caring professions in the lives of disabled people, and in particular the social model of disability and the related critiques referred to above.

Firstly, then, we will need to focus on the history of the learning disability nursing profession from its origin in the nineteenth century asylum system, to the publication of *Continuing the Commitment* in 1995. This will provide us with an important contextual perspective from which to view more the recent developments which have precipitated and shaped the emerging discourse of health that will be the focus of subsequent analysis.

Chapter 2

A Brief History of Learning Disability Nursing

Introduction:

Having introduced and identified the aims of the study we will now turn our attention to an outline of the history of learning disability nursing in order to provide contextual background to the analysis that follows. The history of the learning disability nursing profession is, of course, inter-twinned with the wider history of the states' response to disability as a whole, and to people with learning disabilities in particular, and it is necessary to remind ourselves that history is rarely told from a neutral perspective but tends to follow narratives and explanations that reflect either dominant ideological perspectives in society, or challenges to them. This is certainly the case with disability history where we have only recently begun to see its re-exploration as the history of disabled people, rather than the history of the bio-medical understanding of disabling conditions and the search for cures and treatments. This dominance of the 'bio-medical narrative' has also driven the role of nursing to the margins of historical accounts (Mitchell, 2000a). Mitchell argues that, in the case of learning disability nursing, this marginalisation amounts to a 'parallel stigmatisation', and a sharing of the devaluation attached to people with learning disabilities (Mitchell 2000b).

Another consequence of the medical dominance of services historically has been that learning disability nursing, in common with other branches of the nursing profession, came into being not on its own terms, but on those decided for it by the medical profession. One result has been that learning disability nurses have often struggled to identify and articulate their role, and have not often been in control of the discursive and material processes of identity construction (Jackson 2000). The significance of the *Continuing the Commitment Project* (DoH 1995), as we shall later see, is that it marks the first real, comprehensive, and officially sanctioned attempt to undertake such a proactive form of role construction by leading members of the profession. Before we look at that document, however, we need to examine the origins and development of the profession to see how the situation leading to its production arose.

The Early History and Development of Learning Disability Nursing:

Burchinall et al (1982) argue that the history of learning disability nursing, or mental handicap nursing to use the term current when they were writing, is inextricably linked to the development of social attitudes towards people with learning disabilities, and particularly the rise of modern industrial capitalism. Oliver (1993) argues that people with functional impairments of all kinds found the newly industrialised and urbanised society, with its emphasis on time keeping, productive efficiency and demanding physical wage labour, a hard and hostile place in which to survive. People who were formerly able to contribute to the family income in an artisanal and peasant economy, where production was family based, governed by the hours of daylight and the rhythms of the agricultural year, effectively became an unproductive burden on families living on subsistence wage labour. Also, a strongly expressed moral suspicion among policy makers about anyone unable to work led to the creation of a punitive, institutionalised system of control applied to the workless in all their variety. In Britain this approach was exemplified in institutional form by the workhouse.

This approach contrasted with rather more benign institutional forms of care emerging in France in the mid 19th century. There, the legacy of revolutionary, and enlightenment thought led to a more optimistic view of people with intellectual impairments. Seguin, for example, inspired by the educational work of Itard and his *'cause celebre'* Victor, wild boy of Averyon', developed the idea of the 'Asylum', a place of sanctuary where 'idiots' could be educated, and trained to live and work productively in their communities, to which they would, ideally, be returned (Ryan and Thomas, 1987). In Britain recurrent concern about conditions inside institutions for 'idiots' and 'lunatics' occasionally led to pressure for more benign regimes. Tuke, for example emphasised a compassionate approach, built around a regime of 'healthy work' and 'strict morality' to help 'improve' inmates in his York based institution (Dingwall et al, 1992).

Foucault (1965) took a rather less sanguine view of such developments however, arguing that 'humanitarian' reforms instigated in French institutions were part of a reconstruction of the discourse of 'madness' which led to the 'mad' becoming the exclusive 'property' of the emerging psychiatric profession. The latter half of the nineteenth century has been identified as an era of 'empire building' by the emergent psychiatric profession, with the already existing 'asylums' acting as a ready made institutional base for it to colonize (Szasz,1971).

The late nineteenth century in Britain saw a convergence of moral and scientific authority which reflected both a pervasive protestant religiosity, albeit bitterly divided at times between traditionalism and non-conformism, and the political and economic self-confidence of a supremely self-assured imperial elite. It was an era in which scientific knowledge and classification expanded exponentially, mainly in the service of imperial and economic expansion. It was an era too of grand scientific theorisation;

none more influentially so than that of Charles Darwin in 1859 set out in *The Origin of Species.* The core of his thesis was the revolutionary idea that the evolution of species was driven by a process he described as 'natural selection.' This states that, in any species those individuals better able to adapt to the environment and conditions in which they find themselves are more likely to breed successfully, so passing on the traits that make them successful. Conversely, those individuals less 'fit' in survival terms are less likely to breed, and their lineages are thus likely to face extinction. Darwin focussed on animal lineages to explain his theory, but others, most notably his cousin, the great Victorian scientist Sir Francis Galton, quickly applied its logic to human societies; and Galton it was who coined the term 'eugenics' to describe this 'social' application of Darwinian theory (Desmond and Moore 1991).

It was to such theory, combined with the apocalyptic vision of over-population provided by Malthus, that members of the Eugenic Society appealed when pressing for action to prevent the degeneration of national stock that they feared was happening around them. Bolstered by a belief that they needed to assume responsibility for the protection of the evolutionary development of humanity now that civilisation had nullified the natural selection process, the eugenics movement came to exercise a powerful influence. Adopted across the political spectrum, eugenic ideas came to dominate the social policy agenda towards people with learning disabilities, or 'mental defectives' to use the contemporary term, in the late 19th and early 20th centuries. In the conservative political cultures of the newly industrialised societies it was a right-wing version of eugenics that tended to be adopted however, with the widespread enactment of policies designed to segregate and sterilise the 'feeble-minded' in order to prevent them breeding (Kevles, 1995). Institutional regimes swung back once more toward a custodial and 'therapeutically pessimistic' ethos, given official legislative sanction in the eugenic influenced *Mental Deficiency Act* 1914 (Ryan and Thomas, 1987).

In fact, regimes within institutions varied greatly, with the all-powerful superintendents controlling how things were done at a localised level. These superintendents aligned themselves with the emergent psychiatric branch of medicine, forming the Medico-Psychological Association (The MPA - later to become the Royal Medico-Psychological Association, and ultimately, the Royal College of Psychiatrists) to pursue their collective interests and strengthen their professional base. It was the MPA who introduced in 1891 a national certificate for attendants in institutions; the first move towards the creation of a nursing qualification. The MPA controlled registration, and as the main employing body, held sway over the nature and form of training. The mental institution attendants differed in a number of important ways from most other forms of nursing. however. Like mental nurses they were usually male, drawn, due to the rural location of many institutions, from unemployed agricultural labour, or retired police and military personnel supplementing their low salaries with a police or military pension (Dingwall et al, 1991).

The MPA training emphasised physical, rather than psychological care, an emphasis that continued until the 1930s when a psychiatric emphasis became more dominant. A rival certificate and registration was initiated by the General Nursing Council (GNC) in 1917, though it never seriously challenged the MPA certificate because that was the qualification recognised by the main employers in the field. The MPA (in its different guises) and the GNC disputed ownership of 'mental deficiency nursing' up until the post world war two era when the MPA, under governmental pressure, finally ceded control to the GNC. Despite this, there was within the upper echelons of the GNC a strong strain of ambivalence towards mental deficiency nursing, reflected in its persistent marginalization in relation to the wider nursing profession; a marginalization which , arguably, continues to this day (Mitchell, 2000a). This ambivalence was, and is due, Mitchell argues, to the fact that the 'sickness' orientation of learning disability nursing has never been as explicit or obvious as it is in other branches of the profession. Certainly, mental deficiency nursing was perceived to be more about custodial, than health work. The GNC was finally coerced by the post war Labour government into taking it on as part of the integration of mental deficiency services into the NHS (Mitchell 2003).

Despite the optimistic rhetoric prevalent in psychiatry in the early 20th century, most institutions remained isolated worlds, with staff subject to poor pay and conditions, resulting in a demoralised workforce who offered little in the way of therapeutic activity for inmates. A custodial and punitive ethos often persisted up to and beyond nationalisation of the institutions with the inception of the NHS in 1949 (Ryan and Thomas,1987). In the 1960s and 70s the situation became critical when of a number of high profile scandals exposed brutality by nursing staff in some Mental Subnormality Hospitals, as they were by then designated. This led to a series of inquiries into the care of this client group (e.g. Howe 1969). At the same, a number of significant sociological studies appeared on both sides of the Atlantic challenging the nature, purpose and quality of institutional care for people with mental illness and learning disabilities, regardless of whether they were subject to actual abuse or not (e.g. Goffman 1961. Oswin, 1973).

In response to these inquiries and the changing climate of informed opinion, a government White Paper, *Better Services for the Mentally Handicapped* was published in 1971; the first major review of service provision for this population since 1929. Following on from that White Paper, a challenge was made specifically to the role of mental handicap nursing, as it was by then called, with the publication of the *Jay Report* in 1979. In keeping with the growing research and political impetus for de-institutionalisation the *Jay Report* challenged the whole idea of medicalised, hospital based services for people with 'mental handicap', and with it the need for a specialist branch of the nursing profession. It advocated community based services, run on a social, rather than a medical ethos, and staffed by social workers rather than nurses. The report was controversial, and a minority report disagreeing with these findings was also published. Naturally perhaps, it invoked fierce opposition from within the nursing and psychiatric professions, and the nursing unions (Mitchell 2003).

The recommendations of the *Jay Report* were never acted upon. Having been set up by the Labour government in the mid 1970s, one of its main recommendations was a significant increase in resources, together with a trebling of the number of qualified staff in services for people with a mental handicap. Its publication coincided, however, with the election of a Conservative government which was committed to reducing expenditure on the welfare state. *Jay's* ambitious spending and development plans for mental handicap services thus never saw the light of day, including the recommendation that responsibility for training qualified staff be taken away from the GNC and handed to CCETSW. This move was also anathema to the incoming Conservative government as it meant ceding control to local authorities and the social work profession, both of which it regarded with mistrust. In the end Patrick Jenkin, the incoming Minister of Health, opted for one of the recommendations rejected by *Jay,* that the GNC work with CCETSW to develop joint training that would eventually allow for the 'evolution' of a new profession (Mitchell 2003). Despite never being implemented *Jay* did contribute significantly to the growing impetus for change in service structure and organisation, and in mental handicap nurse training too (Atherton 2003).

At this time also the dominance of traditional medical psychiatry was waning in the mental handicap field. Other influences from human rights philosophy, psychological theory, and the social sciences were leading to a major conceptual change in the theoretical, philosophical and structural approach to support and services for people with mental handicap, and it to these that we will now turn.

Psychology and Normalisation - A New Science and a New Idealism:

The 1960's saw the emerging influence of behavioural psychology in the mental handicap field, a development which helped to inspire a new era of therapeutic optimism. Founded on the insight that human behaviour can be shaped by contingent rewards and punishments, behaviourism offered an explanation for many of the bizarre behaviours demonstrated by people living in institutional environments, showing that many of them were self stimulatory, or learnt, rather than inherent to mental handicap as a condition. Behaviourism also demonstrated that, when the environment and staff behaviour are organised appropriately, people with learning disabilities are able to learn appropriate, socially adaptive behaviours and skills. This knowledge not only challenged the therapeutic pessimism that had so often dominated services, but it also provided a theoretical and practical basis for training nurses (Baldwin, 2003).

In 1982 changes were made to the curriculum for mental handicap nurse training to incorporate these, and other, developments, including elements from humanistic psychology, such as Maslows' 'hierarchy of human needs', and Rogers' 'person centred' approaches to psychotherapy which worked to create a new emphasis on needs led, individualised models of care. Frameworks from developmental psychology were also drawn upon to underpin approaches to assessment and care planning (GNC 1982). These developments reflected a growing influence of psychological and social scientific perspectives which spread across the nursing and healthcare professions in the 1970s and 1980s, underpinning the development of what became known as 'psycho-social', as distinct from 'bio-medical' aspects of health. In mental handicap nursing the development of this psycho-social knowledge base was seized upon to provide a scientifically validated foundation that it had never previously had.

Although it revolutionised practice, the influence of psychology did not in itself challenge the dominance of the institutional model of service provision in the mental handicap field. Behavioural approaches were actually pioneered within hospital settings, although early advocates, such as Tizard, did place great emphasis on the necessity of providing rich and stimulating environments (Ryan and Thomas 1987). Normalisation philosophy, on the other hand, did make such a challenge.

Normalisation philosophy originated in Scandinavia where it was based on a human rights ethos. Pioneers like Bank-Mikkelson (1980) in Denmark, and Nirje (1970) in Sweden argued that large institutional environments were an affront to human rights. They advocated the reorganisation of services to achieve a high approximation to normal social settings, patterns and rhythms of life (Emerson, 1992). Subsequently normalisation philosophy became highly influential in North America where it was further developed by Wolfensberger (1972) with a more 'scientific' emphasis. Drawing heavily upon sociological theories, such as deviancy theory, and labelling theory, Wolfensberger sought to explain the social and cultural mechanisms by which people with 'mental retardation' (sic) came to be devalued in society. He combined this with concepts from social learning theory and behavioural psychology, such as 'role modelling', and the 'power of imitation', to identify what a practice based upon normalisation philosophy should focus upon. Wolfensbergers' argument is that the main role of services should be to reverse processes of devaluation by enhancing the social image and competence of 'mentally retarded' people. From this perspective, an individual with a learning disability should live in an ordinary house, not because it is their right to do so, but because it enhances their social image, and increases the chances of them developing socially valued competencies (Emerson, 1992). So important did Wolfensberger regard this role for services that he ultimately advocated dropping the term normalisation altogether in favour of 'Social Role Valorisation' (SRV) which he argued better captured its central rationale and purpose (Wolfensberger, 1983).

Normalisation theory was initially introduced into the UK using Wolfensbergers' formulation by the campaigning organisation Campaign for People with Mental Handicap (CMH) using intensive workshops focussed on a service evaluation tool, the Programme Analysis of Service Systems, or 'PASS' document (Wolfensberger and Glenn, 1973). These workshops were deliberately aimed at strategically significant management personnel, including senior nursing staff and educators. So intensive were they, and so strict was the format for completion of the PASS documentation that they drew some criticism for being too 'evangelical' in nature (Lindley and Wainwright, 1992). A second, rather more 'user friendly', wave of dissemination was initiated by the King's Fund Centre in London. They dropped the technical and scientific language of Wolfensberger, but retained his core message regarding processes of devaluation and competency enhancement. This became known as the 'Ordinary Life' approach (King's Fund 1980).

Normalisation theory was slower to influence mental handicap nurse training than behavioural and humanistic psychology, its inclusion being dependent initially on the presence of 'converts' in local teaching and management teams. Ultimately, however, it became impossible to ignore, and soon became an integral part of training with the introduction of the1982 curriculum (GNC 1982) introduced as a response to *The Jay Report* (Baldwin, 2003). At last it seemed that mental handicap nurses had a sound technical and philosophical foundation on which to base their practice.

Normalisation theory also created problems for mental handicap nursing, however. In arguing that the enhancement of social imagery was central to the role of services the term 'nursing', with its connotations of sickness, illness and medicine, was perceived as a liability in the eyes of some. This situation was not helped by the incorporation of learning disability nurse training into the 'Project 2000' curriculum in 1986. 'Project 2000' marked the culmination of a longstanding aspiration of the leadership of the wider nursing profession to integrate the training of all four branches of nursing; 'learning disability', 'mental health', 'child' and 'adult'. It also involved raising the academic level of all nurse training to at least Diploma level, and a wholesale shift of nurse training out of the NHS and into higher education institutions. As such, it represented a significant victory for those in the upper echelons of nursing who sought to further the project of 'professionalisation'. In practice it meant that, where previously students of each branch of nursing had followed a three year course specialising in their own particular client group, the first 18 months of the training of all student nurses became integrated into a generic 'Common Foundation Programme' (CFP). Students only specialised in the final 18 month 'branch' programme. For learning disability nurse students this had the effect of diluting the normalisation and psycho-social orientation of their training. For some this represented a backward step, pulling learning disability nurse education back towards a medical model. It also complicated efforts to set up joint training with social work programmes which many saw as the way the profession needed to evolve (Thompson and Mathias 1998).

A subsequent reform of Project 2000 came with the introduction of the 'Making a Difference' (MAD) curriculum in 1999, which reduced the CFP to 1 year, and thus extended the branch programme to 2 years, shifting the weight back towards specialism. It also placed a greater emphasis on practice, with students starting their practice placements earlier, and spending longer in practice settings. This 'retraction' was largely the result of pressure from the New Labour government elected in 1997, and elements within the medical profession, who believed nurse education had become too academic and not practice orientated enough.

It is also the case that, though inspirational in its challenge to institutional regimes and structures, normalisation theory was limited in its use for relatively powerless professional groups like nurses. Often, in the post normalisation era, learning disability nurses found themselves working in and maintaining services they felt and knew to be oppressive (Mitchell 2003).

Despite these problems normalisation philosophy provided a vision of how things could change, and for a time in the 1980s it appeared as though the 'revolution' was actually happening. Community care policies led to the closure and rundown of many of the big institutions, and people who had spent their whole lives living in them experienced for the first time the relative freedom of living in small, group home environments, with access to their own welfare benefits, or even work. Having extricated itself from the large institutions alongside its client group learning disability nursing appeared to be at the forefront of this work. By the late 1980s the apparent congruence with of community care policy with normalisation philosophy had begun to prove illusory however, as its domination by a fiscal rather than an emancipatory agenda became apparent. Though it could not be argued that four or five bedded group homes, or even twenty bedded hostels, were an improvement on the former hospital environments, it also became apparent that even small a group home can become an institution if run on a wafer thin budget, and staffed by poorly paid, untrained, poorly resourced and overstretched staff teams (Emerson and Hatton, 1994).

In the 1990s the influence of normalisation philosophy was further eroded by the emergence of the concept of 'Quality of Life' (QoL) as a means of evaluating service quality. This happened partly because QoL was the preferred tool of the academic establishment in the UK learning disability field which had never been wholly won over to normalisation (Race, 1999). It also won favour beyond academic circles because it involved simpler, more 'user friendly' measurement tools than the large and complex PASS document.

Normalisation philosophy also came to be superseded at this time at the ideological level by the emergence of the social model of disability. This produced, as we have seen, an even more fundamental critique of caring services and professions than normalisation; a challenge that nursing generally appears, thus far, to have largely ignored. In most services at the present time normalisation philosophy rarely appears much beyond a nod in the mission statement, and as a philosophical framework outlined in staff training packs.

The Impact of Community Care:

The 1971 White Paper *Better Services for the Mentally Handicapped* (DoHSS 1971) set out an agenda, widely supported across the political spectrum, for a shift towards community based care for people with learning disabilities. Although it set targets for a 50% reduction of the hospital population by 1991, an increase in local authority service provision, an end to custodial models of care, and a reform of staff training, it did not go into specifics about how this should be done (Atherton, 2003b). The pace of reform was slowed during the 1970s as the Labour government's priorities shifted to deal with an economic crisis precipitated by a sharp rise in the price of oil that severely dented its desired spending plans and acted as a brake on implementation. It was thus the Conservative government elected in 1979, operating to a radical 'New Right' influenced ideology that shaped and enacted the implementation of community care in the UK (Baggott, 1994).

The agenda of the Conservative government involved instigating a shift of power away from health and social care professionals. Though superficially in tune with the goals of normalisation philosophy, the main benefactors of this policy were not, as it turned out, services users, but service managers. Starting with *The Griffiths Report* (1983), the 1980s saw the introduction into the NHS, and across the welfare state, of a new managerial structure that led to a significant cultural shift, built upon knowledge bases not previously accredited within the welfare state, such as marketing, business management and quality assurance. It was in *Caring for People* (1989), part of the governments response to *The Griffiths Report,* that the government set out its intention to give the lead role in community care to local authorities, which effectively meant a reversal of the organisational roles and responsibility initiated at the inception of the NHS. The role of the NHS would henceforth become that of a provider of services which local authorities could choose, via the mechanisms of an 'internal market', to purchase. NHS service providers would then be in competition with voluntary and private sector organisations who were actively encouraged to increase their level of provision. The NHS would act as a partner to local authorities in drawing up community care plans, but a strict division between health and social care needs was to be adhered to when allocating services (Ham.1992).

Caring for People also defined the role and structure of new NHS Trusts, as 'self governing provider units', run by boards of directors, and accountable solely to the Secretary of State for Health, rather than Regional or District Health Authorities (RHAs and DHAs) as before. Trust boards were to have the power to determine their own management structure, set their own terms and conditions of employment, and acquire, own and dispose of their own assets and surpluses, effectively acting as quasicommercial entities. Their income was to come from DHAs, GP fund holders and local authorities, acting as purchasers. The Trusts were to provide services on the basis of contractual agreements with purchasers, and were thus responsible for the quality and quantity of the services specified in the contract (Ham, 1992).

The structural systems set out in *Caring for People* were enacted in the *NHS and Community Care Act* (1990). This Act set the context in which services for people with leaning disabilities have subsequently been organised, and therefore, the organisational context within which learning disability nurses found themselves functioning. It brought into force the 'purchaser/provider' split outlined above, and established the mechanism by which purchasing was to operate in relation to people with learning disabilities. This mechanism was 'care management', where a care manager, employed by a Social Services department in its new purchasing role, assessed the needs of an individual client and put together a 'care package' that the Social Service department would then purchase on the clients' behalf. The funds for purchasing 'packages of care' came from a centrally controlled community care budget which was capped and strictly limited, with the ongoing cost of care being met from benefits to which the client was entitled. A central idea behind this mechanism was that service providers would compete to provide services, but that the limit on the spending power of the purchasers would act to restrain the cost of those services. At the same time, competitive pressure between service providers would act to drive up service quality. Theoretically then, the system should work to drive down costs and drive up standards simultaneously (Thompson, 1998).

The implications of this reorganisation for the learning disability nursing profession was profound, but took time to become fully apparent. Despite some uneasiness at the 'free market' ethos, which seemed to conflict with many of the principles of the welfare state, the new system did seem, initially at least, to encourage some positive trends. These included the continuing rundown and closure of the old mental hospitals, the discharge of many people with learning disabilities into the community, the erosion of the state monopoly on residential services, and the diversification of services into new areas, such as sheltered employment, further education, leisure, and advocacy projects.

Problems quickly began to emerge however. For example, conflict arose between professionals and agencies over what constituted 'health' as distinct from 'social' care needs. Learning disability nurses often found themselves operating across this health/social care divide, sometimes unsure as to which side they were supposed to be on. In non-NHS residential homes, designated as social care services, run by voluntary or private sector agencies, learning disability nurses even found themselves legally unable to function under the designation 'nurse', raising questions about the value of maintaining nurse registration at all. Also, the introduction of the purchaser/provider split meant that learning disability nurses became reliant upon purchasers' knowledge, and a positive evaluation of, their role and identity if their services were to be purchased. It soon become apparent that this was not something that could be taken for granted (Turnball, 2004).

A further pressure which began to work against the profession came from the financial constraints built into the system. Within the internal market both purchasers and providers faced significant pressures to reduce, or at least, maintain costs. With staff salaries acting as a major cost factor it was here that managers frequently looked to make savings. An era of almost permanent review of staffing needs and 'skill mix analysis' was ushered in, with relatively expensive learning disability nurses finding their position gradually eroded. Before long many services, even within the NHS, no longer employed a qualified learning disability nurse in their homes. Where they were used, it was often in a peripatetic role, with responsibility for a number of houses and staff teams. In the expanding voluntary and private sectors, although learning disability nurses were often highly sought after for the knowledge, skills and experience they could bring, they often found pay and conditions to be less favourable than in the NHS. And here the profession was to come under further pressure with the rise of vocational training schemes such as National Vocational Qualifications (NVQs), and later the Learning Disability Awards Framework (LDAF), that trained people on the job, very often for roles that had traditionally been performed by qualified learning disability nurses (Parry and Renouf, 2003).

Overall community care policy, which seemed at first to offer so much promise for learning disability nursing, worked in practice to create an environment in which the future of the profession appeared increasingly doubtful. Removed from the institutional setting in which it had originated and developed over most of its history, the profession appeared to be at risk of being perceived as an expensive anachronism. Service managers, working within strict financial restraints, and legally bound to differentiate rigidly between health and social care needs, came increasingly to question the need for nurses in what was predominantly perceived as a social, rather than health care service. This situation represented the most serious threat yet to the continued existence of the profession.

By the early 1990s the learning disability nursing profession found itself, then, in a seriously beleaguered position, operating in an increasingly hostile political and organisational environment. A period of intense self-examination followed, one result of which was *The Cullen Report* (DoH 1991). This report asserted the continuing need for a specialist practitioner in the learning disability field, able to advise other health and social care workers. It failed to nullify the air of uncertainty, however, prompting the Department of Health in 1993 to organise a 'Consensus Conference' to look at the future of the profession. A number of options were set out in a paper by Sines (1993) including; replacing the pre-registration branch with a post registration training programme (which would effectively reduce learning disability nursing from a distinct profession, to the status of a post-registration clinical specialism for nurses from the child, mental health or adult branches); pursuing joint training initiatives with other disciplines, such as social work; linking learning disability nurse training to the new competency based NVQ programme; or, retaining the pre-registration branch in its current form (Parry and Renouf, 2003). It was the last option that carried the day, demonstrating that the profession still had friends in high places. It was they, from within the Department of Health itself, who then initiated the project that led to the publication of the *Continuing the Commitment Project* in 1995.

Conclusion:

In this chapter I have given an outline of the history of learning disability nursing from its origins in the 19th century institutions up to the era of community care in the mid

1990s. I have described how the history of the profession has been inter-twinned with shifts in the states' response to the phenomena we currently know as 'learning disability'. I have described also some of the key theoretical and ideological influences that have shaped the recent history of services and the profession, particularly from psychology and normalisation philosophy, both of which have worked to challenge the pathological conceptualisation of learning disability, and reconceptualise it as an issue of educational and social devaluation.

Paradoxically, few professions took on the normalisation agenda as wholeheartedly as learning disability nursing, and the profession has proven to be a great deal more flexible and adaptive than some predicted in the era of *The Jay Report* (Atherton 2003). Community care itself, however, has been dominated by a managerial culture and fiscal agenda which has mitigated against the social idealism of normalisation, and offered a major challenge to the continued existence of the learning disability nursing profession. It was in response to that challenge that the *Continuing the Commitment Project* was set up. We will now go on to look at the report that emerged from that project, and to outline subsequent health policy relating to people with learning disabilities. This will complete the contextual picture needed to precede a discussion of methodology, and the data analysis that follows.

Chapter 3

'Continuing the Commitment' and Subsequent Health Policy for People with Learning Disabilities.

Introduction:

Before moving on to an outline of methodology, and as a final precursor to the analytical process, we need to look at the *Continuing the Commitment Project* document itself (DoH 1995), and bring ourselves up to date with more recent policy developments relating to people with learning disabilities. The aim in doing so is to provide the final pieces of historical and policy background to allow us to contextualise the analysis that will follow in subsequent chapters. The texts under analysis in this study were produced in, what I have designated, the 'post *Continuing the Commitment* era', and were heavily influenced by the reconstruction of the role and identity of learning disability nursing set out in that document. To explore the nature of that influence it is necessary, therefore, to have a good picture of the contents of that document. The outline presented here will be descriptive, rather than analytical however, and we will return to consider the influence of this document more fully once our analysis of the texts is complete.

This Chapter will then conclude with an outline of health policy relating to people with learning disabilities in the period after the publication of *Continuing the Commitment.* This will serve both to bring the historical narrative begun in Chapter 2 up to the present time, and to clarify the current trend of policy that continues to influence the direction of learning disability nursing. Firstly though, we will concentrate on describing the content of the *Continuing the Commitment* document itself. Before beginning that description, however, let us briefly remind ourselves of the circumstances which led to the production of the document.

As we saw in Chapter 2, by the early 1990s the learning disability nursing profession was in a seriously beleaguered position. The form in which community care had been introduced in the UK, with its strict division between 'social' and 'health' care, together with the shift of service ownership away from the NHS and towards the private and voluntary sector, meant that purchasers and commissioners of services were increasingly questioning the need for, or unaware of, the role of specialist learning disability nurses. It was in response to this situation that the *Continuing the Commitment* project was initiated from within the Department of Health.

Descriptive Outline of the 'Continuing the Commitment' Document:

The *Continuing the Commitment* project was commissioned by Yvonne Moore, chief nurse at the Department of Health and Director of Nursing at the NHS Executive, and was launched in 1994. It was produced simultaneously to *The Health of the Nation: A Strategy for People with Learning Disabilities* (DoH 1995), and, as we will see, there are strong parallels between the main themes of the two documents. Three project leaders were appointed. John Turnball, chief learning disability nurse at the Department of Health, and Director of Oxfordshire Learning Disability NHS Trust; Steven Rose, from the Southwark Consortium in London; and Brian Kay, a senior nurse at Ashworth Special Hospital near Liverpool. They were supplemented by a twenty-one person strong multidisciplinary advisory group, and a four person steering group. The project aims were stated as follows:-

"

- *to examine, with key stakeholders, the range of skills of the learning disability nurse and to describe them.*
- *To identify best practice initiatives involving qualified nurses in this specialty*
- *To provide advice on how learning disability nursing skills can be articulated to inform purchasers, providers and other interests concerned with the provision of services for people with learning disability."* (DoH 1995, p 4)

Besides these specific aims, the overall purpose of the project was stated to be to 'specify the knowledge and skills of learning disability nurses' for the benefit of managers and purchasers in community care services who may not know what the role of the learning disability nurse is supposed to be. This aim was set out as follows:-

"In the new configuration of services, there will be managers, commissioners and practitioners who will be unfamiliar with the role that learning disability nurses can play in supporting people. To ensure that people with learning disability have access to the support they need and to enhance teamwork, it is important that everyone has clear information and an accurate perception of each others roles." (p 3)

The introduction to the document then goes on to acknowledge the major shift in services from hospital to community based care. Reference is made to the *Better Services* White Paper (DoHSS 1971) and the *Ordinary Life* document (King's fund 1980), thus acknowledging both the community care and normalisation agendas. The *NHS and Community Care Act 1990 is* identified as pivotal in consolidating organisational change. The role of the learning disability nurse is described as having changed significantly as a result, with nurses working in a wide variety of roles and settings. They are identified as being instrumental in setting up new services, both within and beyond the NHS, working in 'partnership' with other professions in multidisciplinary contexts.

It is in the following 'Background to the Project' section that the aim of articulating the learning disability nursing role is spelt out. This articulation is presented as building upon previous work, such as that of *The Cullen Report* (1991), Sines (1993) and Brown (1994), but going into more detail. The project is designed, it is asserted, to have three main outputs. These include, a report containing analysis of findings and recommendations for action; a guide for commissioners of services outlining what constitutes a good service for people with learning disabilities and where learning disability nurses can contribute to this; and a resource pack for learning disability nurses themselves to use to help them identify and articulate their own role (page4).

The methodology for the project involved wide consultation with learning disability nurses and other 'stakeholders', including parents and carers (via the MENCAP charity), managers, and other professionals. People with learning disabilities were involved too through self advocacy groups, facilitated by an independent consultant. Consultation involved the use of seminars, workshops and written submissions, and an estimated 2000 people contributed. (p 5-6)

The project leaders also visited and observed a number of services, looking particularly for examples of 'best practice', some 200 examples of which were ultimately gathered. The criteria used to identify 'best practice' were, interventions that….

" 9.2.1. Had taken place within an explicit framework that values people with learning disabilities as having the same rights as anyone else.

9.2.2. Had demonstrated an exclusive or significant contribution from a learning disability nurse.

9.2.3. Had brought about, directly or indirectly, positive outcomes for the person with a learning disability and/or had reduced the risk of harm.

9.2.4. Had already been formally evaluated or were amenable to formal evaluation.

9.2.5. Had been a planned and sustained initiative.

9.2.6. Were commensurate with local and national policies in the field.

9.2.7. Could demonstrate innovation, at least at local level.

9.2.8. Could demonstrate their ability to meet the needs of commissioners, the service, other staff and/or parents and carers." (p 14)

Commitment to the normalisation agenda is implicitly emphasised (although the actual term 'normalisation' is not actually used) in a section on 'The Needs of People with Learning Disabilities and Service Responses' (p 7-8). In this section changes in service philosophy are recognised, and the needs of people with learning disabilities are identified as essentially the same as for anyone else. It is stated, however, that people with learning disabilities have certain additional needs with which they will require help. These are listed as:-

"

- *epilepsy*
- *hearing and visual problems*
- *communication problems*
- *obesity*
- *cardiovascular and gastro-intestinal abnormalities*
- *respiratory problems*
- *impaired mobility*
- *mental health problems*
- *Alzheimer's disease (in people with Down syndrome)* " (p 18)

It is asserted however, that not all people with learning disabilities will require the same levels of support. A framework of four different levels of support is set out, using criteria of 'intensities of support' developed by Succasunna et al (1992). These are:-

- *'Intermittent' – where support is provided 'as needed'.*
- *'Limited' - where support is provided over a defined period of time.*
- *'Extensive' – where support is regular but not time limited.*

- *'Pervasive' – where support is consistently provided at a high intensity across all environments.*

These levels of support are outlined in some detail, and illustrated by the use of 'case examples'. This section closes by stating that support will also need to be provided to informal carers and staff in residential and other services who will require 'leadership' to develop their effectiveness.

In terms of meeting the main aims of the project, the following section, 'The Knowledge and Skills of the Learning Disability Nurse' is central, and occupies most of the rest of the document. This section begins by reminding the reader that the identification of the knowledge and skills of the learning disability nurse, together with the value system which underpins their work, is the central aim of the project. This goal is achieved, it is asserted, by 'focussing on what learning disability nurse actually do', and thus avoiding the risk of defining the role in too vague and abstract a way. Emphasis is also placed on looking at the contexts within which learning disability nurses work in order to explore how this affects the perceptions of the profession held by others. A challenge is then laid down to the notion (referred to in Chapter 2) derived from some interpretations of normalisation philosophy that the very use of the terms 'nurse' and 'care' carry negative connotations which are devaluing in their effect on people with learning disabilities. This notion is countered by stating that it is based on a misunderstanding of the nature of the support provided by learning disability nurses, which, it is stressed, are intended primarily to increase the 'autonomy' and 'independence' of people with learning disabilities. These are presented as universal human goals which are helped or inhibited by personal characteristics of individuals, and by the context in which they live. This 'context' is described as changeable, with effects that can help or hinder the individual. The better the 'fit' between the personal characteristics of individuals and the context they occupy, the more optimum their health and well-being, it is argued. Thus, for instance, access to good housing, work opportunities and optimum health is likely to help the person 'fill the gap' between personal characteristics and the context in which they live. Conversely, being denied these things is likely to hinder the person in achieving their personal goals. Many people, it is noted, need no formal help to achieve this 'fit', but some do, amongst whom are those people with learning disabilities who require 'specialist help'. The main aim of the nursing role in supporting people with learning disabilities, it is then stated, is not so much to 'fill the gap', but to prevent it widening further. This approach is presented as a 'developmental model', where the aim is to facilitate the development of the individual. It is then, the authors assert, a 'person centred', rather than a 'rehabilitation' model of support.

This outline of a model of support is followed by a sub-section entitled 'Knowledge and Skills' in which an outline is presented of developments in learning disability nurse training. Training at the time the document was published was organised according to the Project 2000 format in which, as described in Chapter 2, all student nurses undertook an 18 month common foundation programme (CFP) before taking an 18 month specialist branch. Project 2000 was designed to follow, it is stated, a developmental model, with an emphasis on the acquisition of 'problem solving strategies'. The knowledge component of training is, it is stated:-

"...only useful in so far as it informs practice and can be demonstrated in the outcomes for the individual client. There has been no attempt here to separate knowledge from skills. Instead, drawing upon actual practice, the contribution of the nurse is outlined in terms of its purpose, parameters and the roles which nurses occupy in services." (p 17)

Thus the strong relevance of knowledge to practice is emphasised. It is then that the 'health' focus of nursing interventions are emphasised, as follows:-

"10.18 Nursing interventions are firmly focused on the goal of maintaining and improving the health of the individual and the distinctive contribution of the nurse is derived from the outcome of this intervention for those individuals. This is achieved by taking action which:

- *mitigates the effects of disability*
- *facilitates access to and involvement in local community life*
- *increases personal competence and feelings of control*
- *maximises choice*
- *enhances the contribution of others involved formally or informally in the support of the person"* (p18).

Having emphasised the 'health' focus of the nursing role, the rest of this section is divided into sub-sections setting out and elaborating particular areas of work in which the contribution of the nurse is deemed to be central, and outlining the skills necessary to undertake them. The areas of work identified are:-

1) *'Assessment of need'* – Assessment is described as the 'cornerstone of the care management approach' initiated as the main organising basis for service delivery under the NHS and Community Care Act (1990). It is presented here as a key nursing role and skill as follows:-

"Nurses will be involved specifically in the assessment of the lifestyle of people in order to determine any health needs, which will include an assessment of physical health as well as an evaluation of the extent to which the individual's personal competence affects their health and well being. More specialist assessment may be undertaken, when appropriate." (p 18)

An example of a 'more specialist example' is given as assessment of a person's 'challenging behaviours'. Assessment will make use of validated assessment tools, and knowledge and skills identified include knowledge of assessment tools and procedures, and the skills to carry out these assessments accurately and thoroughly.

2) *'Health surveillance and health promotion'*: This is presented as the 'central role' of the learning disability nurse, working with local primary health care teams and 'specialist health support'. A number of particular areas are identified as the main focus of work here. These include:-

"

- *Nutrition, including weight loss and gain*
- *Epilepsy*

- *The promotion of positive sleep patterns*
- *The physical comfort of the person, including correct positioning to prevent sores and further limb deformity*
- *Continence*
- *The management of stress and the promotion of positive mental health*
- *The promotion of personal safety including the prevention of injury*
- *Healthy lifestyles, including the promotion of appropriate exercise, personal hygiene and dental care*
- *Monitoring the effects of medication, especially anti-convulsants and tranquillisers "* (p 20-21)

3) *'Developing personal competence'*: This is presented as a 'significant part of the role of the nurse', particularly with regard to teaching skills which will allow the person to develop their competence and increase 'feelings of control'. This part of the role is presented as focussing on a range of activities, from things like washing and self care, to psycho-social skills such as 'self-control'. This part of the role, it is asserted, requires the development of knowledge of learning theories, human development, and 'cognitive processes' such as memory, and how they can be used to enhance and promote learning. (p 22)

4) *'The use of enhanced therapeutic skills'*: This part of the role is directed particularly at working with those people with learning disabilities deemed to have 'complex needs'. The main focus in this document is on working with

people with ‘challenging behaviours’. Working with this group of clients requires, it is asserted, high skill levels and a ‘thorough knowledge of psychological, physiological and environmental influences’ on behaviour and its management. Other examples of work of this kind includes psychotherapeutic input with people with learning disabilities experiencing bereavement or relationship difficulties.

5) *‘Managing and leading teams of staff’*: This is an area where learning disability nurses face major challenges to their role. Traditionally in learning disability services a major role for nurses has been team leadership and management in residential and respite care settings. The localisation of care provision and the growth of service provision by the private and voluntary sector has raised major challenges to nursings’ near exclusive claim to these roles, particularly in services which come under the classification of ‘social care’. Alternative qualifications are emerging through NVQ and the Learning Disability Awards Framework (LDAF) routes, where care staff are provided with competency based training in situ. Even some NHS residential and respite care are now following this route, employing learning disability nurse to work in ‘overseeing’ and peripatetic roles, rather than static management roles as in the recent past. At the time of the publication of this document, however, this was still the main role in which learning disability nurses worked, and, in the ‘post Griffith’s era the nursing role was heavily management and team leadership orientated. This emphasis is reflected here in the stress laid on the necessity of developing a specific management knowledge and skills base. The main rationale given is that such knowledge

and skill is needed to help avoid 'institutional' forms of practice in these services.

6) *'Enhancing the quality of support'*: This part of the role involves focussing on the monitoring and development of quality standards in services. The role of specialist nursing staff is important here, it is asserted, because of their knowledge and skill in 'management processes' in relation to this client group. The inclusion of this 'quality control' related role also reflects the introduction of managerialism in the NHS at this time, and particularly its concern with 'quality assurance'.

7) *'Enablement and empowerment'*: This aspect of the role is implicitly concerned with achieving the goals of the normalisation agenda in challenging the devaluation of people with learning disabilities. It is asserted that particular effort is required to support people with learning disabilities to access ordinary services and facilities. Nurses require specialist knowledge of the ways in which people with learning disabilities are treated in society, and ways which the perceptions of others can be changed positively. This aspect of the nurses role also involves working with individuals to 'shape and achieve their own vision of their life' it is asserted. Specialist communication skills are often required to help this happen, as well as a knowledge and sensitivity to 'the impact of disability'.

8) *'Co-ordinating services'*: It is asserted here that learning disability nurses now work in a multi-disciplinary service context which requires them to develop

> knowledge and skills of co-ordination and collaboration with other professionals and agencies. This will also involve the use of communication and organisational skills, including the ability to measure, monitor and evaluate input and outcomes. A supplementary role mentioned in this sub-section argues that nurses are also ideally suited to becoming involved in commissioning services and in consultancy work, particularly related to health issues for people with learning disabilities. The need to remain flexible and adaptable is asserted in conclusion.

This outline of the areas of work, and the knowledge and skills where learning disability nurse can make a particular contribution, is followed by a section entitled 'Opportunities and Challenges' in which the focus shifts to a number of 'additional issues' facing the profession in the changing service environment. Foremost of these is the shift from hospital to community based settings, which means also a move out of health service care for many people. Thus learning disability nursing is now functioning primarily in 'non-health' contexts. However, it is asserted that, whilst the shift in service context is to be 'celebrated', it is important that nurses do not forget the centrality of 'health' as their area of focus. This is argued to be particularly important given the emerging evidence of unmet health need, and government policy highlighting the additional risk of health problems of some sections of the learning disabled population. Groups particularly at risk are listed as, people who:-

"

- *have multiple or complex needs*
- *are in crisis or where crisis is thought to be imminent*

- *are undergoing some form of transition e.g. from hospital to community, from children's to adult services*
- *are from ethnic groups*
- *have parents or carers who are experiencing difficulties in providing support*
- *are exhibiting behavioural problems or who may have additional mental health needs."* (p 36)

It is also noted that the population of people with learning disabilities is ageing, and that more disabled children are surviving their early years; trends likely to increase the number of people with learning disabilities with additional health needs. The need for learning disability nurses to continue to develop collaborative relationships with other services and professionals is emphasised, with joint education and training particularly highlighted. Issues given great emphasis here include, the need to develop skills and networks to disseminate 'best practice'; the need to develop agreed 'outcome indicators' for interventions in order to satisfy requirements for 'accountability of expenditure'; the need for newly qualified nurses to possess the skills actually required by employers, including new skills, such as IT skills; the need for better links between nurse education and practice, including the involvement of parents, carers and people with learning disabilities themselves in teaching and training; greater involvement of the independent and voluntary sector in the training of learning disability nurses; and also the continuing need to advocate for a better understanding of learning disability in society in general, including support for the development of self-advocacy schemes.

The next section of the document is entitled 'Articulating the Contribution of the Nurse'. Here, it is asserted that infrastructure needs to be created to facilitate this articulation. The best way of achieving this, it is asserted, is by demonstrating positive outcomes for people with learning disabilities. The 'primary aim' for nurses is, it is argued, to further enhance the quality of their interventions with clients. Other important elements include the demonstration of good leadership and management of services by nurses; good local, regional and national forums for information sharing, including involvement in purchasing processes; the use of different media and the need to vary the way information is delivered, in particular, making it clearer for people with learning disabilities and their parents and carers. The principles of information sharing and the skills and commitment to undertake it are things that need to be incorporated in nurse education, it is argued.

The final section of the document is *'Conclusions and Recommendations'*. Here it is asserted that the consultation for the project demonstrated widespread support for the continuation of a learning disability specialism in nursing. Nurses should, then, continue to 'take the lead' in the provision of health care for people with learning disabilities, but, it is argued, they need to take on board the issues raised in this document. These issues are then summarised in a number of recommendations, the main ones for nurses being to:-

"...ensure that their contribution is more explicitly linked to the maintenance and improvement of the health of people with learning disability'; 'devising ways of communicating clearer information about their role to people with learning disability

and their parents and carers'; and 'placing greater emphasis on supporting initiatives enabling people with learning disability to advocate for themselves.' (p40)

There were also a number of recommendations for educationalists, including; 'that they should continue to explore opportunities for shared learning at pre and post registration levels'; that the English National Board (subsequently abolished) 'should review the content of pre-registration training to ensure that appropriate emphasis is given to leadership and management skill development'; that the UKCC, (subsequently replaced by the NMC), *' should consider the accreditation of appropriate prior learning experience for entrants to pre--registration programmes'; and the 'education should make efforts to develop and improve contact with service providers and commissioners'.* (pp 40-41)

For nursing organisations it was recommended that they improve methods of dissemination and develop information sharing networks.

Finally, for the Department of Health itself, it was recommended that:-

"...the chief nursing officer continue to explore ways in which the standard of leadership in the learning disability specialism be developed'; 'the DoH continue to support initiatives for identification of outcomes in learning disability services'; ' the DoH continue to support initiatives to better inform managers and professionals about advocacy and self-advocacy'; that restrictions on the capacity of nurses to practice as 'nurses' in registered care homes be reviewed; and that regional nurse

managers take a lead role in developing resource packages to articulate the role of the learning disability nurse.(p 41)

The document concludes by listing those people involved as project leaders, advisory group and steering group members and observers.

This concludes our outline and description of the *Continuing the Commitment* document itself, the intention of which has been to complete the background picture necessary to contextualise the texts under analysis in subsequent chapters. Significantly for that analysis, we can see that the authors of the *Continuing the Commitment* document sought to reconstruct the role and identity of the learning disability nursing profession in firm attachment to the central concept of health.

Before we focus on the analysis of the texts themselves, however, we need to bring ourselves up to date with major trends in health policy relating to people with learning disabilities in the era since the publication of *Continuing the Commitment.* This will complete our picture of the history and development of learning disability nursing as a backdrop against which to consider the analysis of the texts which follows.

Health Policy in the Post Continuing the Commitment Era:

The authors of *Continuing the Commitment* document sought to specify and define the role of the learning disability nurse firmly linked to a 'health' agenda, and in so doing, opted also to consolidate the alignment of the profession with the wider nursing profession. From a normalisation perspective this could have been seen as a risky and retrograde strategy, shifting the professions' identity back towards a 'medical', rather than ‘social’ model; hence the pains taken in the document to place the role of the profession within a normalisation framework. On the other hand this strategy could also be interpreted as both a principled, and politically astute move given the emergence during the 1990s of a body of research evidence that seemed to show that, whatever the successes of community care policy in shifting service provision for people with learning disabilities out into the wider community, one area where the policy appeared to be failing was in the area of healthcare. This body of research appeared to show serious deficits in the healthcare provision accessible to people with learning disabilities, and served to highlight that the major shift from institutional to community based care had not led to the hoped for improvements in healthcare. A report for Anglia and Oxfordshire Regional Health Authority and the NHS Executive (Greenhaulgh 1994), for example, described how the hoped for integration of people with learning disabilities into the use of generic, primary and other community health care services was either not happening, or happening only sporadically. An apparent lack of preparation for responding to the needs of this client group across generic healthcare services was highlighted (Carter, 2000). Also many staff in community based residential settings, orientated to a ‘social care’ model, appeared not be aware of how to monitor the health of their clients, and to lack knowledge of the health risks faced by their clients. Other problems highlighted included evidence that many people with learning disabilities experience communication and cognitive problems which leave them either unable to communicate or understand the health problems they face (Astor and Jeffries, 2000). And evidence of a pervasive negativity among generic health professionals also began to emerge (French, 1994).

The publication in 1995 of *The Health of the Nation: A Strategy for People with Learning Disabilities* (DoH 1995), with its emphasis on 'health surveillance' and 'health promotion' for this population, marked an official response from the Department of Health to this body of research. And there followed a series of policy statements and guidelines from the Department of Health, the NHS Executive, and other governing bodies in the NHS, and various health care professions, aimed at improving practice and performance in responding to the health needs of people with learning disabilities (Hart 2003). In fact, three years before the publication of either *Continuing the Commitment,* or *The Health of the Nation: A Strategy for People with Learning Disabilities* the NHS Executive had circulated guidelines (HSG(92) 42 (NHS Executive) containing recommendations for good practice in helping people with learning disabilities to access GP and primary care services. The response was very patchy however, and similar guidelines were circulated again in 1999 (NHSE 1999) which sought to highlight to GPs that in a list of 2000 patients 40 would be likely to have a learning disability, 8 of whom could be expected to have severe learning disabilities. Such guidelines, issued alongside other initiatives which sought to make people with learning disabilities and their carers more aware of their own needs and rights, such as *The Patients Charter and You* (Hull and Holderness Community Health NHS Trust, 1995), *The OK Health Check* (Mathews, 1997), *Feeling Poorly* (Dodd and Brunker, 1998), *Getting Better* (Band, 1998), *The Healthy Way* (DoH, 1998), and the *Your Good Health* series (BILD, 1997), were being delivered against a wider policy backdrop which increasingly emphasised the rights of, and need for, people with learning disabilities to access generic health care services, rather than be cared for entirely within specialist service settings.

This emphasis on accessing generic services had been implicit in *The Health of the Nation; A Strategy for People with Learning Disabilities* (DoH, 1995), the last major policy statement relating to people with learning disabilities to emerge from the outgoing Conservative government. It was also present in *Signposts for Success in Commissioning and Providing Health Services for People with Learning Disabilities* (NHSE, 1998), the first major policy statement to emerge under the auspices of the incoming 'New Labour' government elected in 1997. This document marked the beginning of a subtle shift of ideological emphasis in policy, however, in that it gave recognition to the idea that the inadequacy of healthcare provision for people with learning disabilities was an issue of inequality, reflecting their status as a socially excluded group in society; something not explicitly acknowledged in the preceding Conservative health agenda. This shift was also reflected in the emphasis of a new White Paper *Valuing People: A New Strategy for People with Learning Disabilities for the 21st Century* (DoH 2001) on 'integration' and the rights of people with learning disabilities.

Valuing People (DoH, 2001), the first White Paper aimed specifically at people with learning disabilities since *Better Services for Mentally Handicapped People* (DHSS, 1971) can be seen as further pursuing the community care agenda initiated in that earlier document, whilst at the same time placing the policy agenda for people with learning disabilities within a broader agenda of eradicating 'social exclusion'. Published a decade after *The NHS and Community Care Act* (DoH 1990), it can be also be seen as an attempt to address some of the shortcomings of community care policy, including that of inadequacies in healthcare provision. *Valuing People* sets out a policy agenda dominated by the pursuit of the ideal of integration, and based on four key principles of 'Rights', 'Independence', 'Choice', and 'Inclusion'. Included as a priority in this agenda are targets for health screening for people with learning disabilities, the universal registration of all people with learning disabilities with GPs, the carrying out of health assessments and the development of 'Health Action Plans' for all people with learning disabilities by 2005, and the designation of 'health facilitators' to manage and monitor these developments. Learning disability nurses are specifically identified as the professionals best placed to take on this health facilitation role.

Conclusion:

The 1990s and early 2000s then, has been a period of greater change for learning disability nursing than was perhaps anticipated by many in the profession at the inception of community care policy in the late 1980s. The landscape within which the profession operates has changed fundamentally, not just in the shift in physical environment from hospital to community based care, but also in a shift in the ideological and organisational environment, to a situation where the profession has had to reconstruct its role and identity in the face of serious questioning from health and social care service managers charged with achieving specified targets within tight budgetary restrictions. These managers have also been charged with increasing the plurality of service providers, shifting ownerships and control away from the NHS, and towards the voluntary and private sectors. These 'market' pressures seem often to have worked against the learning disability nursing profession, and the *Continuing the Commitment Project* (DoH 1995) was a major attempt to redress the balance in favour of the profession by clarifying and specifying its role for the benefit of purchasers and commissioners of services. Its authors chose to do so by constructing that role and identity around the central concept of 'health', aligning the profession with the direction of health policy set out in the contemporaneous *Health of the Nation: A Strategy for People with Learning Disabilities* (DoH 1995). Since then a change of government has seen a further shift in policy direction towards an agenda dominated by the idea of social integration, including in the area of accessing generic health care services.

At the time of writing, the learning disability nursing profession is engaged in adopting the 'health facilitation' role identified as central to this process in the *Valuing People* (DoH 2001) White Paper, whilst simultaneously pursuing the specialist clinical roles working with those sub-populations specified in *Continuing the Commitment,* including people with 'challenging behaviours', people with a dual diagnosis of learning disability and mental illness, and people with 'complex health needs'.

One area where these developments have been followed with particular interest is in schools of nursing; particularly those involved in training learning disability nurses. Working within the parameters set initially by the 'Project 2000', and later the 'Making a Difference' curriculum, nurse educators have sought to reflect the changing emphasis of professional and policy directions in the programmes and materials they produce. These materials include the learning disability nursing textbooks which form the core data in this study, and it is to the analysis of these texts that we will soon proceed. Before that analysis can begin, however, we need to specify the methodology underpinning it, and it to that task we will now turn.

Chapter 4

Method and Methodology

Introduction:

Having outlined the historical and policy background which constitue important contexts for this study, we can now turn to methodological issues. In this chapter I will outline the approach and procedure for the analysis of the texts which constitute the data in this study. This will involve looking at the central tenets of the broad discourse analysis approach to research, which will be based on an explanation set out by Gill (1996), followed by an outline of the actual approach adopted which draws upon methods developed by Fairclough (2001) and Potter (1998). Before beginning this discussion of the generalities and details of methodology and method however, I will set the scene, with an outline of how my interest in this area of research developed. This outline will serve to provide the reader with relevant aspects of my personal and professional biography which, in keeping with the tenets of the discourse analytic research tradition, is intended to help clarify the perspective from which my own analytical 'gaze' comes.

Burgess (1984) reminds us of the need, particularly acute in qualitative research where the researcher themselves acts as the main analytical tool, to maintain a critically reflective stance towards one's own interpretations. Burgess points out that the theoretical stance adopted by the researcher will inevitably shape his or her interpretations of the data. For that reason it is particularly important to make that stance transparent, both in order to allow the reader to develop an awareness of how the researchers' theoretical leanings may have influenced their analysis, and also to remind the researcher themselves that their interpretations are 'constructions', rather than hard facts. Firstly then let us look at how my interest in this area of research arose.

The Origins of the Study:

The origins of my interest in discourse and the construction of professional roles and identities in the learning disability field dates back to reflections on my own work whilst practising as a learning disability nurse in the late 1980s and early 1990s. At that time the NHS was still the main provider of residential care for people with learning disabilities and the project of deinstitutionalisation still dominated the research, organisational and political agendas. The shift to 'care in the community' was well under way, although the full effects of the 'quasi-market', formally established by the NHS and Community Care Act (DoH 1990) had yet to be fully felt. 'Community care' and 'normalisation philosophy' were still widely perceived as virtually synonymous in many peoples eyes.

It was both an exciting and deeply frustrating time to be involved in the learning disability field. Exciting, because the work largely centred on helping people who had lived since childhood in dreary, under stimulating, impoverished institutional environments, to experience a new degree of freedom, choice, privacy, stimulation and enjoyment in their lives. Being involved in, and responsible for, organising programmes of care and support that produced rapid and positive change in people's lives was highly stimulating and motivating. Turnball (2004) points out that many of the learning disability nurses he interviewed in his research exploring their motivation for joining the profession did so precisely to be involved in this kind of radical and transformative work, rather than to actually become a 'nurse' or 'health professional'.

This certainly echoes my own experience. Training to be a learning disability nurse, or registered nurse in mental handicap (RNHM) as the professional designation was at that time, was the only professional career route to working with people with learning disabilities below the level of specialist psychiatrist, and that, rather than actually wanting to be a 'nurse' was my motivation for entering that profession. This was reinforced by the radical and innovatory nature of the particular nurse training course that I undertook.

I consider myself particularly fortunate in retrospect to have undertaken my nurse training in Portsmouth in the mid 1980s. At that time the RNMH training programme in Portsmouth was among the first in the UK to be deinstituionalised, or rather reinstitutionalised, out of the Mental Handicap Hospital system, and into higher education. Under the programme leadership of a radical nurse tutor, Karl Nunkoosing, and in collaboration with leading Downs' syndrome researcher, and pioneer of integrated education, Sue Buckley, the RNMH programme in Portsmouth was moved out of Coldeast Hospital, and into the psychology department at Portsmouth Polytechnic. The RNMH training programme was run concurrently with a Diploma in Mental Handicap Studies which was a largely psychology orientated course, with a curriculum incorporating humanistic, behavioural, cognitive and developmental psychology, as well as aspects of sociology and social policy. This was all built upon an ideological foundation of normalisation philosophy. Although some practice placements were still based in Coldeast Hospital, most were in small community based residential and respite care units, or with community nurse teams. One particular innovation was a 'family placement', where students spent twelve weeks working in a family home with a child of pre-school age. There were also placements in Social Service run day centres and Special Schools. The result was a very rounded practical experience, in a radicalised academic atmosphere. One of the outcomes of this was a certain antipathy towards the rest of the nursing profession with which we came into contact only sporadically, and especially the 'old school' mental handicap nurses who were very much regarded as part of an outmoded 'medical model'. This term virtually became an insult among students on the course, steeped as we were in the theories and perspectives of Wolfensberger, O'Brien and Nirje.

One of the negative effects, however, of training on such a 'cutting edge' programme was the culture shock that many students experienced on graduating and finding themselves employed in services that, even though community based, were still very much in thrall to medical authority. This authority came in the form of consultant psychiatrists who still exercised enormous control over the lives of residents and users of NHS residential units, deciding, for example, if, when, and sometimes even where, clients were allowed to go on holiday, and how much of their benefits they were allowed to access. Nurses too worked under the authority of consultants, and trainee psychiatrists who often represented them. One of the most obvious effects of this dominance of people's lives was the persistence of a psychiatric orientation to explaining and responding to the behaviour of the clients we worked with. For students who had been trained to interpret behaviour as 'communicative' rather than as symptomatic of 'pathology' this was often hard to accept, and was certainly in my case, a cause of profound dissonance. The nursing role became almost subversive in such a situation, as we administered the drugs prescribed, filled in the nursing notes accordingly, whilst at the same time implementing care plans based on the humanistic and behavioural psychology we had learnt during our training, and advocated for a change of orientation consistent with the principles of normalisation. And we scored some notable successes, bringing about dramatic improvements in the health, behaviour and quality of life of a number of clients with particularly challenging behaviour (Goble 2000). There were intense frustrations too, where clients whose behaviour was clearly, if inarticulately, communicating deep unhappiness with their situation and treatment, were kept effectively trapped in a psychiatric diagnosis where their behaviour was interpreted as symptomatic of psychosis, and where the response seemed only to be more drugs and more restrictions (Goble 2002).

The opportunity for me to reflect upon, and theorise about, this situation came in the early 1990s when I undertook an MSc programme in Applied Psychology in Learning Disability at what was, by then, the University of Portsmouth. This programme had, in fact, evolved out of the Diploma in Mental Handicap Studies that I had taken concurrently with my RNMH training, and like that programme it was heavily tuned into current and radical research agendas in the field. It was there that I began to explore the social model of disability, with its sharp critique of professions and services for disabled people. And it was there also that I came upon 'social constructionist' and 'discourse theory' applied to people with learning disabilities, particularly in the work of authors like Foucault (1965, 1976), Rose (1985) and McKnight (1992). I recognised in the work of these authors, and their theorisation of the role and dominance of biomedical power in the construction and treatment of psychopathology much that echoed my own experience in learning disability services, and I used these theoretical approaches to underpin my own research at Masters level (Goble 2000). What I came to realise through this work was the power of discourse to shape peoples' material reality and life course.

In the research cited I undertook case studies of two women with moderate learning disabilities whose mental and physical health had been left in ruins by the application of, what I called, a 'psycho-medical monologue' in which their behaviour had been perceived and portrayed as symptomatic of psychopathology. The case studies I described and evaluated were based on interventions in which their behaviour was reinterpreted as communicative, and their history had been reinterpreted and retold as 'lifestories' rather than 'case histories'. In similar work undertaken by Gillman et al (1997) those authors described the objectification of people with learning disabilities in medical 'case' histories as a form of 'professional tyranny', a description that seemed very apt in my experience. In my own research the 'retelling' of the life stories of the women concerned played an important part in changing the way they were perceived and responded to by the staff team involved in their care (Goble 2000). This had a major impact in transforming the relationships between staff and the clients concerned in ways that led to great benefits for all; including major health improvements for the two women. A very similar story is told by Abma (1999) in an account of her research in the Dutch mental health system.

Thus, through a mixture of academic work, research and reflection on practice, I developed a major interest in discourse as applied to the learning disability field. Originally, my interest lay in the way that the collective identity of people with learning disabilities was constructed, particularly in relation to the concept of health, but increasingly, I developed an interest also in the construction of the identities of the professionals working with them too. I became particularly interested in the way that the identities of people with learning disabilities, and the roles and professional identities of those who worked with them were linked via the interplay of discourse. I also developed an interest in textbooks in the learning disability field, recognising that they provided both an illuminating record of the history of the field, and a ready made source for exploring the evolution and application of professional discourse. One recent development that particularly interested me was the emergence of 'health' as a distinct and specific topic – a discourse of health - in learning disability nursing textbooks in the immediate wake of the publication of the *Continuing the Commitment* report in 1995. It seemed that here was an example of a discourse emerging directly out of a need to rearticulate the role and identity of a profession in response to external political and organisational pressures.

These interests came together when, in 2001 I became involved in learning disability nurse education at the University of Greenwich. The publication of the *Valuing People* White Paper in 2001 had once again shifted the ground under the profession. As can be seen in Chapter 3, this document placed health among the main priorities of services. However, its main thrust was that health should be provided by generic rather than specialist services, consolidating the policy trend initiated in *the Health of the Nation: a strategy for people with learning disabilities* (1995), and developed further in *Signposts for Success in Commissioning and Purchasing Services for People with Learning Disabilities* (1998). In *Valuing People* however, learning disability nurses were identified as particularly well suited to fulfil the 'health facilitation' role deemed necessary to enable the NHS to meet its targets of health assessment, and to facilitate access to generic services. How this 'health facilitation' programme should be implemented was not specified however, and local services, including the newly established health and social care trusts, have largely been left to their own devices to decide how it is done.

Once again then, the issue of the role and identity of learning disability nurses has become a significant topic of interest. With this in mind, it seemed an opportune moment to conduct a study exploring how and why this distinct discourse of health developed in learning disability nursing at this time. And it also seemed that an obvious place to examine and explore the emergence of this discourse was in the spate of new learning disability nursing textbooks published between 1997 and 2003. In this way, the aim of conducting a discourse analysis of the health related chapters in these books was formulated.

The Research Question and Aims of the Study:

In conclusion then, we can state that the main question this study seeks to address is :-

Why has the discourse of health apparent in learning disability nursing textbooks in the 'post Continuing the Commitment era' (1997 to 2003) emerged at this time and in this form?

The main aims of the study then can be expressed as; to explore the discourse of health in learning disability nursing textbooks in the post-Continuing the Commitment era (1997 to 2003), looking particularly at:-

- *how* it has been constructed
- *why* it has been constructed in this way
- and *why* it has emerged at this time.

Having set out the research question and specified the aims of the study we can now go on to look at the methodological approach adopted.

The Main Tenets of Discourse Analysis:

Before outlining the analytical method used in this study, we need to explore the main tenets of discourse analysis as a general research approach. This will serve to make clear the philosophical and theoretical foundations upon which this form of analytical approach is based.

Discourse analysis fits within the broad spectrum of qualitative research; that is research concerned with exploring and interpreting systems of meaning and perception in human social and cultural life. Walcott (2001) divides qualitative approaches into three main, but interrelated forms. These are 'participant observation', where the researcher is concerned with 'experiencing' a particular socio/cultural context; 'interviewing', where the researcher is concerned with 'enquiring' about the perceptions and interpretations of participants in a particular socio/cultural context; and 'archival research', where the researcher is concerned with 'examining' documents and artefacts which can give important insights into the construction and representation of meaning in particular socio/cultural contexts. Discourse analysis falls into this last 'archival' category, and is a particularly appropriate approach for exploratory research concerned with examining the construction of meaning and identity as it is embodied in texts and artefacts.

Discourse analysis is, however, as Gill (1996) points out, an imprecise term, referring to a group of research methodologies that have emerged in recent decades across a range of social and human science disciplines, including linguistics, psycholinguistics, social psychology, sociology and anthropology. The focus of these various forms of analysis has ranged, according to interest and discipline, across a wide variety of language use. Gilbert and Mulkay (1984) have identified a continuum of approaches in discourse analysis ranging from broadly focussed social structuralist forms which look at the way discourse is used to construct social and cultural institutions, to micro-focussed socio-linguistic forms which concentrate on analysing the fine detail of conversational interactions between individuals. This broad variety of methodologies draws on an equally broad variety of theoretical perspectives, but they are unified to some extent by, as Gill (1996) puts it,

"...a rejection of the idea that language is simply a neutral means of reflecting or describing the world and a conviction of the central importance of discourse in constructing social life" (p141).

This is illustrated by Gill as she elaborates what, with reference to the seminal work of Potter and Wetherell (1987), she describes as the 'four main themes' of discourse analysis - discourse as topic, dicourse as construction, discourse as 'action orientation' and discourse as rhetoric. I shall now outline each of these themes, using them as a framework to discuss in more detail some of the reasons underpinning my choice of this methodological approach in this study.

Theme 1) Discourse as 'topic':

The first major theme is the idea that *'discourse is itself the topic of discourse analysis'*. The term 'discourse' here designates all forms of talk or text, including informal, naturally occurring forms, such as conversations, or more formal, structured forms such as interviews, research papers, and, of course textbooks. In discourse analysis it is, Gill (1996) points out, the text in its own right that is the focus of analysis. The analyst is reading the text to explore how reality is represented by it, and constructed within it, rather than regarding it as a mirror reflecting a reality that lies beyond (Potter, et al. 1990). Such an approach draws from a constructionist theoretical perspective, and adopts what Potter (1998) describes as a 'methodological relativist' stance. From this stance any description of reality depicted within a text is read not as a 'true' description, but as a 'version' of the truth. The task of the analyst becomes to explore 'how' and 'why' the description has been constructed in the way that it has.

In this study I am essentially interested in exploring how and why a discourse of health has been constructed in learning disability nursing textbooks precisely because of the insight it may give into how a profession like learning disability nursing attempts to restructure its role and identity to maintain its existence in the face of changes in its material and ideological environment. The reason such an analysis is likely to give us this insight is because, as we shall see below when looking at theme three, these texts are an important part of the means by which the socialisation of student learning disability nurses is conducted. The discourse they contain can thus be read as an authoritative, 'state of the art' position statement on the role, identity and knowledge base of the profession.

Theme 2) Discourse as 'construction':

The second major theme of discourse analysis identified by Gill (1996) is the idea that language is 'constructive'. Potter (1996) points out that the term 'construction' is a metaphor for the fact that discourse as we use it is produced from pre-existing linguistic resources, or 'repertoires' as he calls them. This refers to the battery of linguistic resources to which an individual has access, and which is one of the hallmarks of their membership of a particular cultural, or sub-cultural group, including, as in this study, professional cultural groups into which the individual has been socialised. Potter et al (1990) describe these 'repertoires' as

"... language and linguistic practices [which] offer a sediment of systems of terms, narrative forms, metaphors and commonplaces from which a particular account can be assembled." (p207).

Gill (1996) points out that the metaphor of construction also illustrates that the generation of a discursive account necessarily involves selection and choice from the available resources. This means that the author of a text will bring to it their own orientation and perception which will inevitably shape their own discursive production. They will 'construct' a world view using the resources available, and those resources will be provided by the linguistic repertoires which give them legitimacy and authority in a given culture.

I noted earlier that Gilbert and Mulkay (1984) have identified a continuum in discourse analytic research ranging from broadly focussed 'social structuralist' approaches, to fine textured 'socio-linguistic' forms. In their analysis of scientific texts, they identified their own approach as lying on the middle ground between these two extremes, attempting to look at discourse as a social process in the construction of scientific accounts, but at the same time looking at the linguistic features of the discourses to see how these constructions were achieved. This also meant exercising a certain restraint as to the generalisability of their conclusions with regard to what they can tell us about the wider cultural context within which they are situated. In particular, they sought to identify ways in which accounts constructed by scientists are systematically and meaningfully patterned in texts, using stylistic, grammatical and lexical features. The repertoires used are, Gilbert and Mulkay show, dependent on the context in which language is being used. They argue that certain types of discourse produce the use of certain types of repertoire. For example, the formal context of the research paper prompts the use of an 'empiricist repertoire' in which authors follow conventions about format and language use that 'de-personalises' the theories, procedures and results described; a strategy that works, as Potter (1998) emphasises, to construct a sense of 'out thereness' to the phenomena being discussed, reinforcing a sense of that phenomena's essential material reality, or 'facticity' as Potter calls it.

Part of the aim of this study will be to look at the repertoires and linguistic strategies used in the texts to assert the 'facticity' of the phenomena being described, and the professional role and identity being constructed in response to it. These linguistic strategies and resources can be read as ways in which the accounts being constructed in the texts are able to assert 'authoritativeness', the accruing of which is important if that account is to gain and maintain legitimacy in the eyes of those who decide whether to commission and purchase the services of the profession or otherwise. Thus discourse can form at least part of the basis upon which the existence of the profession is maintained or dispensed with.

Theme 3) Discourse as 'action orientation':

This last point leads us into the third major theme of discourse analysis according to Gill's (1996) schema. This is what she describes as the search for the 'action', or 'function orientation' of discourse. This reminds us that discourse is more than merely a description of action, but is a form of social action itself. Discourse is therefore 'performative'. People as social actors use discourse to perform social tasks. As Gill puts it

"People use discourse in order to *do* things: to offer blame, to make excuses, to present themselves in a positive light and so on. This underlines the fact that discourse does not occur in a social vacuum. As social actors, we are continuously orienting to the interpretative context in which we find ourselves and constructing our discourse to fit that context" (p142. Emphasis in original).

The 'interpretative context' is an important idea here. It is meant to identify the fact that discourse is both a product of, and reproduces the context in which it occurs. I will illustrate this by using the example of 'textbooks' that are integral to the analysis conducted in this study, in which learning disability nursing textbooks form the interpretative context in which the texts to be analysed are situated.

The 'textbook' from a discourse analysis perspective, is seen as a 'performative object', and a 'cultural artefact'. It is both a product, and reproducer of, a culturally situated conception of knowledge, expressed as a 'discourse type'. According to Fairclough (2001) a 'discourse type' is an aspect of a social and/or institutional order which performs the cultural function of transmitting knowledge and other information in a particularly constrained way. The nature of this constraint is determined by the social and institutional structures of which the 'discourse type' is both a product, and a reproducer. What a textbook does then, is to structure the interpretative response of the reader in a particular way that suits the purposes of the professional, social and institutional subcultures and bureaucracies with which they are aligned; usually the state or other powerful organisations. The textbook can thus be seen to be an interpretative context in which 'authoritative' discourse, discourse as an 'actualisation' and 'mobilisation' of an ideologically laden symbol system, is made manifest (MacDonald, 2002).

From a social constructionist perspective the textbook is seen as a form of 'authoritative' text in which phenomenon of interest are constructed in a context which gives them a particular form of 'culturally authoritative' presence. Myers (1990) analysed this process in biology texts, arguing that the 'cultural authority' of science as a system of knowledge production and presentation used in such texts gives weight to them because they represent a form of knowledge validation which is held in particularly high esteem in this society. They are naturally seen to be a particularly potent reflection of reality, rather a construction of it.

In this way the textbook can be seen to communicate both within, and beyond the disciplinary and professional community from which it emanates, to wider society; and particularly to those powers significant in granting a discipline political, ideological and institutional legitimacy. They in effect 'advertise' that they constitute a serious, scientifically grounded discipline, with a legitimate body of knowledge and expertise. The requirement to achieve these wider communicative objectives can be seen to be the point at which ideological factors exercise constraint over the discursive and knowledge validation processes embodied in the textbook. This is the point at which a textbook becomes a product of a wider culture, rather than purely an expression of a local, technically oriented subculture. The textbook can thus be seen to be a quite complex interpretative context.

Theme 4) Discourse as 'rhetoric':

The fourth major theme elaborated by Gill (1996) is that discourse analysis involves exploring the 'rhetorical organisation' of text; that is, discourse as a form of persuasion. A feature of the discourse analytical approach I am adopting in this study, drawing particularly from Potter (1998), is to regard texts as means by which authors and groups seek to 'persuade' readers and interpreters of the salience and facticity of their 'version' of the world. We have already seen that the assertion of the veracity of accounts and knowledge is part of the cultural function of the textbook as a genre. The textbooks in which the texts to be analysed in this study are contained form, as we have also seen, the 'interpretative context' for the discourses they contain. This 'interpretative context', as noted earlier, imposes 'constraints' on the nature of the text. These 'constraints' largely define the types of discourse and repertoires we are likely to encounter. For example, a health related discipline which claims to base its knowledge base and expertise on a scientific foundation will be obliged to use empiricist repertoires in constructing accounts of its phenomenon of interest and ways of working. Also, the nature of empiricist discourse, with its emphasis on a 'depersonalised' style of presentation, corroboration through reference to bodies of research, and a strong rationalistic and explanatory narrative style, have strong parallels in academic, scholarly, and pedagogic discourse which are also, of course, major features of the textbook genre.

From an analytical point of view the fact that we may be aware beforehand of some of the types of discourse and repertoires we are likely to encounter in a text, does not mean that the way they are organised rhetorically will necessarily be obvious or self evident. Part of the interest in using a discourse analytic approach in studying texts of this kind is to seen how these apparently 'objective' and 'conventional' forms of knowledge presentation and argumentation are, in fact, used in rhetorical ways to construct a particular way of looking at, and responding to, a phenomena; ways which are frequently laden with assumptions that reflect, the material, institutional and political interests of those making the case, and which may also work to preclude, or marginalize other ways of looking at the same phenomena.

This emphasis of some forms of discourse analysis on 'exposing' the rhetorical dimension of texts and their representations of the world is what gives this form of research its 'critical' and radical appeal in the eyes of some of its proponents (e.g. Fairclough 2001); and I would argue that a critical edge in this study comes from exploring the discourse of health in relation to the insights of the social model of disability. Potter (1998) introduces a cautionary note however, arguing that 'critical' discourse analysis risks leading us to look at the rhetorical construction of texts purely as if they are obfuscations, rather than genuine and meaningful attempts to explain, interpret and structure relationships with the world and with others.

Taking Potter's lead here, I would like to make clear here that it is not my intention to treat the texts under analysis, and, by default, the authors of the texts, as 'co-conspirators' in some attempt to maintain the oppression of people with learning disabilities. Such an approach risks reducing the analytical process to an elaborate form of cynicism, and would rightly invite ethical censure. Despite the fact that the texts under analysis are published material, and therefore in the public domain, such an approach could be said to compromise the ethical obligation of the researcher to 'do no harm' – even if the authors of the texts are not themselves the 'subjects' of the study. My intention in exploring the rhetorical nature of the texts under analysis in this study is not therefore to 'expose' the authors of the texts as somehow disingenuous, but rather to illustrate how authoritative figures in a profession use particular discursive strategies to try and solve the problem of how that profession can continue to act with a sense of integrity in relation to its client group in a rapidly changing structural and ideological environment. In exploring the arguments made in these texts I have found much with which I agree, as well as certain aspects with which I don't. Whilst I firmly believe that there is a strong case for specialist health care provision and support for people with learning disabilities, I freely admit that I am by no means convinced that there remains a case for a distinct branch of nursing devoted solely to working with this client group. But the aim of my analysis in this study is not so much to reinforce, or rubbish the case for the continued existence of learning disability nursing – although such an analysis cannot help but relate itself to this issue. My primary aim is rather more modest however - to explore the way that theorists from this branch of the nursing profession are using discourse as a resource to reconstruct and restructure its role and identity in the face of external challenges.

As such I hope to produce a study which will offer insights into the way that this branch of nursing, and perhaps other branches of the nursing and caring professions engage in struggles to defend or extend 'jurisdiction' over certain areas of work with certain groups of people; a struggle in which 'discourse' is often both a battleground and a resource.

Existing Discourse Analytic Research in Health and Nursing:

For a methodological approach that potentially offers such a rich vein of analysis in the health and nursing fields there seems to be a dearth of its actual application in the research literature. The main concentration of discourse related research has been related to the critical analysis of the psycho-medical understanding of mental illness, particularly psychosis (e.g. Rose, 1985., Levin, 1987., McNamee and Gergen, 1992., Shotter, 1992., Parker, Georgaca, Harper, McLuaughlin and Stowell Smith, 1995.,and Fee, 2000), with some recent extension into the analysis of health psychology (Willig, 2004). This literature builds mainly on the analytical tradition established by Foucault (1965) and his seminal work on the relationship between language, psychiatric diagnosis, and the power and authority of rationalistic (modernist) scientific discourse in shaping the cultural context in which mental distress is responded to. This form of analysis had strong appeal to a generation of young psychiatrists and psychologists influenced by the critical 'anti-psychiatry' perspectives of Szazs (1971) and Scull (1977), among others.

This critical approach to 'psycho-medical' discourse and power has had some influence too in the critical analysis of the construction of learning (or more recently, 'intellectual') disability, echoing many of the arguments and analytical approaches applied to psychiatry in the literature cited above (e.g. Bogdan and Taylor, 1989., Goodey and Stainton, 2001., Goodley, 2004, and Rapley, 2004). Interestingly though, this analysis has come from a 'disability studies', rather than a nursing, or other professional research direction. Comparatively little nursing research has used a discourse analytic approach, even in the mental health field where more might have been expected given the existence of the critical mass of research referred to above (e.g. Adams, 1998., Mason and Mercer, 1998., and Mohr, 1999). Some discourse orientated literature is also evident in the midwifery field, perhaps reflecting the tradition of critical analysis applied in that professions' ongoing struggle with medicine (e.g. Hunt and Symonds, 1995., Symonds and Hunt, 1997., and Redwood, 1999). More generally, there has been some discourse analytic work applied to the study of narrative accounts of patients and nurses (e.g. Hallett, Austin, Caress and Luker, 2000., Harden, 2000., Ashworth, Gerrish and McManus, M. 2001., Hardin, 2003., and Taylor, 2003), reflecting the well established and ongoing interest in nursing research with the analysis of personal accounts. Strangely perhaps, very little research seems to have been conducted which focuses on the analysis of nursing literature and documentation, with the studies by Mohr (1999) on psychiatric nursing notes, and Redwood (1999) on midwifery literature and media accounts relating to water birthing, very much the exceptions. No discourse analysis of nursing textbooks comparable to that undertaken in relation to medical literature (e.g. Turner, 1987., Lupton, 1992) seems to have occurred to date, despite the fact that, as we have already discussed above, this body of literature presents us with a rich source of potential data from which to analyse the socio/historical and ideological development of nursing.

Overall then it seems that discourse related research in nursing seems to have remained, as Cheek (2004) has put it, very much at the margins, and the current study represents an attempt to address what might be seen as a gap, not just in the research literature, but in the overall orientation of nursing research both within and beyond the learning disability specialism.

We will now go to look at the selection of the data for analysis in the study.

Selecting the Data:

Burr (1995) has suggested that, in discourse analysis, the parameters set for the selection of textual data for analysis should be 'context driven'. In the context of this study that effectively means that the data will consist of those textbooks aimed specifically at student learning disability nurses published in the period after the publication of *Continuing the Commitment* (DoH 1995), and the specific chapters within them that refer to health in a general, rather than specific way. This means that I have excluded chapters that refer to particular aspects of health, such as mental health, sexual health or women's health for example, and have focussed on those that discuss 'health' in general terms.

Note also needs to be taken of the decision to exclude one book from the study. The book in question is Thompson J. and Pickering S. (2001) *Meeting the Health Needs of People who have a Learning Disability.* London: Bailliere Tindall. The decision to exclude this book was made for two reasons. Firstly, although it is a textbook aimed at student nurses, it is different in orientation from the textbooks included in that the whole book deals with health as a specific topic, rather than as one among the various topics relevant in the broad learning disability field. None of the chapters deal, therefore, with health in the same kind of generalistic way that the texts actually selected do, but focus rather on detailed outlines of various facets of health. Secondly, and following on from the first reason, the only legitimate way to include this book would have been to have included all of the chapters as data. This would have made the amount of data unwieldy given the time available to undertake analysis. In an ideal situation perhaps, with much more time available, this book could have been included. For the purposes of this study, however, it will have to suffice to note its existence, and regret that time restrictions precluded its inclusion.

I have also avoided books that, though they may refer specifically to the health of people with learning disabilities, are aimed at students of medicine and psychology rather than nursing. Examples would include for instance Moss S. and Turner S. (1995) *The Health of People with Learning Disability*, published by the Hester Adrian Research Centre, and aimed primarily at a medical and clinical psychology audience. I have then, in order to maintain focus, stayed with those books which specify nurses as their primary audience. The five chapters used, drawn from four textbooks, represent the totality of texts that meet these criteria.

The texts to be analysed then are, in chronological order:-

1. Vernon, D. (1997) *Health.* in B.Gates (ed) **Learning Disabilities** (3rd Edition) London: Churchill Livingstone. pp 89-101.

2. Vernon, D. (1997) *Defining Health.* In B. Gates **Dimensions of Learning Disability.** London: Bailliere Tindall. pp 89-101

3. Wake, E. (1997) *Health Loss, Gain and Maintenance in Learning Disability.* In B. Gates **Dimensions of Learning Disability.** London: Bailliere Tindall. pp 45-74.

4. Barr, O. (1998) *Responding to the Health Needs of People with Learning Disabilities.* In Thompson, A. and Mathias, P. (eds) **Standards and Learning Disability.** (2nd Edition) London: Bailliere Tindall. pp 306-320.

5. Hart, S. (2003) *Health and Health Promotion.* In B. Gates (ed) **Learning Disabilities: Towards Integration.** (4th Edition) London: Churchill Livingston. pp 289-309.

Method and Procedure:

Potter and Wetherell (1998) point out that discourse analysis has no specific prescribable method that can be presented in recipe form, like experimental method for instance. Nonetheless they, among others, have attempted to break the procedure down into distinct stages. The format adopted in this study is derived from Fairclough (2001), and breaks the analytical procedure down into three main stages, which are:-

1. 'Description'
2. 'Interpretation'
3. 'Explanation'

The aim of these three stages of analysis are set out below, but I should stress here that it is the overall framework for analysis that I have drawn from Fairclough, rather than the detailed linguistic and rhetorical aspects of his approach. As a linguist, Fairclough's analytical procedure tends to focus on a level of linguistic detail not appropriate to my study aims. For these components of my analysis I have relied more on the work of Potter (1998). Focussing for the moment on Fairclough's 'three stage' framework however, I will now outline the general procedure followed.

Stage 1 – 'Description' – Describing the data and identifying implicit themes:

The initial 'descriptive' stage of analysis in this study is intended to achieve three things. Firstly, to describe the textbooks in which the texts to be analysed are found. This is in order to clarify what Fairclough (2001) describes as the 'interpretative context' within which the texts to be analysed are situated. The second aim is to describe the form and content of the chapters - the texts that constitute the discourse of health itself. Parker (1992) defines a discourse as "...a system of statements that constructs an object" (p5). In this case that 'object' is 'health' in relation to people with learning disabilities. Parker (1992) also notes that a unified discourse will have major common themes, and the third aim of this first phase of analysis will be to identify such themes. These themes will then become the main focus of the second phase of analysis which involves looking at 'how' the discourse is constructed, exploring in particular linguistic and rhetorical strategies used. The main themes of the discourse were identified using a simple colour coding procedure, with different themes being identified by the use of different colour shading during analytical readings.

Stage 2 – 'Interpretation' – Exploring how the unifying themes are constructed:

Stage two of analysis will focus on examining in greater depth common themes identified in stage one. In this second phase of analysis we will treat the discourse of health as transcendent of the individual texts. This means that analysis will be presented 'theme by theme' rather than 'text by text' as in phase one. In this way the discourse will be focussed upon as a unified whole, giving a clearer overall picture. Analysis itself will involve exploring the linguistic and rhetorical organisation of the main implicit themes identified in phase one, and exploring how this works to construct the discourse. This analysis will be based on an approach suggested by Potter (1998) which has two distinct, but interwoven elements. These are, firstly, the identification of patterns, particularly the use of what Potter calls 'interpretative repertoires'. These have been defined by Potter (1996) as;

"….. systematically related sets of terms that are often used with stylistic and grammatical coherence and often organised around one or more central metaphors." (p131)

As well as identifying repertoires, other linguistic and rhetorical features identified by Potter (1998), will also be explored, and particularly features significant in constructing, what Potter calls, the 'facticity' of representations of phenomena and concepts in the text. These include:-

- Identifying features such as the *'action orientation'* of the text, which involves exploring the semantic and rhetorical goals of the text, in particular 'defensive' and 'offensive' strategies. That is, ways in which the text is organised rhetorically to 'defend' positions and/or concepts from alternative explanations, or 'offensively' to actively confront and counter alternative explanations and conceptualisations;

- Management of 'stake' and 'interest', which involves exploring ways in which the 'stake' and 'interest' that the authors might have in promoting or countering particular positions and conceptualisations are managed – for example, by establishing the 'facticity', or 'out-thereness' of key phenomena and problems so that a response to them can be seen as a response to a 'real need'. Strategies used to achieve this include the use of particular forms of 'detail' in description and classification of phenomena, and the use of 'classificatory systems', 'corroboration' and 'consensus construction' through reference to authoritative sources.
- Other features to be explored will include the use of particular forms of vocabulary and phrasing which may carry emotive, value-expressive and ideological connotations.

This interpretative stage of analytical process was facilitated by the use of 'key passages', a procedure designed, as Fairclough (2001) points out, to make analysis more manageable by concentrating on those passages in texts where the rhetorical and linguistic strategies used to construct the themes are most strongly evident. The interpretative analysis itself is presented in extended commentaries appended to the relevant passages of the texts, which will necessarily be quoted in full. These passages were identified and marked out alongside the coding of themes referred to in phase one of analysis.

Stage 3 – 'Explanation' – Exploring why the discourse has emerged:

Stage three of analysis will consist of a summary discussion of the findings of stages one and two, in which we will consider the question of 'why' the discourse of health in learning disability nursing textbooks has emerged at this time. An important part of the discussion will involve mapping the emergence and development of the discourse against ideological and policy developments that relate to the health of people with learning disabilities. In this way we will explore the way the discourse, and the themes that constitute it, relate to the broader socio-political context surrounding the learning disability nursing profession, and, in particular how its emergence and development been shaped and driven by policy developments described in the historical narrative that runs through the study.

Conclusion:

In this chapter I have sought to explain the approach and method I will adopt in the three analytical chapters that follow. I began by explaining how my interest in this area of research emerged, and in so doing so provided some relevant biographical information intended to help the reader assess the perspective from which the reading and analysis of the data in this study originates, and how this perspective influences that analysis. I have also sought to explain the central tenets of the discourse analysis research approach in order to clarify the appropriateness of its use in this study. I then outlined the actual approach adopted, based on a three-stage framework of 'description', 'interpretation' and 'explanation' adapted from Fairclough (2001), and involving analysis of linguistic and rhetorical features of the texts, drawing on an approach developed by Potter (1998). Having explained the background and methodological approach to be used, it is now time to turn our attention to the analysis itself.

Chapter 5

Data Analysis 1 – Describing the Discourse of Health

Introduction:

In this chapter we will begin the actual process of analysis. The overall aim of this first stage of analysis is to make clear 'what' it is that is being analysed. This process will begin with a descriptive overview of the textbooks from which the texts are drawn. This overview will serve to contextualise the texts to be analysed further, and will include details of editors, publishers, and where each book falls chronologically in relation to other editions of the same title where this is the case. Also included are outlines of cover notes and other relevant introductory and background material, such as 'Forewords', 'Prefaces' and 'Introductions' which explicate the aims of each book and its relationship to the education of learning disability nurses.

As the overview of the each of the textbooks is completed we will move on to look at detailed descriptive outlines of the chapters within them that constitute the actual texts to be analysed further. These descriptions will be presented as outlines of the structure, organisation and content of each of the texts, so that each can be viewed as a structural whole before the focus switches to 'interpretative' and 'explanatory' phases of analysis in subsequent chapters. Both books and texts will be described in chronological order of publication.

Finally, this first stage of analysis will conclude with an identification and specification of common themes identifiable across the texts; themes that serve to make these texts constitute collectively a distinct and unified discourse, rather than a series of unrelated texts with a common topic. We will begin then by describing the earliest of the four textbooks to be outlined.

Textbook 1)

B. Gates (1997) **Learning Disabilities** (3^{rd} edition). London: Churchill Livingstone.

This book is the third edition of the '*Learning Disabilities*' textbook, and the first published after the publication of *Continuing the Commitment* (DoH, 1995). The editor is Bob Gates, a leading nurse academic in the learning disability field, listed as 'Lecturer in Nursing at the Institute of Nursing Studies at the University of Hull'. The author of the chapter *'Health'* which constitutes the text to be analysed from this book is Deborah Vernon, who is listed as 'Graduate Teaching Assistant, School of Health, University of Hull. The publisher, Churchill Livingstone, is a well known, international publisher of nursing textbooks.

The notes on the back cover of the book talk of 'dramatic changes' in services for people with learning disabilities, informing the reader that such services are now primarily 'community based' and occur in a 'multi-disciplinary team' context. Learning disability nurses, we are told, have passed through "...a period of uncertainty about their role" but, "...they have emerged a stronger, more adaptable group, able to apply their knowledge and skills in a wide variety of settings and positions from specialist practitioners to community care managers and assessment officers". These cover notes conclude by stating that this book "...will continue to provide an essential core text for pre-registration nursing students, and an ideal reference book for all other nurses and health care workers involved in the care of this important group." Below the cover notes on the back cover is a diagram in which the main subject areas of the Project 2000 curriculum, and the four branches of nurse training, are set out.

Inside, the editor presents a short two page preface in which thanks are expressed to Shanley and Starrs (1993), the editors of the previous, second edition, and the 'model of excellence' they set. The editor then gives us a brief outline of the books contents, informing us that this edition has been expanded to include 'new chapters', one of which is on 'Health'. Tribute is paid here to the 'expertise' and 'common commitment and vision' of contributors. There then follows a substantial paragraph in which we are told that this book 'arrives at a tremendously important time for learning disability nurses'. Learning disability nursing, we are informed, has survived the transition to community care formalised by the NHS and Community Care Act 1990. A brief outline is given of the diversity of roles, service settings and agencies in which learning disability nursing is now to be found. Particular reference is made to The Cullen Report (Four Chief Nursing Officers, 1991) and its observation that learning disability nurses were 'facility independent'. This comment is described as 'prophetic'. The observation is then made that learning disability nursing has had to learn some 'harsh lessons' about itself. In the short paragraph that then concludes the preface we are told that...

"Learning disability nursing is now responding to this challenge with confidence and the contribution of this book to the debate is to articulate the role of the learning disabilities nurse. However its primary aim is to provide a useful standard text on a range of issues in learning disabilities for diploma and degree courses, and to present the information in a way that readers find informative and accessible in directing their study and professional development."

This preface clearly seeks to establish continuity between editors and editions, invoking a sense of 'professional' tradition and gravity in the reference to a 'model of excellence' having been set. Importantly for this study, we are informed that 'health' is among a number of new areas to be addressed in this edition, introducing it by implication, as a topic of new significance in this new and updated core textbook for learning disability nurses. Reference is then made to the 'calibre of the contributors', thus reminding us that what is contained herein is 'expert' knowledge. The conclusion to this paragraph lays emphasis on the 'shared commitment and vision' of contributors, conveying the strong connotation that this is a 'moral' as well as an 'expert' community.

The contents of the book are set out in three main sections. After 'Contributors' and 'Preface', these are listed as follows:-

'Section 1' is entitled '*Understanding learning disability and service provision*' and consists of five chapters;

1. *'Understanding learning disability'*
2. *'Causes and manifestations'*
3. *'Development of services'*
4. *'Providing quality care'*
5. *'Ethics'*

Section 2' which follows is entitled *'Helping people towards independence'*. It consists of 10 chapters, which are:-

6. *'Health'*
7. *'Education'*
8. *'Accessing Services'*
9. *'Behavioural difficulties'*
10. *'Complementary therapies'*
11. *'Profound and multiple disability'*
12. *'Communication'*
13. *'Leisure'*
14 *'Representation'*
15 *'Sexuality and personal relationships'*

Finally, in 'Section 3', there are two chapters:-

16. *'Interventions in a family context'*
17. *'Helping agencies for the family'*

The chapters in 'Section 1' are clearly intended to present the foundational areas of knowledge for this profession. 'Learning disability' is presented, by implication, as an actual phenomena that has 'causes and manifestations'. The three subsequent chapters shift to focus on the profession rather than the phenomena, contextualising the response to the phenomena of learning disability as having developed historically, and requiring an imperative of quality, and being ethically and morally based. These last two chapters are thus establishing the profession as organisationally and morally, as well as materially bounded.

Section 2 is the central section of the book, delineating the main areas of focus for professional interest and action. These areas of interest are split between aspects of life, such as 'Health' , 'Education', 'Leisure', and 'Sexual and personal relationships'; various issues relating to those aspects, such as 'Accessing services', 'Representation' 'Communication', and 'Behavioural difficulties'; working with a particular sub-population of people with learning disabilities, in 'Profound and multiple disability; and the application of a particular approach, in 'Complementary Therapies'. These chapters can thus be seen as presenting a conceptual 'map' of the professional territory for the orientation of the reader.

The final section of the book consists of two chapters relating specifically to working with families. There is also a single 'appendix', entitled 'Legislation and social policy over the past 100 years.' This appendix provides a brief overview of policy from the 1913 *Mental Deficiency Act,* through to *The Health of the Nation: a strategy for people with learning disabilities* (1995*)* and the *Continuing the Commitment* (1995) document. These latter documents are identified as shifting the orientation of the profession towards a focus on the health of people with learning disabilities. In the conclusion to this appendix it states that for nurses, "... to move forward in promoting the care of people with learning disabilities will depend on the development of advanced nursing skills. In order to achieve such advanced skills, nurses will be required to apply research based practice focused on the health needs of this group of people (p319)." As virtually 'the last word' in the book, this statement clearly orientates this text as being in alignment with this orientation.

The specific text from this textbook to be analysed further is:-

Text 1)

Vernon D. (1997) *Health.* In B. Gates, **Learning Disabilities** (3rd edition). London: Churchill Livingstone. Pp89-101. (Identified hereafter as **'Vernon 1'**)

The chapter begins with an introduction, followed by four sections. In the introduction 'Health' is set up as a contestable concept. A problem identified early on is the historical application of a medical model of health, focussing on disease and diagnosis, with this client group. This is deemed inappropriate and limiting, forcing nurses to respond only to symptoms of ill health rather than the whole person. The 'danger' of people with learning disabilities having their health problems ignored or missed is emphasised, with examples given from research on health screening.

There then follows a section entitled *'What is health?'* in which various definitions and conceptions of health are discussed, with 'lay' understandings of health given particular emphasis. The idea of health as 'multidimensional', and linked to broad areas of everyday life and activity is given prominence. People with learning disabilities are characterised as being particularly vulnerable to the development of ill health. The nature of this vulnerability is related to two main dimensions of health, the 'physical' and the 'psychosocial'.

In the next section '*Challenges to health*', the actual vulnerability of people with learning disabilities to the development of health problems is specified. Firstly, physical health problems are described and discussed, with particular reference to genetically related conditions. Down's syndrome is given prominence in this section. Subsequently, psychological aspects of health are described and discussed, followed in turn by a description of sociological factors affecting the health of people with learning disabilities. Great emphasis is placed in this discussion on the vulnerability of people with learning disabilities to developing health problems due to a mixture of biological propensities, social isolation and a lack of competence. Nurses are urged to develop a strong awareness and knowledge of physical and psychosocial aspects of health as a basis for responding effectively to this vulnerability. The aim of learning disability is nursing is identified as helping people with learning disabilities to 'overcome obstacles' to health.

In the next section, '*The Achievement of Health*' a strong emphasis is placed on the application of an 'holistic' model of health, with particular reference to Maslow's (1954) hierarchy of needs, and Seedhouse's (1995) definition of health as 'the basis for the achievement' of individual potential. A broad conceptualisation of health is advocated, situated in everyday life, with a key component being an innate 'striving' to maximise potential and achieve independence.

In the next section, '*A Programme for Health Education*', learning disability nursing is described as having a 'key role' in helping people with learning disabilities to strive towards, and achieve the maximisation of individual potential, acting through 'direct care', 'assessment of need and health status', and 'monitoring and surveillance' of the health of people with learning disabilities. The aim of these interventions is identified as helping people with learning disabilities to overcome biological, social and educational deficits. 'Health promotion' is presented here as central to the learning disability nursing role, focussing not just on a response to 'acute' health care need, but on helping people with learning disabilities to maintain and promote their health regardless of whether they are actually ill or not. A threefold model of health promotion is set out, involving 'Primary prevention' – helping to prevent health problems occurring; 'Secondary prevention' – early detection of health problems; and 'Tertiary prevention' – action to avoid 'needless progression of health loss'. A health education role is identified as being at the core of the learning disability nurse role at all three levels of intervention. Other aspects of the nurses role are also identified, including advocacy, liaison and co-ordination of service delivery. To re-emphasise the centrality of health education, the text concludes with an outline of 'aspects of learning' which learning disability nurses are exhorted to grasp and develop skills in delivering.

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We will now move on to look the second textbook, and the two texts to be analysed further that will be drawn from it.

Textbook 2)

B, Gates and C, Beacock. (eds) (1998) **Dimensions of Learning Disability.** London: Balliere Tindall.

The book in which the next two chapters, which together comprise a distinct 'Health' section, appear, is a single edition, thus far without revision. It is edited by Bob Gates and Colin Beacock, both recognised as leading figures in the learning disability nursing field. Gates is listed, as before, as 'Lecturer in Nursing at the Institute of Nursing Studies at the University of Hull, and Head of Profession for Learning Disability Nursing, Hull and Holderness NHS Trust'. Beacock, in turn, is listed as 'Professional Officer, Royal College of Nursing, Sheffield, formerly Senior Education Manager in Learning Disability Studies at Rampton Hospital'. The authors of the two chapters which form the texts under analysis here are listed as Deborah Vernon, 'Graduate Teaching Assistant, Institute of Nursing Studies, University of Hull', and Eileen Wake, 'Lecturer in Paediatric Nursing, School of Health, University of Hull. Both are qualified as learning disability nurses, among their other professional qualifications. The book is published by Bailliere Tindall, a leading international publisher of nursing and health related textbooks, in association with the Royal College of Nursing.

The cover notes state that the advent of the NHS and Community Care Act 1990 and the Project 2000 nursing curriculum has led to the role of nurses being questioned in the care of people with learning disabilities. It is then asserted, however, that nursing has a 'crucial role' to play in what is described as a 'complex arena', but that "...nurses must identify and promote their unique knowledge and skills."

The aim of this book, it is stated, is to meet this challenge by placing learning disability "...firmly on the health agenda." It does this by looking at various dimensions influencing health and well-being, including 'biological, psychological, educational, cultural and spiritual, and political dimensions'. It is argued that these dimensions can be located in the book "... within the context of national and international issues and ongoing research, illustrating how health, in its broadest sense, fundamentally determines the lives and experiences of people with learning disabilities." The book, it is claimed, embraces theory, research and practice, and is designed as an educational tool with case studies, activities and discussion questions to encourage 'reflection' and 'critical examination'. The target audience of the book is identified as diploma and degree level nursing students, qualified nurses and other professionals, such as social workers and therapists.

In a brief 'Foreward' John Turnball, then Nursing Officer (Learning Disabilities) at the Department of Health, and one of the authors of '*Continuing the Commitment*' (DoH, 1995), reminds us that it is 25 years since the publication of the '*Better Services*' (1971) white paper that set out the agenda for the shift to community care for people with learning disabilities, and thus a good time to 'take stock' of achievements, and to think about further progress. He states that the aim must continue to be "... a vision of life for people with learning disabilities in which they feel they belong to the communities in which they live." He goes on to state that 'we', meaning learning disability nurses, need to promote a future also in which "... we are confident of our part" in this project, and that this book contributes to that goal. He then identifies 'health' as the central concept in the field in what, in relation to this study, can be seen as significant paragraph, "... As a nurse and a health professional, my experience and education has taught me the value of health in people's lives. Health is a resource for us to draw upon to get the most out of life. In choosing health as the major theme for this book, Bob and Colin have earned my strongest approval." This foreword finishes by observing that that this book should help people understand the ‘part they play and work together’, thus to ‘harness all our talents’. Emanating as it does from such a professionally and politically authoritative source, this foreword can be seen as providing a significant official sanction to the focus on health.

Subsequently, in a brief ‘Preface’ by the editors, they state that this book has been written for those ‘who care for and work with’ people with learning disabilities, including students, qualified nurses and other health and social care professionals. They state that “… [C]entral to this book is the idea that one way to understand learning disability is to portray it as a complex state of health…” comprised of the various dimensions that are identified in the contents, and that the book is designed to allow people to explore these dimensions. The section on health is presented as an attempt to articulate “…the role of the nurse in bringing about health maintenance and/or gain,” as advocated by leading nurse theorists.

The sections into which the book is divided are then described in brief, and in a concluding paragraph the editors write that, in response to the argument that the NHS and Community Care Act (DOH 1990) marked an ‘abdication of responsibility’ for people with learning disabilities by the NHS.

“ … [T]his is clearly a book that attempts to place learning disabilities firmly back on the agenda of health. Learning disabilities, in spite of recent legislation, cannot simply be located into the separate arenas of either health or social-care provision. To talk of health and social care as mutually exclusive concepts, whilst politically convenient, is both dangerous and inaccurate. Dangerous, because the clearer this false distinction becomes, the greater the gap will develop for people to fall in between services, and subsequently fail to receive any services. Inaccurate, because health, by all contemporary definitions is concerned with the wholeness of well-being, not simply the absence of disease or illness".

In conclusion the editors state that it is the books aim to provide an 'authoritative account' of learning disability, encompassing theory and practice, and to help to "...enhance the lives and health of people with learning disabilities."

The books contents are set out in nine 'parts', most of which contain 2, sometimes 3, complementary chapters looking at the various 'dimensions' of learning disability. After a list of contributors, a 'Forward' and 'Preface' these are listed as:-

Part 1 - Learning disability
   1) The nature of learning disability
Part 2 - Health and learning disability
   2) Defining health
   3) Health loss, gain and maintenance in learning disability
Part 3 - Educational dimensions of learning disability
   4) Educational theory and curriculum issues
   5) Learning throughout life
Part 4 - Biological dimensions of learning disability
   6) Causation of learning disability
   7) Manifestations of learning disability
Part 5 - Psychosocial dimensions of learning disability

    8) *Leading a normal life*

Part 6 - Cultural and spiritual dimensions of learning disability

    9) *Cultural diversity: Issues of race and ethnicity in learning disability*

    10) *Spiritual dimensions of learning disability*

Part 7 - Political and economic dimensions of learning disability

    11) *Political dimensions of learning disability*

    12) *Economic dimensions of learning disability*

Part 8 - National and international dimensions of learning disability

    13) *Services for people with learning disabilities in the UK*

    14) *Mature services; a case history of Sweden*

    15) *Establishing services: a case history of Romania*

Part 9 - New dimensions of learning disability

    16) *Contemporary and new horizons in learning disability research*

There is also a brief appendix, entitled 'Learning *disability policy development'*.

We can see that the content of this book presents a rather different kind of 'map' of the field of learning disability than that presented in Gates (1997). In particular we can see that, although a broad range of areas are covered , unified here as 'dimensions' of learning disability, the topic and concept of health is given a pre-eminence in the organisation of the contents. This emphasises the idea of 'health' as foundational to all the other others areas covered; an emphasis which reflects the desire of the editors, stated in the preface, to 'reclaim' learning disability for the health agenda. With this in mind we will now describe the two chapters that constitute the texts to be analysed from this book.

Text 2)

Vernon, D. (1997) *Defining Health.* In B, Gates and C, Beacock. **Dimensions of Learning Disability.** London: Balliere Tindall. Pp89-101 (Identified hereafter as **'Vernon 2'**)

The 'Health' section of this book opens with a brief introductory page which sets out the main aims of the two chapters of which it consists. This states that the aim of these chapters is to provide "...a guide to health and the fundamental influence it has upon the life styles of all people." It is also stated that the chapters include descriptions of 'clinical' approaches intended to illustrate "...how the maintenance and promotion of health in people with a learning disability is an elemental issue..." in care organisation and delivery.

Vernon's chapter **(Vernon 2)** '*Defining Health'* then opens with an *Introduction* in which health is introduced as a 'basic' concept for nursing. Subsequent discussion then emphasises health as an essential part of 'humanity', and not just related to people with learning disabilities. The discussion outlines an historic shift from the linkage of health with 'cleanliness', towards a more rationalistic and scientific conceptualisation, with the World Health Organisation's 1946 definition, in which health is linked to social and psychological aspects of being, and not merely the absence of disease, as the culmination of this process.

In the next section, '*What is Health?* there follows a discussion of various models of health, with particular emphasis on 'bio-medical' and 'humanistic' models which are deemed as the two most relevant to people with learning disabilities. The conceptualisation of health is presented as an issue of contention, with the main conflict being between these two models in the area of learning disability. The bio-medical model is presented as problematic when applied to people with learning disabilities because of its emphasis on deficit and impairment. This is presented as a form of oppression, part of the problem which has pervaded services and locked people with learning disabilities into 'expert' systems. The humanistic model of health is then presented as a superior alternative because of its emphasis on a holistic view of health, incorporating physical, psychological and social aspects of being. Health is described here as being a 'complex and multilayered phenomena', common to all humanity.

This discussion of concepts of health is followed by a section entitled of *'The Notion of Need'*. Malsow's hierarchy of needs – 'psychological', 'safety', 'belongingness and love', 'esteem', culminating in 'self actualisation' , with each layer being a prerequisite for the next - is set out as a framework of reference here, and related to O'Brien's five service accomplishments – 'choice', 'opportunities for integration', 'opportunities for participation', 'ability to form and maintain relationships', and 'opportunities to acquire skill and competence' - from his version of normalisation theory (O'Brien and Lyle, 1987). These are combined to provide a frame of reference for 'carers' whose role becomes to 'maximise abilities and potential' so that 'the individual is empowered to embrace health'.

There then follows a section entitled *'A Physical Perspective of* Health' in which the concept of 'homeostasis' is presented as a central idea. Physical health is presented as the achievement and maintenance of 'balance' or 'equilibrium' in the face of variations in external conditions. Homeostasis is presented as a biologically based regulatory system for self preservation, and physiological examples are given as examples, such as temperature maintenance. This is illustrated in relation to people with learning disabilities by reference to a case study of a young man with Downs' syndrome named 'Paul', in which the link is made between maintenance of his physical health and his opportunity and capacity to work.

Psychological aspects of health are discussed in a similar vein, in the section *'A Psychological Perspective of Health'*, with homeostasis again presented as a basic concept. There is discussion of mental health issues for people with learning disabilities, with their 'vulnerability' to psychological problems emphasised. The establishment and maintenance of good mental health is related to other aspects of life, including physical health, relationships, material well-being and security, a decent living environment and satisfying occupation. A discussion of 'coping' follows, in which people with learning disabilities are presented as often lacking physical, cognitive and emotional competence to cope with life's problems. The metaphor of 'balance' is invoked strongly again here. Finally, the notion of 'personal control' is presented as a key component of mental health. The role of a 'carer' is presented as important in enabling people with learning disabilities to achieve this, facilitating the maintenance of psycho-biological equilibrium.

There then follows a short *Conclusion* in which a summary statement is made in which health is described as a 'balance of human functions', with 'physiological, psychological, social, cultural and spiritual needs' of individuals needing to be met. Recognition of this is presented as important for the future development of services.

Text 3)

Wake, E. (1997) *Health Loss, Gain and Maintenance.* In B, Gates, and C, Beacock. **Dimensions of Learning Disability.** London: Bailliere Tindall. Pp45-74. (Identified hereafter as '**Wake**')

The next Chapter, '*Health loss, gain and maintenance in learning disability*' constitutes the second part of the '*Health & Learning Disability*' section in the *Dimensions of Learning Disability* book (Gates and Beacock, 1997). The '*Introduction*' begins by establishing continuity with the previous Chapter, **(Vernon 2)** identifying 'homeostasis' as a key concept, and something towards which everyone strives. Threats to homeostasis are identified as coming from external social, environmental, and economic factors, as well as internal psychological and biological factors. For people with learning disabilities, attitudes of 'able-bodied' people, and especially those adopted by staff within services, are presented as crucial external factors. It is asserted that people with learning disabilities should have a 'right' to an adequate service which is organised to meet their broad health needs.

The need for people with learning disabilities to be able to access 'specialist' learning disability services, as well as generic 'community' services is asserted, and is also presented as a 'right' in line with the principles of normalisation. Reference is also made here to research which highlights a lack of knowledge and awareness of the health needs of people with learning disabilities among other health professionals. A need for services and health professionals to change and become more responsive and user friendly for people with learning disabilities and their carers is asserted. It is stated in conclusion that there is a need for 'a range of services that are enabling rather than prescriptive'.

The focus then shifts to 'economic' factors, with the link between poverty and ill health being raised. This is presented as an issue for people with learning disabilities and their carers who are identified as often being reliant on benefits.

Environmental factors are also discussed, with the issue of the living environment of people with learning disabilities being presented as a particularly important issue. The crucial role of staff in small community homes is highlighted, particularly in helping people in their care to 'feel empowered' about decisions regarding their health.

There then follows a section entitled *'Specific health care needs'*. This section serves as an introduction to a range of specific health issues commonly found in people with learning disabilities, outlines of which form the bulk of the remainder of the chapter. Before these outlines are presented, however, it asserted that, although there is a need to avoid 'medicalising' all aspects of care', people with learning disabilities nonetheless should have 'a right' to the health care they need. It is stated that many of the health care issues faced by people with learning disabilities are chronic in nature, and should be responded to at the level of the individual with their own 'genetic make-up, health needs, life style, and experiences'. The need for carers who have good relationships with their clients, and good communication awareness and skills, particularly in relation to people who lack verbal communication is identified as of particular importance.

The rest of the chapter consists of brief outlines of a range of specific health issues commonly found in people with learning disabilities. These include:-

- *Epilepsy*
- *Oral health care*
- *Vision*
- *Hearing*
- *Continence*
- *Nutritional and feeding issues*
- *Cardiac (Heart) problems*
- *Mobility problems*
- *Respiratory problems*

These issues are all addressed in a similar format, exemplified here in the example of 'Epilepsy' which is set out as follows:-

What is epilepsy?'
What causes can be identified?
How is epilepsy diagnosed?
Types of epilepsy
What should you do if someone is having an epileptic seizure?
Treatment of epilepsy

The other issues listed above are all dealt with in a similar way. The chapter concludes with a list of 'Useful Addresses and Publications'.

Having now described **'Vernon 2'** and **'Wake'**, we can now go on to look at the third textbook, Thompson and Mathias (1998), in which the fourth of the texts to be analysed further is found.

Textbook 3)

Thompson, T. and Mathias, P (eds) **Standards and Learning Disability.** (2nd Edition) London: Bailliere Tindall.

This is the second edition of this particular textbook. The first edition '*Standards and Mental Handicap'* was published in 1992, before the publication *Continuing the Commitment* (Doh, 1995) whilst this, the second edition, was published three years afterwards. The editors are the same in both editions, Tony Thompson, listed as 'Director of Practice Development, Ashworth Hospital Authority, Liverpool'; and Peter Mathias, 'Director of Joint Awarding Bodies, London'. The author of the chapter to be analysed is Owen Barr, who is listed as a Lecturer in Learning Disability Nursing in the School of Health Sciences, University of Belfast. The publisher is Bailliere Tindall, a leading international publisher of nursing and health related textbooks, in association with the Royal College of Nursing.

This textbook is explicitly constructed as a response to contemporary policy developments, among which at the time were *The Health of the Nation: A Strategy for People with Learning Disabilities* (DoH, 1995), and *Continuing the Commitment*

(DoH, 1995). The cover notes give acknowledgement to the first edition, stating that it "...established itself as a leading textbook in the area of learning disability", going on to state that "... its innovative approach to the discussion of interprofessional standards and competencies in this complex field make it a standard of its own." The new edition is presented as 'continuing a discussion' started in the first edition, and reflecting ongoing change in service policy and practice. The main themes of the book are then set out as four questions:-

"

- *How should services develop to meet the needs of users?*
- *How should care be delivered effectively?*
- *What are the challenges for user-centred practice?*
- *What are the implications for professional roles and their interrelationships?"*

The cover notes list 'health' as among the 'new' areas to be covered in this edition.

The target audience for the book is stated to be "...students of mental handicap nursing, social work and integrated courses", as well as "...practitioners, tutors and managers in these fields". In conclusion, it is stated that the aim of the book is to 'encourage reflection on practice and debate', and to provide a 'resource for further reading, aimed at students and qualified professionals alike'.

After an introductory Chapter entitled *Trends in Education and Training for Health and Social Care* the contents of the book is divided into four sections. The first section is called '*The Services*', and contains chapters entitled :-

1. *'The National Health Service'*
2. *'The Independent Sector'*
3. *'Local authorities'*
4. *'Education'*
5. *'The Community as an Arena for Shared Learning and Practice'*
6. *'Commissioning and Providing Services'*

Section two, '*Effective Care Delivery'* contains chapters entitled:-

7. *'Care Management in Community Care – Advantages, Disadvantages and Developments'*
8. *'Care Management and Key Working'*
9. *'Balancing Risks and Needs'*
10. *'Implementing the Care Programme Approach'*
11. *'Supervision'*

Section three,' *Challenges for User-Centred Practice'* contains:-

12. *'Active Contributors: Service Users, Advocates and Support Networks'*
13. *'Competency in Diversity: Providing care in a Multiracial Society'*
14. *'Risk Management'*
15. *'Income and Money'*
16. *'A Lifetime of Caring'*
17. '*It Doesn't Happen Here'*

18. *'Responding to the Health Needs of people with Learning Disabilities'*

Finally, section four *'Professional Roles and their Interrelationship'* contains the following chapters:-

19. *'The professions and their interrelationships'*
20. *'Professions in Teams'*
21. *'The Social Educator in Western Europe'*
22. *'The Changing Practitioner Support Systems'*

In a short 'acknowledgements' section the editors state that they were asked by the publishers, Bailliere and Tindall, to produce a new edition in response to 'a variety of pressures' being exerted on services and professional training. The editors state that it is their intention to "...examine theoretical insights and developments which have grown from and contribute to practice."

We can now look at the chapter to be analysed further in this book.

Text 4)

Barr, O. (1998) *Responding to the Health Needs of People with Learning Disabilities.* In Thompson, T. and Mathias, P (eds) **Standards and Learning Disability.** (2nd Edition) London: Bailliere Tindall. pp 306-320 (identified hereafter as **'Barr'**)

This chapter begins, in a section entitled *'Health – an Elusive Definition'* with a discussion of definitions of health. These are described as 'elusive' and variable in their levels of complexity. It is asserted that most 'lay' definitions of health, based on a notion of the 'soundness of body and mind, would be likely to regard people with learning disabilities as inherently unhealthy. A definition of health by Naidoo and Wills (1994) is then cited which presents health as '...a resource for everyday life, not an object of living....[A] positive concept emphasising social and personal resources, as well as physical capacities'. This definition is identified as being 'positive' in nature, and having a flexibility which allows people with learning disabilities to be seen as healthy. The appraisal of health based on diagnostic tests and measurement of an ability to complete activities is identified as problematic, and other variables affecting individuals, such as age, gender and genetic influences, are noted. Other factors such as one's 'subjective' assessment of one's own health, the influence of 'time' and 'culture', 'social class' and 'personal expectations' are all identified as significant.

The issue of 'negative expectations' of the health of people with learning disabilities prevalent in society and health and social care services is presented as problematic. The risk of 'self fulfilling prophecies' resulting in a negative impact on the health of people with learning disabilities is identified. It is then asserted that 'strenuous efforts' must be made to 'promote positive expectations' and 'reduce the impact of negative expectations' within services. Seedhouse's (1986) definition of health, which describes health as "...equivalent to the set of conditions which fulfil or enable a person to work to fulfil his or her realistic chosen and biological potentials. Some of these conditions are of the highest importance for all people. Others are variable dependent upon individual abilities and circumstances" (p61)..., is cited with approval because of its incorporation of the notions of choice and individuality. Such a definition, it is argued, allows people with learning disabilities to be seen as healthy despite the presence of physiological and intellectual 'disabilities'.

In the next section *'Difficulties Experienced in Accessing Health-Promotion'* there follows a discussion of strategies of health promotion. This begins by stating that many generic health promotion strategies and services are not accessible to people with learning disabilities, and asserts that this is a situation that has to be improved. Some reasons why access might be restricted are set out, including some related to 'characteristics of people with learning disabilities themselves. These include fear of people, places and procedures involved in screening and medical investigations; inability to understand information and technical terms; and the presence of 'challenging behaviours'. Great emphasis is laid on the importance of communication as an issue, with the onus placed on service staff to develop the necessary communication skills and strategies which will facilitate access. It is asserted that health service staff may need to adapt the techniques and procedures they use in order to take the needs of people with learning disabilities into account. The 'critical challenge' is, it is stated, to 'overcome the assumption' that negative changes in both the behaviour and/or health of an individual can be put down to their learning disability. It is then asserted that learning disability nurses are in a good position to help overcome many of these problems because of their 'knowledge of health issues' in their client group. The improvement of services should nonetheless be regarded as a 'multidisciplinary issue' however.

There then follows a section, *'Developing Health-Promotion Services for People with a Learning Disability'* which begins with an attempt to define 'health promotion', and to differentiate it from 'health education'. Using definitions developed by Tones, et al (1990) the latter is defined as "...any planned activity which promotes health or illness related learning, that is, some relatively permanent change in an individual's competence or disposition". This is presented as only one component of health promotion, which is defined, citing the same source as "... all measures deliberately designed to promote health", up to and including public policy. The aim of health promotion with people with learning disabilities is, it is asserted, to 'overcome challenges' that exist in using 'mainstream health services'. The need for health promotion to be congruent with the principles of 'normalisation' are asserted as well.

Three levels of health promotion are identified; 'primary', which occurs before the onset of illness and is intended to improve health; 'secondary', which occurs before a person realises they are ill, and is focussed on the detection of health problems; and 'tertiary', which occurs when ill health is present and involves ensuring appropriate treatment is provided, and effects are mitigated.

Five different approaches to health promotion are identified and are discussed in the final section of the text, *'Putting it into Practice'*. The first approach, '*Medically focused activities'*, are described as including screening of various kinds - particularly with groups where there are known risks, such as people with Down syndrome and older people with learning disabilities. An outline then follows of how this process can be made more 'user friendly' and accessible for people with learning disabilities, with measures such as adequate preparation of the person, and building trust with clinical staff presented as examples.

Next *'Behavioural-focused activities'* are described. This approach is described as involving the application of behaviour modification techniques in helping people with learning disabilities to change health related behaviours in their lifestyle, the aim being to 'replace unhealthy behaviours with healthy behaviours'. The discussion then focuses on the need for individualising reinforcement, with good assessment, planning and implementation asserted to be the key. The aim is to 'to establish healthy behaviours', and the need for multidisciplinary input and liaison with family and other carers is stated.

Thirdly, '*Educational-focused activities*' are described. These are presented as focusing on the provision of information and the development of new skills in people with learning disabilities. This approach is asserted to be more appropriate for the majority of people with learning disabilities, particularly those who fall into the 'mild' category. The discussion that follows looks particularly at the use of different formats and media which may be used to educate people with learning disabilities, such as drawings, photographs, audio and videotape. The active involvement of people with learning disabilities in developing these materials is advocated. Different approaches to educational work is discussed, including one-to-one approaches, and small group work. 'Naturally occurring' educational opportunities in day to day life are highlighted as being particularly useful. Stress is placed on the need to evaluate the effectiveness of educational programmes, and the need to have objectives which are measurable. A list of topics on which material has been specially developed for people with learning disabilities is presented at the foot of this page.

Fourthly, *'Empowerment-focused approaches'* are discussed. This approach is described as helping people with learning disabilities to develop the knowledge and skills to make choices and decisions about their own health. It is stated that this can be done at either the individual or group levels. One aim here, it is asserted, should be to increase the use of generic health services by people with learning disabilities. Comment is made that staff in some generic services may need to be persuaded about the merits of this approach. Self-help and self advocacy groups for people with learning disabilities are presented as useful sites for this particular approach to health promotion to be developed. It is stated that this approach may well involve 'the management of risk', but that a collaborative approach can be used to minimise difficulties. The empowerment approach may, it is asserted, involve adapting to changes in role and status, and that, ultimately, 'easy access to independent representation' is crucial to allow it to work.

Finally '*Social change focused activities'* are discussed. This is presented as involving 'collective action' over longer periods of time, thus differentiating it from the empowerment based approach. The kinds of approach discussed under this heading include organisational and service development and change, and addressing wider social issues such as housing, poverty and transport. The central issue here, it is asserted, is to ensure that the interests of people with learning disabilities are represented accurately.

The concluding section of this text asserts that 'health promotion' is a necessity for all people with learning disabilities, not just those with a mild learning disability. It is argued, indeed, that people with more severe learning disabilities are in most need of health promotion activities. A multidisciplinary and collaborative approach is advocated. The concluding paragraphs talk of the need for 'a determined and co-ordinated approach' to achieving good health promotion for people with learning disabilities, giving priority to those areas identified in the growing body of research on the health of this group. The need for effective interdisciplinary working, resources and a 'commitment to provide high quality services' is presented as being essential. A combination of specialist and generic services are advocated. The commitment to improving the health of people with learning disabilities is presented as the 'responsibility' of all involved in services. A 'focus on health' is, it is argued finally, not as an 'extra', but a service to which this group is entitled.

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We will now look at the fourth and final book to be described, in which the fifth and final text to be analysed further is to be found.

Textbook 4)

B. Gates (ed) (2003) **Learning Disabilities: Towards Integration.** (4th Edition) London: Churchill Livingston.

This book is the fourth edition of the *Learning Disabilities* textbook, and the next edition on from that in which our first text **'Vernon 1'** appeared. As with the earlier edition, the editor is Bob Gates, now listed as 'Head of Learning Disability, Faculty of Health and Human Sciences, Thames Valley University, Berkshire'. The particular chapter which constitutes the text to be analysed from this book is authored by Sue

Hart, who is listed as 'Lecturer (Clinical) in Learning Disability, European Institute of Health and Medical Science (EIHMS), University of Surrey, Guildford'. The publisher is Churchill Livingstone, a well known international publisher of nursing textbooks.

This is the first edition of the *Learning Disabilities* textbook to appear following the publication of the *Valuing People* White Paper (DoH, 2001), and the organisation and contents of the book reflects the influence of that document. This book covers the broadest range of topics of all of the books looked at in this study, and is, indeed, approximately twice as thick as the previous edition. The cover notes begin by stating that the 'care' of people with learning disabilities has undergone major change in recent times, being situated now in 'community based settings' and 'multi-professional contexts'. Of learning disability nursing in particular, it is stated that "... learning disability nurses, having gone through a period of uncertainty about their role, have emerged a stronger, more adaptable group; able to apply their knowledge and skills in a wide variety of settings and positions, from specialist practitioners and health facilitators to community care managers and assessment officers". The notes go on to describe how, in this new edition of this 'highly respected textbook', recent developments are taken up, particularly the agenda of the English White Paper '*Valuing People*', and its guiding principles of 'rights, independence, choice and inclusion'. This is followed by a list of 'new topics' covered in this edition that are said to reflect this change. These are:-

- *History*
- *Residential Services*
- *Further Education*

- *Person Centred Planning*
- *Employment, leisure and training*
- *Learning disability services in Europe*
- *Services for 'offenders'*
- *Art, drama and music therapy*
- *Education training, management and leadership in learning disability services*
- *Monitoring and evaluation of services*
- *Psychological approaches*

Discussion of all of these topics is, it is asserted, supported by reference to contemporary research, and backed by other resources, including case examples and useful website addresses. Finally, it is asserted that this book continues to constitute the 'core text' for pre-registration nursing students at diploma and degree level, and is also useful for qualified staff and other relevant professionals. It is also cited as a 'useful reference' for the newly developed Learning Disability Awards Framework (LDAF) training scheme.

In a brief preface Bob Gates links this book to the agenda and values set out in the '*Valuing People*' White Paper (DOH 2001). He goes on to state how important he believes this policy document to be in terms of shaping an agenda for the social integration of people with learning disabilities in England, and in reconfiguring services to achieve this purpose. The four guiding principles of the White Papers' approach are identified – 'rights', 'independence', 'choice' and 'inclusion' – and their proposed use as benchmarks for local and national services is acknowledged. An outline of the content of *Valuing People* follows, and the emphasis throughout on identifying barriers and working to overcome them is supported. This overview includes an outline of Chapter 6 of the White Paper which focuses on 'Health', and it is stated that "…this issue has been repeatedly reported in the research literature for at least two decades. Attention to issues around consent to treatment, specialist learning disability services, the identification of Health Facilitators (by 2003) and Health Action Plans (by 2005), will impact on the way we work with people with learning disabilities for many years to come" (pxii). This overview of the white paper is generally supportive, although some concern is expressed with regard to the issue of 'advocacy', that people with profound learning disabilities and complex needs may not have their particular perspectives represented if people with learning disabilities are regarded as 'too homogenous' a group.

Gates presents this book as a 'small contribution' to the agenda for change proposed in the White Paper, stating that "…hopefully, it will assist nurses, social workers, therapists - indeed any one with an interest in this area – by providing them with a sufficient knowledge base concerning people with learning disabilities" (pxiii). To this end, Gates goes on to say the book has been 'completely rewritten, not just to reflect the influence of *Valuing People,* but also to reflect wider developments in the field. This is why, it is asserted, the scope of the book has been widened, and made 'more substantive'. This transformation is also intended, we are told, to widen the books readership and to make it appeal to those people undertaking the Learning Disability Awards Framework (LDAF) route of training.

In conclusion, it is stated that the *Learning Disabilities* textbook has become widely respected through previous editions, and used by a wide range of professionals in the learning disability field. The editor then acknowledges the contribution of the authors of the various chapters, and thanks them for their 'trust' in him in the editorial role. He finishes by stating his hope that the readers will find it useful and that it will assist in… "bringing about the inclusion of people with learning disabilities into our communities." (pxiii)

The contents of the book are presented in eight sections, and are listed as follows:-

Section 1 *'Understanding learning disabilities'* has three chapters –

1. *The nature of learning disabilities*
2. *Causes and manifestations of learning disabilities*
3. *A history of learning disabilities*

Section 2 *'Services and support for people with learning disabilities'* has six chapters:-

4. *Accessing services and support*
5. *Residential alternatives for people with learning disabilities*
6. *Evaluating the quality of support services*
7. *Compulsory school education*
8. *Post compulsory education*
9. *Employment, leisure and learning disabilities*

Section 3 *'Distressed states of learning disability'* has five chapters:–

10. *Challenging behaviour*
11. *Autistic spectrum disorders*
12. *Mental ill health in learning disabilities*
13. *Self-injurious behaviour*
14. *People with learning disabilities who have offended in law*

Section 4 *'Helping people achieve independence and well-being'* has five chapters:–

15. *Communication*
16. *Health and health promotion*
17. *Profound and multiple disability*
18. *Specialist learning disability services in the UK*
19. *Person-centred planning*

Section 5 *'Therapeutic interventions for people with learning disabilities'* has three chapters:–

20. *Complementary therapies*
21. *Art, drama and music therapies*
22. *Psychological approaches*

Section 6 *'Relationships and learning disabilities'* has three chapters:–

23. Sexual and personal relationships

24. Working effectively with families of people with learning disabilities

25. Helping to empower people

Section 7 *'European dimension'* has three chapters:–

26. The Netherlands

27. Sweden

28. Germany

And finally, Section 8 *'Education and leadership'* has two chapters:–

29. Education and training

30. *Management and leadership in learning disability.*

We will now turn to focus on the chapter by Hart, which constitutes the text for analysis from this book.

Text 5)

Hart, S. (2003) *Health and Health Promotion.* In Gates, B. (ed) **Learning Disabilities: Towards Integration.** London: Bailliere Tindall. Pp289-309. (Identified hereafter as **'Hart'**)

This text begins with a title page which lists the content of the chapter and sets out the *'Key Issues'* to be covered as bullet points. In the *'Introduction'* section that follows the intention of giving a brief historical introduction before focussing on the current situation regarding health and health promotion for people with learning disabilities is set out. It is stated that recent development in health promotion, as well as literature, current research and policy initiatives will be referred to.

In the next section '*Health and Health Promotion' there* follows a general discussion of the notions of health and health promotion, where their desirability as human concerns is asserted. The establishment and basic principles of the NHS are described, and the right of people with learning disabilities to access this service is asserted. Reference is then made to research shows that people with learning disabilities are frequently not 'satisfied' with their access to health services. This access is portrayed as congruent with the principles of 'integration', and reference is also made to O'Brien's version of normalisation philosophy (O'Brien, 1986) to support this assertion. Helping people with learning disabilities to achieve access to health services is then described as an 'important role dimension of learning disability nursing'. The government white paper *Valuing People'* and it's assertion that accessing health services is a policy priority is then cited.

There then follows a brief description of changes in service provision for people with learning disabilities from large hospital based care, to community based care. It is stated that people with learning disabilities used to have their physical health dealt with within the closed environment of the old hospitals, often in special wards designed for this purpose. Now, however, with people with learning disabilities dispersed in the community, they should be eligible to access generic healthcare services. This is described as posing a major challenge for health services and professionals because they often lack the necessary awareness and skills to respond to the needs of people with learning disabilities. Important demographic changes are also cited, such as the increased rate of survival into adulthood of children with severe learning disabilities and complex needs. Research suggesting that people with learning disabilities tend to have greater health needs than the general population is also cited.

There then follows a section entitled *'Why is a Consideration of Health Needs for People with Learning Disabilities Now Important?'* where it is asserted that the main problem is 'the widespread and systematic failure' of health services to meet the needs of people with learning disabilities. Various research studies which highlight the poor detection rate of health problems in people with learning disabilities, and a range of other service deficiencies, are then cited. A strong assertion of service failure is made here with 'value for money' indicators cited as highlighting these failures further. This is described as problematic, especially given projected increases in the use of health services by people with learning disabilities. Health problems associated with ageing are cited here, along with research highlighting increased incidence of age related health problems. The change of balance between specialist and generic health provision for people with learning disabilities, with specialist services concentrating on specific areas of need, such as epilepsy, sensory impairment and mental health problems that is advocated in current health policy (DoH 1998), is also highlighted. It is argued that this will create still more pressure for generic services to improve their responsiveness. There then follows an overview of various specific health related problems faced by people with learning disabilities, with the problems associated with Downs' syndrome cited, among others. This section ends by listing a wide variety of generic health care professions that need to be involved in responding to the health needs of people with learning disabilities. It is stated finally, that learning disability nurses need to review and reorientate their role in line with the requirements of the *Valuing People* White Paper (2001).

The section that follows, entitled *'Where Are We Now?',* looks specifically at, what are identified as, serious shortcomings of generic health services in responding to the health needs of people with learning disabilities. Recognition is given to the fact that many people are very pleased with, and grateful for, the service they receive from the NHS. However, 'dissatisfaction' among people with learning disabilities is also highlighted, and it is asserted that people with learning disabilities are subject to 'inequalities' in treatment in the NHS. The author then outlines her own qualitative research into how people with learning disabilities describe their treatment in general hospitals and primary care services. The results of this research are used to illustrate the negative experiences which people with learning disabilities frequently have when accessing health care.

There then follows a section entitled *'Developments to Address Concerns with Health Matters for People with Learning Disabilities'* which looks at positive developments in addressing the issues highlighted. A number of policy documents from the NHS Executive and the Department of Health are cited, aimed at promoting good quality health care for people with learning disabilities (NHS Executive, 1992; DOH, 1995; NHS Executive, 1998; NHS Executive, 1999). 'User based' initiatives are also cited (Hull and Holderness NHS Trust, 1995, Matthews, 1997; Band, 1997; Dodd and Brunker, 1998; Hollins, 1997 and 1998). Staff training packs are also cited positively, with a warning that these should not be seen as a panacea for dealing with health related issues. A brief subsection on positive developments in practice then follows, which cites the *Continuing the Commitment* (1995) document among its examples.

In the next section, *'The Role of Learning Disability Nurses in Helping People with Learning Disabilities Access Health Services'*, the extent of organisational change from the large institutions to community based care, and the major change of role this has required from learning disability nurses is described. Comment is made about the transfer of some negative forms of practice from the large institutional settings to community based units. It is asserted that the learning disability nursing profession needs to ensure that old forms of working are given up and replaced with 'positive' forms. In relation to health care, the new role that is asserted is one that centres on helping people with learning disabilities to access the health care they need, rather than actually providing that care. This is in alignment with the 'health facilitation' role identified for the profession in the *Valuing People* White Paper (2001). The main role set out here is oriented towards supporting people with learning disabilities to access and interact with generic health services.

The final section *'Health Promotion'* focuses entirely upon strategies for, and examples of, health promotion with people with learning disabilities. Learning disability nurses are identified as having an important, though not exclusive role here. It is asserted that some learning disability nurses may need to reflect on changing aspects of their role, relinquishing some traditional areas of work, in favour of developing the health promotion focus. A World Health Organisation (WHO, 1978) definition of health promotion is then given. This defines health promotion as... "[A] process of enabling people to increase control over and improve their health." Three main forms are identified; 'primary' focussing on the prevention of ill health; 'secondary' focussing on the early detection and treatment of illness; and 'tertiary' focussing on preventing the 'needless progression of disease'. There then follows an outline of policy initiatives cited to underpin the argument for the development of health promotion as a role for learning disability nurses. These include; '*Continuing the Commitment*' (DoH, 1995), which stresses the need for learning disability nurses to develop a 'health surveillance' focus; '*The Health of the Nation: a strategy for people with learning disabilities*' (DoH, 1995), which stresses making health promotion available and accessible for people with learning disabilities; and '*Signposts for Success*' (NHS Executive, 1998), which highlighted the need to develop specialist health promotion for people with learning disabilities to counter particular health risk such as drug and alcohol abuse. It is then stated that recent trends in general health promotion have emphasised 'social' rather than 'medical' conceptions of health, and have emphasised the development of 'positive and healthy lifestyles'. This is presented as particularly appropriate for people with learning disabilities, and examples are given of projects promoting health activity and exercise. The need to keep messages simple and focused on single issues is asserted, and examples are given of areas such as 'weight loss', 'safer sex', 'smoking cessation' and 'health and relaxation'. The use of approaches built on existing knowledge of 'the way people with learning disabilities learn' is recommended, as is the need to develop 'user friendly approaches and techniques'. A list of key terms relating to health and people with learning disabilities is then given, together with definitions. These include 'health gain', health surveillance', health facilitator', 'health awareness', and 'healthy lifestyles'. Examples of practice developments in this area are then given, such as 'health clinics' for people with learning disabilities set up by community learning disability nurses. It is stated however, that there is a need to avoid perpetuating segregated services when this can be avoided; an example being to set up such clinics in mainstream primary care settings rather than segregated day centres. Learning disability nurses are described as 'ideally placed' to help generic services develop the knowledge and skills they need to meet the needs of people with learning disabilities. Further examples are then given of such collaboration between learning disability nurses and generic services, such as in 'well woman' clinics and in the broad area of sexual health. Others examples are also given of work undertaken with adolescents with learning disabilities, and in the area of complementary health.

In the *'Conclusion'* section, the failure of generic services to meet the health needs of people with learning disabilities is again highlighted, and 'key actions' for bringing about change are listed as bullet points .These include:-

- *Reducing health inequalities*
- *Challenging discrimination against people from ethnic minorities*
- *Identification of health facilitators*
- *Registering all people with a learning disability with a GP by 2004*
- *Ensuring all people with learning disabilities have a 'Health Action Plan' by 2005*
- *Ensuring all generic NHS services are accessible*
- *Development of specialist services for people with challenging behaviours*
- *Developing a new role for learning disability nurses based upon use of their expertise*

These are all goals set out in recent policy documents, especially *Valuing People* (DoH, 2001). It is asserted finally that if these initiatives can be backed by commitment from local services then there is room for 'cautious optimism' about the future.

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This concludes our description of the texts to be analysed, and our descriptive overview of the textbooks from which they are drawn, although we will return to look at these books again in Chapter 7 as part of the 'explanatory' level of analysis. Our focus now must switch, however, to consideration of the texts as a unified discourse that transcends the individual texts themselves, in preparation for the 'interpretative' phase of analysis to follow in Chapter 6. This process will now be initiated by identifying the main common themes found across the texts, and the 'subject positions', to use a term coined by Fairclough (2001), which are assumed by the common orientation of the texts.

Common Themes Across The Texts:

Having given descriptive outlines of the texts themselves, and the textbooks in which they are situated, we are now in a position to identify the main themes commonly discernable across the texts that suggest that they can be considered to collectively constitute a unified discourse of health in relation to people with learning disabilities. As we have seen, the five texts described appear in four different, but similarly orientated textbooks, the common stated purpose of which is to set out the foundational knowledge base for student learning disability nurses, and others. As such, they are clearly intended to be read as assertions of both the epistemological foundation and value base of the profession. The textbooks all make claims to be authoritative, and provide an essential 'mapping out' of the field of learning disability as a discipline, locating 'health' as an important, and sometimes central, concept.

It could also be argued that the texts are mapping out and asserting the desired 'jurisdiction', to use a concept developed by Abbott (1998), of the particular area of work to which this profession lays claim. This idea will be explored further in Chapter 7. It will suffice here, however, to recognise the unity of these texts as a vehicle for a distinct 'discourse of health' in the learning disability nursing literature in the 'post *Continuing the Commitment*' era, of which 'health' is the primary object. We can see also that this 'discourse of health' is built up around three main themes that appear across the texts, albeit with varying degrees of emphasis. These themes are:-

1) The identification of a holistic and humanistic model of health as the most appropriate in relation to people with learning disabilities.

2) The problematisation of health as an issue of the vulnerability of people with learning disabilities to the development of health problems.

3) The problematisation of the standard of generic healthcare services in understanding and meeting the health needs of people with learning disabilities.

In the descriptions above we can see that **'Vernon 1'** is explicitly constructed around these three themes, and that they appear, and are all elaborated upon in **'Vernon 2'** and

'Wake' in Gates and Beacock's book *Dimensions of Learning Disability*. This particular textbook was, as is made explicit in the editors' cover notes and preface, an attempt to place 'health' back at the centre of the 'learning disability agenda'. 'Health' is specifically identified by the editors, with overt backing from the chief learning disability nurse at the time, as the core organising concept for the field, and the **'Vernon 2'** and **'Wake'** texts form the foundational section of the book from which all other dimensions are dealt with.

In contrast, the fourth text described, **'Barr'**, appears in a textbook (Thompson and Mathias, 1998) in which health is depicted as an aspect of a much broader 'social' agenda, rather than as a foundational, organising concept. Nonetheless, the same three themes - defining health around a holistic/humanistic model; emphasising the vulnerability of people with learning disabilities to the development of health problems; and, the problematisation of generic health service responses to that vulnerability - are all apparent in the organisation of the text.

In the fifth text described, **'Hart'**, (Gates, 2003) the emphasis given to the three themes varies somewhat. The textbook in which this chapter appears is the subsequent edition of the textbook in which **'Vernon 1'** appears. In the intervening time however, the *Valuing People* White Paper (DOH 2001) was published. The **'Hart'** text reflects this by focussing on the 'health facilitation' role for learning disability nurses; a role identified for the profession in that document. This role is related very strongly to the theme of the inadequacy of generic services in meeting the health needs of people with learning disabilities, and consequently this theme is given great emphasis in this text. The other themes of the 'vulnerability' of people with learning disabilities, and the 'identification with a holistic and humanistic model of health' are nonetheless still evident however.

Conclusion:

In this chapter we have undertaken the first 'descriptive' phase of analysis. This has involved providing descriptive outlines of each of the textbooks in which the texts to be analysed further are situated, together with descriptive overviews of the texts themselves. The main aims of this chapter have been, firstly, to provide us with a descriptive overview that allows us to contextualise the texts to be analysed, illustrating where they sit in the literature, and the micro-historical period under review; designated for the purposes of this study the 'post-Continuing the Commitment' era. These descriptions can also be seen to establish that these texts constitute a distinct and unified discourse of health, albeit with certain variations of emphasis. This is evident in the three main common themes around which all of the texts are constructed. It is these themes that will provide the main focus for the second 'interpretative' phase of our analysis to which we will turn in the next chapter.

Before moving on to the second, 'interpretative' phase of analysis however, it would be useful to make some tentative comments about the discourse of health as it is beginning to emerge from our analysis. Already, for example, we can see that the form the discourse is taking suggests that *the* important task being undertaken here is to give scientific and empirical legitimation to the idea that health is a significant issue for people with learning disabilities in a way that is separate and distinct from the wider 'non-disabled' population. The homogeneity of people with learning difficulties as a distinct population is assumed within the mapping of the discourse as it is presented here. Although some variations are identified – such as people with complex needs, or people with challenging behaviour for instance – these subcategories are presented, as they are in *'Continuing the Commitment'* (Doh, 1995), unproblematically, as concrete 'givens', rather than as possible constructions which represent the judgement and classification of others (Rapley, 2004).

Thus we can see, that, despite the attempt to establish a distance from an oppressive 'medical model' of health, manifest as the first major theme identified above, the discourse emerging here is still one that is being constructed from a position of professional expertise *about* people with learning difficulties, rather than as any attempt to find or establish a dialogue with them about the nature, range and variety of their experience. People with learning difficulties still emerge here as passive 'objects' to be gazed upon and described from a position of professional expertise, rather than as potential participants who could become involved in an attempt to redefine the nature and meaning of health for them. We are then, despite the claim to be shifting to a 'non-oppressive' humanistic model of health, looking nonetheless at the emergance of an expert monologue – one of the hallmarks, from a social model of disability perspective, of a traditional elitist, and disabling professionalism (e.g.Gillman, et al, 1997., Goble, 2000).

To explore how this discursive monologue has been constructed at a rhetorical level, however, we will have to turn our attention in greater detail to an examination of its content, as manifest in the construction of the three main themes identified above. This takes us into the second, 'interpretative' phase of our analysis.

Chapter 6

Data Analysis 2 –Interpreting the Discourse of Health.

Introduction:

Having described the textbooks and the texts under analysis, and identified the three main themes around which the discourse of health in these texts is constructed, we can now move onto the second, interpretative, stage of analysis. This stage will focus on identifying and illustrating the use of 'interpretative repertoires', and rhetorical and linguistic features significant in constructing, what Potter (1998) calls, the 'facticity' of phenomenal objects and concepts identified in the discourse. Features examined will include, the 'action orientation' of texts; 'defensive' and 'offensive' rhetorical strategies; management of 'stake' and 'interest'; and the use of 'detail', 'authoritative corroboration', and 'consensus construction'- as described in Chapter 4.

To facilitate this process 'key passages' drawn from across all five texts will be used. As explained in Chapter 4, these 'key passages' were identified during analytical readings of the texts, and are used to serve as illustrations of the rhetorical and linguistic features under analysis. Analytical explanations of these passages are presented as commentaries appended to each of the passages, which are necessarily quoted at length. The 'discourse of health' will be explored at this stage as a phenomenon which transcends the individual texts, with the focus on commonalities and unities in the construction of the texts, rather than differences and variations. Consequently, the emphasis will be on presenting those passages from across the texts which best illustrate the features being examined, rather than on giving equal weight to all of the texts in the analysis.

Firstly then, let us remind ourselves of the three major themes identified in the first, descriptive stage of analysis. These are, it will be remembered:-

1) The identification of a holistic and humanistic model of health as the most appropriate in relation to people with learning disabilities.

2) The problematisation of health as an issue of the vulnerability of people with learning disabilities to the development of health problems.

3) The problematisation of the standard of generic healthcare services in understanding and meeting the health needs of people with learning disabilities.

Let us now look at how each of these three themes is constructed in turn.

Theme 1)

The identification of a holistic and humanistic model of health as the most appropriate in relation to people with learning disabilities.

As we saw in Chapter 5, the assertion that a holistic and humanistic model of health is the most appropriate basis from which to address the health of people with learning disabilities is made strongly in four out of the five texts analysed, and is also present, if not elaborated upon to the same extent, in the fifth. The tone is set in **'Vernon 1'**:-

PASSAGE 1 – 'Vernon 1' - Page 90:

"An examination of the relevant attributes of health provides the foundations for working with people with learning disabilities. It is only through the acquisition of such knowledge that nurses can contribute to the enhancement and maintenance of the health of this group of people."

In this brief passage from the opening of the section *'What is Health'?* We can see that, at the outset, **'Vernon 1'** is asserting that this is foundational knowledge for nurses in this field. In fact, the initial statement suggests that knowledge about health is 'foundational' for working with people with learning disabilities generally. This is then qualified by the specific reference to nurses that follows. Likewise in **'Vernon 2'**:-

PASSAGE 2 – 'Vernon 2' - Page 3:

"Health is a basic concept in the discipline and profession of nursing. The search for a definition of health pervades the literature. Philosophers, economists, health educators, psychologists and sociologists have all written about health from their own perspective. Hence, definitions of health are varied and contrasting. Understanding of the term 'health' varies between individuals and cultures, depending on the meaning and importance people give to it. The versatility of the word 'health' has led to vagueness and ambiguity. Thus, the concept of health is a complex one, with no immediate point of focus."

In this passage the imperative to 'understand' and 'define' the concept of health is set up, together with the notion of health as a 'complex' idea. This serves to create in the reader a measure of uncertainty and ambiguity as what the term 'health' means, which in turn allows for the subsequent discussion of various models of health to be read as a rational attempt to overcome that uncertainty. The reader is placed here in a position of 'naivety', in the sense of being presented with a complex issue, the resolution of which requires an expert interpreter to help achieve a clear understanding. We are also presented with the assertion that acquisition of this knowledge and expertise is a fundamental requirement for nurses in particular, 'health' being presented as the central concern of nursing.

These texts present extensive discussions of the meaning of health and how it relates to people with learning disabilities, including outlines and discussion of a variety of models of health. Models addressed included religious, psychosomatic, existential, transpersonal, biomedical and humanistic models. A choice is made in this discussion to regard only the 'biomedical' and the 'humanistic' as worthy of consideration, however; a choice presented as an opting for the 'rationalistic' and 'scientific', over the 'esoteric'. This firmly locates the discourse presented here as 'rationalistic' in nature. An example of this can be seen in the following passage, where, in a discussion of Beck, et al s' (1988) assertion of the multidimensional nature of health, we can see how the abstract concept of 'health' is given attributes that would normally be regarded as forms of human agency – health being a 'dynamic, active process of continually striving' for example. Potter (1998) points out that this is a frequently used rhetorical strategy where an author is seeing to establish the 'empirical reality', or 'reification', of an abstract concept, and is characteristic of an 'empirical repertoire':-

PASSAGE 3: 'Vernon 1' – Page 91

"Within this model health is defined as 'more than the absences of disease. It is a dynamic, active process of continually striving to reach one's own balances and

highest potentials. Health involves working towards optimal functioning in all areas. This process varies among people and even within individuals as they move from one life stage to another.' Beck is careful to define health in terms of the individual's specific potentials throughout life. Health is thus an individualised notion whose emphasis changes from person to person. Indeed, ideas of health mean different things to different people at different points in their life. How we may conceptualise health in the lives of people with learning disabilities requires further examination".

We can see here too a stress on 'lifestages' which establishes a 'longitudinal' as well as 'latitudinal' focus. The notion of health being worked up here is one that pervades all aspects and all stages of life. It is also presented as 'individualised'; a characteristic of individuals, with their own idiosyncrasies and potentials. These emphases are all heavily worked up in subsequent sections of the same text. For example, with particular reference to research by Herzlich (1973):-

PASSAGE 4: 'Vernon 1' – Pages 91-92:

"The study also suggested that health cannot be assumed to be the condition of someone not carrying a medical diagnosis. Rather, concepts of health connect with many areas of life, giving it meaning in terms of emotions and abilities regarding activities and other people. The important idea to grasp here in relation to people with learning disability is that to think of oneself as healthy is to think of oneself in a particular relationship to society. That is, health is something that is exercised and proved in the person's active involvement in society."

The case being constructed here is one of equating health with an 'active involvement in society'. This works to construct a link between the role of learning disability nurses involved in supporting people with learning disabilities to live in mainstream society to a concept of 'health', rather than 'social' care. What might be argued to be 'social care' work, can legitimately become 'health work' then, if health can be distanced from a pathology orientated medical conceptualisation, and reconceptualised as being located in the relationship of individuals to society.

In **'Barr'** we can see a similar argument being constructed, using a slightly different approach. As in both **'Vernon 1'** and **'Vernon 2'**, **'Barr'** opens with a quite detailed discussion of models and definitions of health. He ultimately opts for a definition of health proposed by Seedhouse (1995) as being of particular relevance:-

<u>PASSAGE 5: – 'Barr' - Page 308:</u>

"In an attempt to bring together varying theoretical perspectives on what health is, Seedhouse defined health as

"... a person's optimum state of health is equivalent of the state of the set of conditions which fulfil or enable a person to work to fulfil his or her realistic chosen and biological potentials. Some of these conditions are of the highest importance to all people. Others are variable dependent upon individual abilities and circumstances. (Seedhouse, 1986. p. 61)

The definition has similarities with the philosophy of services for people with learning disabilities; in particular, the emphasis on choice and individuality in

priorities, both aspects that are key components of inclusive services….. Within the parameters of this definition people with learning disabilities, including people with multiple disabilities, may attain a 'healthy state' despite the presence of some physical and psychological disabilities."

Seedhouse's definition is settled on here as the most 'user friendly' in relation to people with learning disabilities. A particular issue raised in **'Barr'** is that of people with learning disabilities not having their health recognised as a serious issue, and thus not receiving the level or type of health promotion input they need to maintain their health. As in **'Vernon 1'** and **'Vernon 2'**, we see in **'Barr'** an attempt to establish a distance from bio-medical conceptualisations of health in which learning disability is equated with pathology, a particular manifestation of which is identified as the 'self fulfilling prophecy' of low expectations of the health of people with learning disabilities on the part of service providers, workers and professionals, leading to a toleration of poorer standards of health for people with learning disabilities in their care. This is presented in **'Barr'** as part of what makes people with learning disabilities 'socially vulnerable' to the development of ill health. The theme of vulnerability, to be discussed subsequently, is thus beginning to emerge.

We can also see the establishment of a 'moral imperative' to act being set up; the imperative at this point being to establish a 'non-devaluing' conceptualisation of health in relation to people with learning disabilities. This is an argument that will have a strong resonance for many learning disability nurses educated within a normalisation framework, where the models of the 'self-fulfilling prophesy' appears as a 'vicious circle' argument, with it's reversal from a 'negative' to a 'positive' circle, being a central theme (O'Brien and Tyne, 1981). A congruence with normalisation philosophy, in **'Barr'**, simply referred to as 'service philosophy', is pursued also in the linkage made with Seedhouse's definition of health. These linkages acts to give the argument a strong philosophical and political legitimacy.

Further legitimacy for the 'facticity' and 'empirical reality of the issue of health as an imperative issue in relation to people with learning disabilities is constructed across the texts by drawing upon 'empiricist repertoires'. A particularly strong version of this is evident in **'Vernon 2'** and **'Wake'** for example, with the use of the biological concept of 'homeostasis':-

PASSAGE 6 – 'Vernon 2' – Page 35:

"Hence health may be equated with balance or *equilibrium.* Conversely, disequilibrium leads to health loss. The impetus for these balance-based definitions of health derives from the concept of *homeostasis.* Homeostasis concerns the physiological processes by which the internal systems of the body are maintained at equilibrium, despite variations in the external conditions. Homeostasis then, refers to a regulatory subsystem within the body whose aim is self-preservation."

The use of a biological concept such as homeostasis here can be seen as a strategy which lends a material factuality to the otherwise abstract and ambiguous concept of 'health'. The stress on 'equilibrium' also serves to construct around the concept of homeostasis a legitimising framework for surveillance and intervention in the lives of people with learning disabilities. A prime example of the development and use of the concept of 'homeostasis' in this way can be seen in a 'case study' used in **'Vernon 2'** to demonstrate the applicability of the concept to the situation of a person with a learning disability:-

<u>PASSAGE 7 – 'Vernon 2' – Pages 35-36:</u>

"Paul is 20 years old and has Down's syndrome. He is in a temporary state of psychophysiological balance and, therefore healthy…Because Paul's needs for food and fluid are met, the need for elimination is met. The need for adequate nutrition, fluid and electrolyte balance and healthy elimination are thus in equilibrium. Moreover, Paul is fortunate in that he is meeting his needs for sleep and rest. Because Paul's basic needs have been met he may now progress to addressing the need for self-actualisation. However, because Down's syndrome is associated with mouth breathing (Craft, et al., 1985), Paul has a reduced capacity to combat infection as a result of poor immunological response. Consequently he develops a respiratory infection. Hence the homeostatic mechanism responsible for the maintenance of an intact defence mechanism is disrupted. Because of difficulty in breathing, Paul finds it hard to sleep at night. He loses his appetite and feels unable to attend his workplace whilst he is ill. As a result, his relations with others are temporarily affected. Consequently, the need for self-actualisation is halted. These manifestations have compromised his need for adequate oxygen, nutrition and sleep. Paul is in a state of psychophysiological imbalance and has, therefore, suffered a health loss. If assistance is not sought, then Paul's health will not be restored. This example clearly illustrates that health loss deriving from a homeostatic imbalance may give rise to disequilibrium or imbalance in all areas

of life. This example also serves to highlight that the concept of homeostasis has far wider applications than simply physiological processes."

Here we can see a stretching of the bio-medical concept of homeostasis to add empirical legitimacy, or 'facticity', to the broad and pervasive nature of the conceptualisation of health being constructed in this discourse. A strong empiricist repertoire is evident in the form of a technical and detailed discussion of both physiological and psychological health, complete with corroborative reference to research literature. This is all works persuasively to establish the empirical basis, for, and thus the facticity of, the application of a holistic model of health to address the vulnerability of people with learning disabilities to health problems, and also to establish a biological, and empirically demonstrable basis to this vulnerability. The emphasis on 'needs' draws heavily also upon a 'humanistic psychological repertoire', derived from a model of psychological need developed by Maslow, (1954). The vulnerability of people with learning disability is also worked up here by the juxtaposition of the technical nature of the discussion of 'Paul's' physiological and psychological health with the personalised identification of 'Paul' as the passive subject of the case study. The use of the first name here acts, arguably, as a diminutive, in the same way as it might in a description of a child, where it is culturally acceptable to not make use of the more respectful prefix 'Mr'; a convention applied to subjects we wish to present as holding adult status. The need to maintain 'balance' and 'equilibrium' in health is asserted, with people with learning disabilities depicted as requiring particular help order to maintain this. There is, thus, a strong sense of paternalism present here, with the 'passivity' of people with learning disabilities strongly implied. This particular text sets up what might be described, to paraphrase

Foucault (1973), a 'holistic health gaze' in which people with learning disabilities are depicted as passive recipients of services, in need of expert surveillance, to maintain optimum health.

Similarly, in **'Wake'** the concept of homeostasis is also invoked:-

PASSAGE 8 – 'Wake' – Page 47:

"Homeostasis is something that everyone strives for even if they have never heard of the actual term. It includes wanting to feel healthy physically and emotionally in everyday life – at work, in relationships with others and at leisure. However, there are many constraints on our attempt to maintain this homeostasis. These include external influences such as economic and environmental factors, as well as internal influences, for instance feelings, worries and fears as well as aspirations for one's life. The expectations of others also affect feelings of self worth and value. For the person with learning disability goals to be achieved are often dictated by able-bodied people."

Once again the biological concept of 'homeostasis' has its meaning stretched beyond its normal biological parameters, and is linked with social and psychological health, and their expression in 'everyday life'. Use of the term 'strives' here also creates a sense of a conscious process, and links into a 'personal growth' theme that is a strong element of humanistic models of psychology.

Only in **'Hart'**, is a discussion of models and definitions of health absent. Nonetheless here is still a clear, if implicit, affirmation of a holistic model of health as the model to be aspired to, as we can see from this short passage relating to health promotion:-

PASSAGE 9 – 'Hart' – Page 303:

"Recent trends in heath promotion have included an emphasis on the notion of 'positive and healthy lifestyles' (Cowley 1996). Here health is emphasised more from a social than a medical perspective, recognising self-determination and lifestyle choices."

'Hart' then alludes to a holistic, socially orientated model of health in the context of a discussion of the practice of health promotion. As we shall see later, the theory and practice of health promotion are presented as central to the reconstruction of the role and identity of learning disability nursing being constructed in this discourse. The establishment of a holistic and humanistic model of health as a foundational concept can be seen as an important part of this reconstruction process.

Conclusions:

In conclusion, we can see that, with the exception of **'Hart'** the need to clarify a model and definition of health that is distinct and distant from an 'oppressive' medical model is clearly given a significant priority in this discourse. The model of health emphasised is a 'holistic' one, with a strong 'humanistic' element apparent as well. Health is presented in these texts as a precious personal possession which arises from 'striving'; a reward for effort. It is described as having a 'dynamic' quality in which the aim and aspiration of the individual is to attain 'optimal functioning in all areas' of one's life. A broad cultural repertoire being drawn upon here is that of humanistic individualism which focuses on the 'growth' of the individual, attained through hard work and aspiration. Such language echoes powerfully dominant discourses within western society about the virtue of individual aspirations and working to achieve them. The very act of making such effort is seen as virtuous, whether it is successful or not.

Strong emphasis is also placed on locating health beyond a disease led conceptualisation, and thus, what Parker (1992) has described as a 'counter discourse' is being set up in opposition to a 'medical model' of health. An 'holistic' notion of health, located in and linked to everyday life in emphasised. Thus, a conceptualisation of health is set up which reaches 'beyond the clinic' and into the everyday life. This model of health also allows for the surveillance and intervention in the lives of, people who are not actually diagnosed as sick or ill. To give material weight and 'facticity' to the model of health being presented, however, a strong 'empiricist repertoire', using concepts normally associated with a bio-medical discourse, is nonetheless drawn upon. This is most obvious in the invocation of the concept of 'homeostasis' in **'Vernon 2'** and **'Wake'**, but the texts also present a similar 'empiricist' foundation for their case, seeking corroboration from sociological, epidemiological, and bio-medical sources. As we have also seen, particularly in the 'Paul' case study, the 'empirical' quality to the account being constructed across the texts is reinforced by, and strongly related to, the second major theme evident in this discourse, 'the problematisation of health' in people with learning disabilities. It is to that theme that we will now turn.

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Theme 2)

The problematisation of health as an issue of the 'vulnerability' of people with learning disabilities to the development of health problems.

The problematisation of the health of people with learning disabilities constructed in the discourse of health in the texts is centred on the notion of 'vulnerability'. Once again, **'Vernon 1'** sets the tone when discussing physiological aspects of health in people with Downs' syndrome.

PASSAGE 1 – 'Vernon 1' – Page 93:

"In particular, people with genetically determined causes of learning disability have unique health concerns. For example, there are 'some important features of Down syndrome that may impinge upon the health of the individual' (Burns and Gunn 1993). The most serious of these are congenital heart defects, which have been reported in about one-third of children born with Down syndrome. If neglected such defects seriously reduce life expectancy. Fortunately, most defects are correctable by medical and surgical intervention. There are a number of orthopaedic problems associated with Down syndrome that may affect the mobility of the individual. The most severe of these is atlantoaxial instability. Tredwell et al (1990) warned that instability occurs in 9-22% of adults and children with Down syndrome. This condition can lead to dislocation of the vertebrae and subsequent damage to the spinal cord. Clearly, if left undetected severe mobility disturbances occur that have an adverse impact of the quality of the individual's life. Other impairments associated with Down syndrome include hypothyroidism. Hypothyroidism has an effect upon levels of activity and is

generally associated with sluggishness. Burns and Gunn (1993) pointed out that hypothyroidism also has a 'permanent deleterious effect on intellectual functioning'. From this brief account it can be seen that there are certain characteristics of Down syndrome that may affect the physical health of the individual."

This passage illustrates the strong use of a technical, biomedical form of 'empiricist repertoire' to construct a strong sense of the biological vulnerability of people with learning disabilities to the development health problems; in this case people with 'genetically determined' learning disability - Downs' syndrome specifically - as an example. The use of this repertoire here involves the listing of 'facts' about 'defects' and 'impairments' commonly found in people with Downs' syndrome, drawn from referenced research, together with descriptions of symptoms. This works to construct the facticity of the biological frailty and vulnerability of this group of people. The passage is laced with a number of 'warnings' which highlight the potentially dire consequences of failing to recognise or address these problems. For instance we are warned that 'if neglected' heart defects in people with Down syndrome may shorten their life. Also, we are told that if spinal problems in people with Down syndrome are 'left undetected' then severe mobility problems could result.

These warnings can be seen to establish an imperative for monitoring and ongoing observation; 'health surveillance' is the term used in **'Barr'** and **'Hart'**: a term drawn directly from *Continuing the Commitment* (DoH 1995). This works to establish, what we might term an 'interventional space' for learning disability nurses to occupy. Learning disability nurses are not mentioned explicitly here, but by leaving this idea implicit, rather than making it explicit, the case for 'specialist' observation and intervention is created organically; arising naturally, rather than engineered artificially. This can be seen as a form of what Potter (1998) calls 'stake management', or 'management of interest'. By constructing the problem as an empirically existing phenomena which exists 'out there', the interest, or 'stake' which an author may appear to have becomes concealed beneath the concern that is generated about the nature of the problem identified. The professional role in responding to it is thus not constructed explicitly, but rather is 'allowed to emerge' implicitly, as an apparent necessity in the face of the reality of an external problem.

A great emphasis on the establishment of the material 'facticity' of the vulnerability of people with learning disabilities to the development of health problems, is found in **'Barr'**, and is similarly laced with 'warnings' about the dangers of ignoring them:-

<u>PASSAGE 2 – 'Barr' - Pages – 309-310:</u>

" .... increased longevity among people with learning disabilities has resulted in an increased number of deaths as a result of conditions such as myocardial and vascular diseases, cancer and Alzheimer's disease (Jancar 1988; Bycroft 1994; Day and Jancar, 1994). Considerable evidence exists to support the concerns about the health of people with learning disabilities in respect of cardiovascular disease, strokes, cancer, mental illness, sexual health and accidents (Bouras et al., 1993; DOH 1995; Turner and Moss, 1996).

There is some evidence to suggest that many potential health problems and associated health risk factors among people with learning disabilities go

undetected. Langan and Russell (1993) found that people with learning disabilities were less likely to be offered cervical screening, breast examination, blood pressure monitoring and advice on the dangers of smoking. One health screening project (Meehan et al., 1995) reported that out of 191 people with learning disabilities assessed, 176 had previously undetected conditions that either increased their risk of developing ill health, caused pain and discomfort, or reduced their opportunities for social integration. It is important to remember that these impairments are reported as particularly responsive to treatment, especially when reported at a younger age (DOH, 1995; Evenhuis 1995).

It has been suggested that aspects of the lifestyle of people with learning disabilities may contribute to their increased chances of developing ill health. These factors include a reduced level of fitness, increased obesity, reduced self-care abilities and similar cholesterol profiles to people in the general population (Rimmer et al, 1993, 1994; Turner and Moss, 1996). The incidence of risk factors has also been linked to where people live. Significantly higher rates of obesity, smoking, coffee intake and reduced exercise levels have been associated with community residential homes .... when compared with people living in hospital or at home.

Although family members and carers may be aware of the signs and symptoms of ill health in people with learning disabilities, they may fail to recognise the significance of these and seek appropriate treatment. This could in part be due to low expectations of the health of people with a learning disability."

Again, a strong 'empiricist repertoire' is invoked. 'Ageing' and its associated health problems is highlighted among the factors that make people with learning disabilities vulnerable. A warning note is included about the risk of many conditions that are 'particularly responsive to treatment, especially when reported at an early age' going undetected. Clearly, the implication here is that the lack of detection is as much the problem as the biological frailty of people with learning disabilities. Similarly, the emphasis that follows on health problems related to 'lifestyles, such as diet, and levels of fitness and exercise raises the implication that the health problems of people with learning disabilities are potentially worse than they might be if sufficient levels of 'surveillance' were in place. Family and other carers' levels of knowledge and beliefs are also presented as problematic here when they are based upon 'low expectations' of the health of people with learning disabilities. All of this works to create an imperative for 'expert' and specialist' intervention of some kind, whether it be health assessment and screening, promotion of healthy lifestyles and activities, or education and supervision of families and carers.

Similarly in **'Hart'**, we see in a discussion of the physical and mental health of people with learning disabilities:-

PASSAGE 3 – 'Hart' – Pages 292-293:

"...we now understand and should act, where people with learning disabilities are known to have an increased health risk. Conditions such as epilepsy, cerebral palsy and other physical disabilities are found in about one third of people with learning disability, and it is also associated with spinal and postural deformities,

hip dislocation, eating and swallowing problems, gastro-oesophageal reflux, constipation and incontinence (NHSE 1999a, Vernon 1997).

Research has demonstrated that people with learning disabilities also have an increased likelihood of experiencing mental health problems (HoNOS-LD 1998) with some suggestions that there is occurrence in up to 50% of the population (NHSE 1999a). *Once a Day* (NHSE 1999a, p17) also suggests that depressive illnesses and withdrawal are frequently not diagnosed or treated.

Certain syndromes have come to be associated specific health needs. People with Down syndrome are known to be prone particularly to cardiac disorders, respiratory problems, frequent chest infections, megablastic anaemia, acute lymphoblastic leukaemia, disorders of the thyroid, hearing impairments and orthopaedic problems (Vernon 1997). Klinfelter syndrome is linked with cardiac disease, osteoporosis, kidney problems and gastrointestinal bleeding (DOH 1995, NHSE 1999, Vernon 1997).

There is also evidence to suggest an under-detection of sensory disabilities, in particular hearing and vision problems. Somewhere in the region of 24% of people with learning disabilities are believed to have some problems with hearing, and as many as one-third may have problems with their eyesight (NHSE 1999a). Of course as people grow older these needs are likely to increase."

Again, we can see the strong use of a 'biomedical style' empiricist repertoire. The use of percentage proportions to illustrate the extent of the problems being highlighted within the population of people with learning disabilities works to construct both a sense of 'facticity' and a certain 'ominous ness' about the picture emerging from this research. This 'ominous' quality is accentuated by the apparent vagueness of the figure given for 'mental health problems'; the implication being that we are dealing with a problem, the true extent of which is actually unknown. Also, the use of technical bio-medical terminology and classificatory terms in relation to physiological problems, such as 'megablasitc anaemia' and 'lymphoblastic leukaemia' works beyond the purely descriptive level to accentuate both the sense of the 'facticity' of the account being given, and the 'ominous' quality already noted. The image being constructed here is one of a biologically, and psychologically frail group whose level of vulnerability requires a specialist response.

A 'working up' of the psychological vulnerability of people with learning disabilities is also evident across the texts. In **'Vernon 2'** for example:-

<u>PASSAGE 4 – 'Vernon 2' – Page 39:</u>

"Research evidence indicates that the incidence rates of mental ill health is higher among people with a learning disability than for the rest of the population (Corbett, 1979., Lund, 1985., Jacobson and Ackerman, 1988). Reasons for this are relatively unknown due to a lack of research in this area. Theories have been put forward suggesting that mental health problems are related to underlying abnormalities of brain structure and function or the effects of epilepsy (Holland and Murphy, 1990). In many other cases, however, emotional and behavioural disturbances can be attributed to social and psychological factors. These factors

have been described by Russell (1991) in terms of 'burdens'. Russell identified three psychosocial burdens that may be summarised as:

1. **Not being sufficiently skilled to be able to adapt quickly to the world of work and the social demands of other people.**
2. **The burden of living in a society which fails to provide resources for those who are disabled and in which social attitudes to disability encourage rejection, segregation and isolation.**
3. **The burden of being aware that one has a learning disability and the self-doubt that this can generate.**

These burdens expose the individual with a learning disability to *psychological stress* and to the possible development of mental health problem. Identifying those who may be at risk and providing them with psychological support is, therefore, an important task for people working with people individuals who have a learning disability."

The psychological vulnerability of people with learning disabilities is presented here using the central metaphor of 'burdens', drawn from Russell (1991). The references to 'brain structure and function' and 'epilepsy' work to reinforce the idea that this vulnerability has a biological basis, though its manifestations may be behavioural and social. In particular, people with learning disabilities are depicted as lacking the coping skills which allow most people to function psychologically and socially, and it is here where a space is located for the work of 'carers'. There is, it could be argued, an underlying sub theme of paternalism present here too, represented by the pervasive implication of the 'passivity' of people with learning disabilities. People with learning disabilities are depicted as passive recipients of services, and passively vulnerable to the development of physical and psychological ill health and thus in need of expert surveillance.

A strong link is made too between mental health and the social context of the lives of people with learning disabilities. This 'social' dimension of health is given emphasis across the texts. In **'Wake'**, for example, people with learning disabilities are depicted as particularly vulnerable to the impact of environmental factors past and present:-

PASSAGE 5 – 'Wake' - Page 49:

"Perhaps one of the main issues facing the person with a learning disability, relating the environment to their health, is where the person lives. It is acknowledged that institutional care can have a profound impact on an individual's mental health, for example in terms of self worth and individuality. Goffman (1961) highlighted the impact of institutionalisation on the individual. It should be remembered by carers of people with learning disabilities that those currently residing in group homes may have spent a significant part of their lives in large institutions."

As we shall see later, the solution to the problematisation of health in people with learning disabilities is presented as the presence of 'carers', particularly nurses, who understand the complexity and nature of the health problems people with learning disabilities face, and who are committed to working to help them restore or maintain 'balance', and thus health. This is particularly the case with mental health. Whilst physical health is portrayed as an area for surveillance across the texts, mental health is portrayed as an area where direct intervention is very much in the hands of 'carers'. This is illustrated in the following passage from **'Vernon 2'**:-

PASSAGE 6 – 'Vernon 2' (1998) Pages 40-41:

" ….individuals who feel a personal lack of control to overcome threats to psychological well being are likely to show more stress-related problems such as anxiety and depression. This is particularly relevant to people with learning disabilities whose mechanisms for successful coping may be compromised by a primary impairment or by psychological factors. To illustrate this point, consider the function of communication. Communication, turning to a comforting person or talking through problems, are everyday ways of coping with stress. Indeed, Zeimer (1982) found that over 50% of his study sample reported that their preferred method of coping was to talk to someone. Clearly, this has profound implications for those individuals whose verbal communication is limited. Moreover, coping mechanisms operate within the limitations of the individual's genetic make-up, physical condition and level of intelligence. It follows, therefore, that some people may find it difficult to cope with stress successfully. Such knowledge must be put to good effect. Carers must strive to enable personal control, thereby assisting the individual to cope with stressful events. In so doing the carer will be facilitating the restoration or maintenance of psychological equilibrium." (P 41)

This, and the previous passage, emphasises the social vulnerability person of people with learning disabilities, depicting them as lacking those skills necessary to protect them from the psychological impact of stress. The construction of such a passive and vulnerable identity for people with learning disabilities means that a role is also, by implication, constructed here for an 'idealised carer' – one who fulfils the roles of confidant, counsellor and listener; filling the void left by a society that is, by implication, hostile, and acting as a crucial support to the person with a learning disability who lacks the competence to cope. Again, we can see then, that the construction of vulnerability in this way works also to construct an interventional space for a carer to step in and provide the vital support these 'individuals' - the repeated use of the term 'individual' arguably reinforces the sense of vulnerability even further - need to maintain their psychological health and well-being. The construction of this vulnerability as a 'fact', existing 'out there' in the 'real world', also allows for the imperative for intervention to emerge again as a 'natural response' rather than a possible manipulation rooted in the 'stake' held by the author.

Conclusions:

The construction of the vulnerability of people with learning disabilities can be seen then to work in these texts to create an 'interventional space' in which the need for specialist services and input are presented as necessary to protect the health of people with learning disabilities from the 'threats' to which they are vulnerable. This vulnerability is constructed by the strong use of 'empiricist repertoires' which work to place the threat firmly 'out there' in the material world. This is corroborated by reference to an array of empirical research and authoritative sources, which, both within, and across texts, works to construct a 'consensus' about the 'facts' being presented. There is a particularly strong emphasis on the 'biological root' of the vulnerability of people with learning disabilities to the development of health problems, including psychological and social health problems. A 'frail' identity is, by implication, constructed for people with learning disabilities, who are presented as passive recipients of services, and passive 'victims' of social discrimination.

The emphasis on the vulnerability of people with learning disabilities, given 'facticity' by the weight of corroboration and consensus of empirical evidence presented to support it as 'factual' works persuasively to construct both the rationale and the space for specialist professional intervention. We can also see, however, that the professional identity of those who would do the intervening has not been made explicit, at least in relation to the health problems identified above. This 'silence' about who should intervene can be seen as a subtle form of 'stake' management. The priority of the passages cited above appears to be to emphasise the facticity of the problems identified, but at a distance from the possible 'stake' which may be associated with the professional identity of the authors. Later in the texts however, the response to the problem of vulnerability is constructed, and it is here that the link to the role and identity of learning disability nursing begins to emerge strongly. This process of role and identity construction is consolidated further in relation to the third and final theme, and it is to that which we now turn.

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Theme 3)

The problematisation of the standard of generic healthcare services in understanding and meeting the health needs of people with learning disabilities.

The construction of the health related vulnerability of people with learning disabilities illustrated above works, in turn, we can see, to construct an imperative for action to address their health needs. This leads us into our exploration of the third major theme of the discourse of health; the problematisation of the response of generic services. It is around this theme that the construction of a new role and identity for the specialism of learning disability nursing emerges in the discourse. Critiques of NHS provision and the 'inadequacy' of skills and knowledge among generic health care staff relating to people with learning disabilities loom large in these texts. In **'Vernon 1'** for example, the 'problem' is summarised as follows:-

PASSAGE 1 – 'Vernon 1' - Page 90:

"It is clear….. that there are deficits in essential aspects of healthcare, and it appears that 'many health care professionals appear to adopt complacent attitudes towards people with learning disabilities' (Meehan et al 1995). The movement towards care in the community underpins the need for staff to become more responsive to the changing needs of people with learning disabilities. Specialist learning disability nurses have a key role to play in ensuring the healthcare of their patients are given top priority, and that such individuals are served by an appropriate range of services. In doing so, however, carers must avoid overemphasising physical symptoms and diagnoses. Rather, a much broader, holistic model of health should be embraced."

Here we can see here how the 'problematisation of the response' is used to create the space for the emergence of the role of the specialist learning disability nurse. The role emphasised in this particular case is that of 'advocate' for people with learning disabilities in accessing generic health services. We can also see here how, once again, the articulation of the role of the learning disability nurse here is constructed in alignment with a holistic model of health, and stress is laid on the need to avoid 'overemphasising physical symptoms and diagnoses', thus establishing a distance from an oppressive 'medical model' of learning disability.

A similar cautionary note is sounded in **'Wake'** with regard to a medicalised conception of health in relation to learning disability:-

PASSAGE 2 – 'Wake' – Page 49:

" ...it is important to point out that although some conditions are perhaps encountered more amongst people with learning disabilities than in other groups, it would be wrong to medicalise all aspects of care for people with learning disabilities just as one wouldn't for any other group of individuals. What it does mean, however, is that, for people with learning disabilities who do require ongoing health care or monitoring of chronic health problems, they are entitled to the level of health care they need as individuals, regardless of whether they have a learning disability or not. This includes the right to access specialist health-care provision, where appropriate, as well as the skills of a primary health-care team."

Here we see a distance being established from a pathological model of learning disability with the assertion that it is 'wrong' to medicalise services for people with learning disabilities, despite their high vulnerability to health problems. We can also see here, however, the invocation of a 'rights-based' argument to support the idea of an entitlement of people with learning disabilities to access specialist, as well as generic services. The rights of the client then, rather than a defence of the specialist learning disability nursing profession, is presented as the core argument. This can possibly be seen as a further form of 'stake management', in that the case for specialist services, and thus for a specialist profession, is constructed on the basis of a response to 'rights' of the client group, alongside deficiencies in the quality of generic health care provision, rather than the self interest of the profession. We shall see further examples of this invocation of a 'rights repertoire' subsequently.

Although criticism of current NHS provision is pervasive across the texts, the most thorough-going critique is that found in **'Hart'**. The main argument constructed in this text is a damning critique of generic NHS provision for people with learning disabilities. In particular, 'systemic failures' and 'poor staff attitudes and beliefs' are identified and emphasised, and we are given an extended warning that health issues will become more significant for people with learning disabilities in the future, an argument corroborated by reference to empirical epidemiological research and projections, for example, as follows:-

PASSAGE 3 – 'Hart' – Page 292:

"The failure in health provision for people with learning disabilities is now fairly well established and questions of quality and value for money in the public sector highlight the deficiency. Numerous strategies have been implemented to address this situation locally, however, to date these have been impotent in effecting major change, and this is a concern because as the following will highlight, several indicators predict that people with learning disabilities will require increased health care in the future.

First, as more people with learning disabilities are living longer there is an increased likelihood that more people will develop illnesses of old age (DOH 1998, Edgerton et al 1994, Jenkins et al 1994), and we are already witnessing an increased incidence of people with Down syndrome developing Alzheimer's disease (Holland and Oliver 1995, Whitehouse et al 2000). Patterns of illness are already altering as a result of longevity and are increasingly reflecting the mortality and morbidity levels in the general population (Barr et al 1999).

Secondly ..... increased numbers of younger multiply disabled children are surviving into adulthood with severe and complex health needs (DOH 1998).

Thirdly, as deinstitutionalisation nears completion the few remaining segregated services, once located in long-stay hospitals will close, and yet more people with learning disabilities will access health care across generic services. In a truly inclusive health service, there will be no role for 'specialist' dentists, physiotherapists and chiropodists who offer their services to individuals primarily because they have learning disabilities. There may be a future for a small number of specialist services that focus on particular needs, for example sensory disability, epilepsy, mental health (DOH 1998). Significantly these will offer additional specialist input, rather than (as before) being a poor relation in what was essentially a two tier health system (DOH 2001a). This is not to criticise some of the excellent services provided to people with learning disabilities by hospital based health care professionals, and the high order skills many people developed to work effectively with the more challenging of their patients. But it

nevertheless remained the case that health services delivered outside of the mainstream (in segregated institutional environments) were largely disengaged and isolated geographically from their mainstream counterparts."

Here we can see a particularly strong articulation of the 'problematisation of the response' theme. We can see how in **'Hart'** an image of a health service that is currently lacking a clear strategy for responding to the health needs of people with learning disabilities is invoked. This assertion is then followed up with a selection of current and projected epidemiological evidence, some of it sourced in policy documents, which asserts that there is likely to be a significant increase in the demand for access to generic health care services from people with learning disabilities in the future. This argument is constructed using a 'listing' strategy that builds the case with a sense of ominous ness that also works to maximise its persuasive impact. The references to a mixture of empirical research and policy documents also maximises the sense of 'gravity' in the argument, constructing it around powerful warranting and legitimising sources. The opening paragraph carries the assertion of consensus about the 'failure' of the health service response to the health needs of people with learning disabilities, and weaves this together with elements of a 'managerial repertoire', emphasising themes of 'quality' and 'value for money'. Overall, these rhetorical and linguistic features work to give the argument being constructed a powerful 'authoritative' gravity upon which, subsequently, the articulation of the role of learning disability nurses is built, as we will shall shortly see.

This passage in 'Hart' works towards an assertion of the need for a 'health promotion' role for learning disability nurses. Similarly, in **'Barr'** we see the construction of an imperative for a 'health promotion strategy' in relation to people with learning disabilities:-

PASSAGE 4 – 'Barr' – Page 318:

"Little dispute exists that urgent attention is needed to the health promotion needs of all people with a learning disability. What is now needed is a determined and co-ordinated approach in respect of a health promotion service which incorporates the abilities and needs of people with a learning disability (Thornton, 1994). This service must target areas of health which have been identified in the literature as needing attention. There is also an urgent need to research the effectiveness of health-promotion approaches used with people with learning disabilities in order to establish a body of knowledge to guide and co-ordinate practice, reduce duplication and reinvention of the wheel, and identify those areas that have been effective and ineffective. This research needs to be methodologically sound, completed with rigour and needs to overcome the present deficits identified (Moss and Turner, 1995)."

The working up of an imperative for specialist action that we see here is a strong element in the construction of a restructured role and identity for learning disability nursing across the texts. The passage opens with an allusion to the existence of a consensus that exists regarding the 'urgency' of the need for a health promotion strategy. Elements of a 'rational/managerial repertoire' are apparent here, with references to 'effectiveness' in both the development of appropriate health promotion strategies, and the establishment of a 'sound', empirically demonstrated knowledge base. This is interwoven with elements of a 'moral/political repertoire' in the assertion that what is needed is a 'determined' approach, which 'must target' particular health issues. In this way an imperative of commitment and political will is set up as necessary to achieve the goals being identified, and we can see a blend of 'moral' and 'rationalistic' repertoires which are woven together to produce a powerful 'offensive action orientation' in the rhetorical construction of the argument being developed. We will return to look at further use of this 'moral/political discourse' shortly, but firstly, we will continue to focus on the way that health promotion is worked up as the framework within which the new role of learning disability nursing is constructed.

For example, **'Vernon 1'** establishes health promotion and education as an important element in the reconstructed role of learning disability nursing,, placed within a 'health gain' framework:-

PASSAGE 5 – 'Vernon 1' – Page 100:

"....health is inextricably entwined with the physical and psychosocial aspects of the individual. The existence of a learning disability compromises the individuals' ability to achieve health independently. Hence, learning disability nurses have a central role to play in maximising the potential of the individual to achieve health. A high standard of preventive care can minimise the occurrence of health loss and its complications. Effective preventive care is likely to produce significant health gains that have a beneficial impact upon many areas of an individual's life. Learning disability nurses also have a role to play in health education. They can assist people to 'choose a healthy way to live (Department of Health 1995), based upon individual needs. Of equal importance, nurses must enable people with learning disabilities to gain access to comprehensive healthcare services. This

means that the learning disability nurse must establish alliances with generic health services and enable appropriate care to be developed in an atmosphere that is receptive to the individual's needs. In conclusion, health promotion, preventive interventions, the teaching of skills and enabling access to appropriate services form the core components of the health gain approach. Assistance will be needed to some degree if people with learning disabilities are to achieve a significant health gain. Surely, this principle must underpin the terms upon which learning disability nurses base their practice."

Here we see a broad image being constructed of the health related work of learning disability nurses, particularly in the area of 'health education'. Firstly, the nature of the 'problem' is established; that a learning disability 'compromises' the capacity of the person with a learning disability to 'achieve health independently'. This is the space then in which learning disability nurses should find their niche. Not to address sickness or ill health as such, for, as we have already seen, a distance has been established from any notion that learning disability equates with sickness or illness, but rather to 'prevent' sickness or ill health arising in a group of people who are frail, passive and socially vulnerable. And is it a role performed in the name of maintaining 'independence' and helping the 'individual' to 'achieve health'. Thus the role and identity being constructed here is one of helping people with learning disabilities to meet some of the most valued requirements of autonomous citizenship; namely, to 'achieve health, to 'function independently', and to do so as an 'individual'. We can see also here, the extension of the role also into making a vital link with generic healthcare services.

We see a similar assertion of an 'imperative' for specialist, alongside generic health promotion in **'Barr'**, with an argument rhetorically constructed with the problematisation of the response of generic services at its foundation:-

PASSAGE 6 – 'Barr' - Pages 311-312:

"It is important that all mainstream health services are accessible to people with a learning disability. In addition it is also necessary to have access to additional services that can recognize and respond to physical, psychological and social factors that influence the health of people with learning disabilities.

Even though health promotion is a major part of current health provision in community settings, it is clear that people with a learning disability have unequal access to services and advice available. People with a learning disability could face a variety of problems in accessing mainstream health-screening and health-promotion services. These difficulties may relate to the personal characteristics of both people with learning disabilities, and carers and staff involved. People with learning disabilities may experience difficulties such as fear of unknown places, people and investigations; difficulty in reading and understanding published material or technical terms; or the need for investigations. The presence of challenging behaviour will reduce opportunities to utilize mainstream services. Failure to appreciate the intricacy of socially appropriate behaviour, for example waiting in queues, taking turns, acceptable responses to fear and confusion may result in a reluctance among carers and family members to avail of mainstream health-promotion services."

It is interesting here that specialist services are presented as not just necessary to 'meet' health promotion needs, but also to 'recognise' them in the first place. The problem is portrayed as one of inequality of access to service provision for people with learning disabilities. A complex picture is painted of a variety of problems and issues that could prevent people with learning disabilities accessing the services they are deemed to require. For example, the problem of managing 'challenging' or inappropriate behaviour is presented as an issue which may complicate an already difficult situation. A silent implication here (made explicit later in the text) is that there is need for a 'specialist' to oversee the system and the relationships therein for these to be managed for the benefit of people with learning disabilities.

In **'Barr'** also, we see an articulation of a model of health promotion involving three levels of intervention, 'primary', ''secondary' and 'tertiary'. The same model is presented in **'Vernon 1'**, and in **'Hart'** too, where perhaps the most succinct outline is given, establishing a direct link between this and the role of learning disability nurses:-

PASSAGE 7 – 'Hart' – Page 302-303:

"*The Alma Ata Declaration* (WHO 1978) has defined health promotion as a process of enabling people to increase control over and improve their health. In the UK a standard definition of health promotion in practice is that developed by Ewes and Signet (1985). It refers to 'health' in a broad sense, including physical, mental and social health. Health promotion can be seen as having three main goals: primary prevention, with a focus on preventing ill health and disease; secondary prevention, which includes early detection and treatment; and tertiary

prevention, which aims to stop the needless progression of disease (Nightingale 1992).

Continuing the Commitment*: *the report of the learning disability nursing project **(DOH 1995, p20) made explicit that 'health surveillance and health promotion' should be seen as areas where learning disability nurses need to develop their knowledge and skills. This was considered to be necessary if learning disability nurses were to be able to 'have a direct or indirect role in the assessment, provision and evaluation of support that contributes to bringing about the optimum health status of the individual'.**

The Health of the Nation: A Strategy for People with Learning Disabilities **(DOH 1995) has stressed that people with learning disabilities should be included in all the programmes offered to the rest of the community. Also that all health promotion programmes should be presented in such a way as to make them accessible to all people, including those who may have difficulty in understanding some of the concepts.**

Signposts for Success **(NHS Executive 1998) recognised that an increasing number of people learning disabilities needed help in managing aspects of their and lifestyles. The increasing number of people with learning disabilities who have become involved in the misuse of alcohol and/or drugs has heightened the need for specialist health promotion in these areas (Parrish and Kay 1998)."**

As with the previous passage drawn from **'Hart'**, we can see how authority and legitimacy for the assertions made is drawn from reference to policy. A close echoing of policy agendas is a strong rhetorical feature here. Nationally and internationally recognised sources on health promotion are cited, establishing an authoritative warranting and corroboration of the model being advocated. We can also see again the operationalisation of a holistic model of health, with its broad conceptualisation, embracing physiological, psychological and social dimensions, and also, of course, the presentation of the three levels of health promotion. Subsequently, the case for health promotion and 'health surveillance' as the primary role for learning disability nurses is constructed, again presented in direct relation to policy, particularly *Continuing the Commitment. The Health of the Nation: A Strategy for People with Learning Disabilities* and *Signposts for Success* are then cited, in a way that further works to align the role being worked up with the goals and orientation of key policy initiatives. This emphasis on reference to policy, and thus to 'political authority' works here to present the role and goals of learning disability nursing as being in sympathy with key aspects of policy, rather than in conflict with it; an important rhetorical strategy if the aim is to convince managers and purchasers of health and social care services that learning disability nurses are necessary.

In **'Wake'** a 'moral/political repertoire' is invoked to support a health promotion focus:-

PASSAGE 8 - 'Wake' – Page 47:

The right to realistic life-goal planning, informed choices regarding one's life style and issues such as health education and health promotion for people with

learning disabilities is.... of importance. As is the right to adequate resources to enable the above to occur. Attitudes of able-bodied people towards people with a learning disability are also important when considering health and people with learning disabilities. It is an important issue to consider as it affects health-care delivery by professionals for and to people with learning disabilities. Health care tends to focus upon the short-term physical needs of the individual with a learning disability rather than a holistic approach including, for example, preventive health work and the impact of social, cultural and environmental aspects of that person's life style."

Here we see the strong use of a 'moral/political' repertoire. Firstly the 'right to life planning' – a cornerstone of learning disability nursing practice – is asserted, followed by the assertion of the 'right' to expect that the resources for this to occur will be provided. Thus, the input of learning disability nursing is constructed around a defence and promotion of the rights of people with learning disabilities, rather than as a defence of the learning disability nursing profession and its practices. This strategy also works to position those who might resist providing these resources and the professional input that goes with them, in a defensive position morally. This rhetorical strategy is also evident in the final sentence in this passage which works to construct a moral argument for the application of a 'holistic' model of health with a preventive emphasis, contrasting this with the short term focus of a medical approach, which is, by implication, left in a morally questionable position.

The right to specialist provision is pursued further subsequently in **'Wake'**, drawing support from 'social role valorisation' (a form of normalisation philosophy) which, it is argued, supports rather than conflicts with, the case for specialist provision where this is seen as appropriate:-

<u>PASSAGE 9 – 'Wake' – Page 47:</u>

"It is a common misconception that social role valorisation means exclusively using local services 'because that is what we all do'. This denies the right of the individual with a learning disability to seek specialist help, in epilepsy management when required, for example. Everyone should have the right to seek the best care possible. This is particularly pertinent in that it has been argued that GPs may lack experience in co-ordinating the care for people with learning disabilities and that they may feel that this responsibility lies with the a consultant. A lack of liaison between professionals involved in the care of people with learning disabilities was seen to be linked to this (Howells, 1986). This was despite the fact that over 60% of people with learning disabilities living in the community required ongoing support for chronic physical and/or mental health problems (Mininhan and Dean, 1990)."

Use of the phrase 'denies the right' here works to increase the intensity of the argument being made in this passage, working as a rhetorical strategy which turns what might be portrayed as a 'defensive argument' into an 'offensive argument', with the position of someone who would adopt a counter argument effectively implicated as an attack on the rights of people with learning disabilities, rather than on the existence specialist learning disability nurses. Use of the expression 'individual with a learning disability' also works to emphasise vulnerability – 'individuals' being more vulnerable than groups. The rights of the individual are asserted then, not just in relation to people with learning disabilities, but as a universal right. This further works to reinforce the sense that what is being argued here is in tune with widely held moral values, and thus, by implication, locates alternative arguments as in conflict with those values. A question mark is then placed against the capacity of the medical profession to organise and co-ordinate care for people with learning disabilities. This is backed by corroborative research evidence which serves to accentuate the 'facticity' of the problem being highlighted – the inadequacy of generic service provision for a particularly vulnerable group. A powerful mix of moral, scientific and political repertoires is invoked then to construct the case for specialist provision.

The solution to the 'problem' of the vulnerability of people with learning disabilities to the development of ill health is being constructed in these texts as 'health promotion', within a broad 'health gain' framework. Health is presented as multidimensional, and enacted in people's everyday lives, in line with a 'holistic' model of health, and a key goal is identified as helping people with learning disabilities to achieve independence. Learning disability nurses are presented as the key professionals who, via processes of assessment, monitoring and 'surveillance', as well as advocacy and 'health education', help people with learning disabilities to overcome biological, psychosocial, and educational deficits which compromise their health.

Despite the apparently positive message being conveyed about the role and identity of learning disability nursing across the texts, an assertion is also being made that learning disability nurses themselves have a responsibility to reconstruct their role and identity in line with the changing service context in which they are operating. We saw this kind of assertion earlier in a passage from **'Barr'** when a commitment to developing a health gain focus that 'must underpin' the work and role of learning disability nurses was stressed. We can also see this assertion being made with even more strength in **'Hart'**:-

<u>PASSAGE 10 – 'Hart ' – Pages 300-301:</u>

"The resettlement into the community of individuals who have lived in long-stay hospitals heralded a momentous change in the lives of those people with learning disabilities who were involved. What is less often acknowledged, is both the extent to which learning disability nurses have been required to change their practice in order to work in the new style of service provision, and the challenge that this has posed for the profession. There have been some worrying examples of working practices more typical of a long-stay hospital environment being transferred almost wholesale into the community (Brown and Walmsley 1989). As Collins (1995) has argued, genuine community presence and participation for people with learning disabilities means something more than just being resident in the community.

Learning disability nurses share responsibility for the future of the profession, through their supervision of student nurses in practice, and the mentorship of newly qualified nurses. It is essential for the future development of the profession that practice is contemporary, building on positive ideologies of today, and abandoning any routine and segregated practices of the past. How learning disability nurses' new roles have needed to evolve can be illustrated well through the example of health care.

This shift in the role of learning disability nurses needs to be reflected in practice, in attitudes and in interactions with others. In the new culture of community care learning disability nurses have a very important and central role. But this is not the same as it was, and we do a disservice to out clients if we do not accept the challenge of our new role in relation to helping people with learning disability obtain the health services they need."

Here we can see a strong argument being presented for learning disability nurses to be proactive in reconstructing their role and identity. The passage begins with a historical reference which is used to illustrate both the extent and the nature of the transformation of the context in which learning disability nurses find themselves. The need to leave the old identity and role associated with 'institutional' models of care behind is strongly affirmed, with the use of the term 'worrying examples' in reference to the persistence of attachment to such practices noted in research, working to convey a sense of moral disapproval. The necessity for learning disability nurses to be proactive in reshaping their identity and practice to be congruent with 'contemporary' and 'positive ideologies' of today is made explicit, and the focus on health care is presented in this light. Finally, a strong rhetorical assertion of the need to change to fit in with the new 'culture of community care' is made, with the implication that, only if this change is made will the profession be able to maintain its 'important role', and its moral integrity. The implication here is the ultimate professional sin is 'to do a disservice' to the client group and this moral failure is what is finally invoked to give maximum weight to the argument being made. Overall, this passage appears designed to invoke a strong sense of professional responsibility. The argument works rhetorically to place the subject position of the reader in a position whereby resistance to the restructuring of the new role and identity being promoted for learning disability nurses is to position oneself in alignment with outdated and oppressive models of working. Conversely, the reader is led to feel that, to be in agreement, positions one in line with 'new, 'morally and ideologically' sound position.

The **'Hart'** text contains a more elaborate articulation of the role of learning disability nursing than the other texts under analysis here. This is undoubtedly due to it being the only one of the texts to be published after the *Valuing People* white paper (DoH 2001) wherein the 'health facilitator' role is identified as being particularly suited to learning disability nurses. The **'Hart'** text works to articulate what this role actually might be; something not actually specified in the white paper. For example, in the following passage:-

PASSAGE 11 – 'Hart' – Page 300:

At Bournewood Community and Mental Health NHS Trust in Surrey a community learning disability nurse was given a specific health surveillance role. The nurse needed to identify if there were people with learning disabilities resident in the community who were not having their health needs met. Once contact had been made the nurse could support the people in identifying their own health needs, and assist them in obtaining the help they needed. Explanations about health matters and health promotion information are further dimensions of the role. Recent developments have included facilitating a programme designed to enable general hospital staff members to develop an awareness of the needs of people with learning disabilities."

The **'Hart'** text thus seeks to establish a link between the 'health facilitation' role identified in *Valuing People,* and the 'health surveillance and promotion' role identified as being at the heart of the role of the learning disability nurse in *Continuing the Commitment.* Here, however, we see an attempt to articulate what such a role would look like in practice by describing the work of a particular nurse in a local initiative. This description works to 'ground' the abstract arguments about the role of the learning disability nurse in 'reality', and demonstrate their practical application. This is important in a profession such as nursing which is widely perceived, from both within and without, as being intensely practical in nature. The description of a practical example works then to give a 'practical authority' to the case being constructed. Rhetorically, this also works to make the 'health surveillance and health promotion role' specified in *Continuing the Commitment* appear to be a natural foundation for the 'health facilitation' role identified , but not specified, in *Valuing People.* A significant element in the description given is that the nurse is depicted as working 'with' people with learning disabilities to identify the issues that matter to them, and then helping them to identify and access appropriate generic services. The role described then, aligns with themes of partnership and access which appear prominently in *Valuing People.* Thus themes from policy are drawn upon to give an implicit moral and political authority and legitimacy to the role being constructed, a strategy which also implicitly positions anyone challenging this role in apparent conflict with those moral and political imperatives. The passage concludes with an allusion to the role of educating generic healthcare staff about 'the needs' of people with learning disabilities. Here we can see how the role of the learning disability nurse is being constructed in direct relation to the 'problematisation of the response' theme. This theme is developed still further **'Hart'**:-

PASSAGE 12 – 'Hart' – Page 293:

"Now, midwives, dentists, operating department practitioners, dieticians, radiographers, health visitors, outpatient department personnel, porters surgeons, GPs, practice nurses and receptionists, as well as doctors and nurses in general hospitals to name but some, will most days be meeting people with learning disabilities in the course of their work. This constitutes an enormous task for the National Health Service, as well as for people with learning disabilities and their families and supporters. It also requires learning disability nurses and other learning disability professionals to embrace the guidelines in *Valuing People* (DOH 2001) and reconsider significantly their roles in relation to health care delivery for their clients."

This detailed listing, of generic healthcare staff and professions, together with the juxtapositioning of the 'lowly' porter, alongside the 'lofty' surgeon, acts as a rhetorical device to work up the extent and range of the issue, and a sense of urgency and magnitude of the task of education and training required. Learning disability nurses are not left beyond the embrace of change however. The message is clearly conveyed that they must adapt their role and priorities to that of helping people with learning disabilities access the health care they need, rather than seek to maintain control over the delivery of that care themselves, with, once again, a reference to policy being used to provide the stamp of authority to the assertions being made.

In **'Hart'** also we can see the use of a 'consumerist repertoire'. Though echoing the same themes as the other texts about the problems people with learning disabilities face in accessing healthcare, in **'Hart'** we see the presentation of the corroborative evidence taken one stage further by bringing in 'the voice' of people with learning disabilities. Evidence is built up around the issue of 'dissatisfaction' expressed by interviewees about the treatment they have received in primary and hospital settings. The 'dissatisfaction' experienced by people with learning disabilities is presented as being particular and distinct from that which might be expected from the general population however:-

PASSAGE 13 – 'Hart' – Pages 293-294:

What is now emerging is accumulating evidence that people with learning disabilities have particular reason to be displeased with aspects of the health service they receive, over and above any of the 'mainstream' complaints about which all citizens may have a view. These inequalities are emerging as more and more people are being asked their views about health care. This is coming to light as a result of the welcome recent trend in research in reporting directly the views of people with learning disabilities (Booth and Booth 1994, Northway 2000, Richardson, M. 1997). Recent research has focussed on how people with learning disabilities actually experience the health care they have received (Hart 1998, Fovargue et al et al 2000). Evidence of what people with learning disabilities themselves say about general hospitals, nurses and GPs is growing. In a climate of consumerism, where services users' views are actively being sought, these findings should be regarded as especially significant. Even if it makes for uncomfortable

reading for professionals, there can be no better judgement about the quality of health care than from those who use the service."

Linkage is made here between 'discontent' felt by people without learning disabilities, and that expressed by people with learning disabilities; this works to legitimate discontent expressed by people with learning disabilities in a way that makes it appear in tune with current 'consumer' criticism of health services. This arguments work also to prepare the ground for the assertion of the 'particular' dissatisfaction on the part of people with learning disabilities which are depicted as a form of 'inequality'. A strong emphasis is given to the voice of people with learning disabilities as the voice of the 'customer/consumer' of health care services, and, via experiential accounts, as the best judges of service quality. Indeed, we are told that it is the emergence of this voice, via the medium of qualitative research, with people with learning disabilities being asked for their views, revealing, what is implied to be, a hitherto undetected level of discontent. Thus a powerful phenomenologically based critique of NHS provision is constructed, based on the views of people with learning disabilities as 'consumers', and set up as a major problem to be addressed.

The emphasis on the presentation of research evidence and the reference to a 'consumerist repertoire' may mark the argument presented in **'Hart'** out from the other texts which constitute the discourse of health explored in this study, but the overall theme being pursued is the same across the texts; generic NHS services and professionals, charged with taking responsibility for the delivery of healthcare to people with learning disabilities in the context of community care, are, currently at least, not prepared or equipped to do so. The case for specialist health promotion is constructed as the solution to this shortfall in NHS provision, and learning disability nurses whose core role has been specified as 'health surveillance' and 'health promotion' are presented as ideally and 'naturally' suited to fill this niche. For the profession, this requires shaking off the overly controlling practices associated with their institutional history and embracing the 'new' role of 'health facilitation'.

Conclusions:

One of the main unifying features of the texts under analysis is the way they can be seen to construct a coherent system of meaning relating to the health of people with learning disabilities. This coherence of meaning is constructed around the three main themes identified in the first, descriptive phase of analysis. For example, the theme of the identification of a holistic and humanistic model of health as the most appropriate in relation to people with learning disabilities is a theme that can be seen to be present in all of the texts, although there is some variation in the emphasis it is given. It appears very strongly in **'Vernon 1'**, **'Vernon 2'** and **'Barr'** for example. It is alluded to also in **'Wake'**, although it needs to be remembered that this text forms the second part of a two part exposition that begins in **'Vernon 2'**. Thus in **'Wake'** the prior assertion of this theme is taken for granted in the argument being made. Likewise, in **'Hart'**, although it is not given an extensive outline, the theme is alluded to, and its assertion forms a foundation for the argument being constructed. We can, therefore, see a clear coherence in the way health is conceptualised across the texts, and thus also, by implication, the presumption of a consensus that this is the most appropriate conceptualisation of health in this context. We will go no to explore the reason why this may be the case in the third and final stage of analysis in Chapter 7, but here, it is enough to note the clear coherence of meaning that exists in relation to this theme across the texts.

A similar coherence of meaning is also evident with the second major theme discussed; the 'problematisation' of health as an issue of 'vulnerability' to the development of health problems of people with learning disabilities. It is in relation to this theme that an 'empiricist repertoire' is most powerfully invoked. The assertion of the material reality of the biological, psychological and social vulnerability of people with learning disabilities appears strongly across all of the texts, and is used to form the foundation of arguments about how this 'problem' should be responded to.

Finally, we see a strong coherence of meaning across the texts in relation the third theme of the problematisation of generic health services' understanding of, and response to, the health related vulnerability of people with learning disabilities. It is against this theme in particular that the need for a specialist learning disability branch of the nursing profession is constructed. There is some variation in the explicitness of this construction, with **'Hart'** giving it the fullest and most explicit exposition. But the assertion that generic health services and professionals are often ill prepared, and lack the knowledge and skills to respond properly or adequately to the health needs of people with learning disabilities is a significant feature of all the texts.

This second, interpretative phase of analysis has been concerned primarily then with rhetorical strategies, and with identifying and illustrating the use of particular 'interpretative repertoires' to construct the discourse of health in these texts. These include, as we have seen, various forms of 'empiricist repertoire' - sociological, psychological, epidemiological and biomedical - which all work to help construct the 'facticity' of the main themes of the discourse, and particularly themes 2 and 3. These repertoires can be seen to work as important sources of authoritative legitimation for the argument being constructed in the texts. This authority arises from the fact that these repertoires constitute culturally 'privileged' sources of knowledge presentation and validation in western societies. In particular, they work to construct an apparently indisputable materiality, and, what Potter (1998) describes as 'out thereness' to the existence of the concepts and problems being identified. The presentation of empirical evidence, presented in disembodied, objective, 'scientific' terminology, and making frequent use of bio-medical concepts and classificatory systems, all works across the texts to construct an apparently unassailable materiality to the phenomena being described, which in turn works to reinforce the existential legitimacy of a specialist learning disability nursing profession.

This case is further reinforced by reference to interpretative repertoires which draw from other culturally valued, and strategically significant discourses, such as 'rights', 'moral/political', 'rational/managerial' and 'consumerist' repertoires. These repertoires are also drawn upon to support the construction and legitimation of the case being made in relation to each of themes, and ultimately, the role and identity of learning disability nursing. Thus we can see that there is a clear congruence of style in the texts, showing that important discursive conventions are at work in the way the texts are produced and presented; conventions seen as culturally appropriate for academic and pedagogical texts. This issue will arise again in stage three of our analysis where we move on to explore 'why' this discourse has been constructed in the way it has.

In conclusion then, we can now see that the discourse of health being constructed here is one that claims legitimacy for a scientifically and empirically specifiable object – health - in relation to a scientifically and empirically identifiable category of people – people with learning disabilities. As we saw at the end of the previous chapter, however, this category, and indeed, this form of categorisation is assumed to be unproblematic. We noted then that what we could see emerging was a 'professional monologue' which, despite claims to be manifest of a shift towards a 'non-oppressive' humanistic model of health, distanced from an 'oppressive' medical model, can, from a social model of disability perspective, be seen as merely another form of disabling professional discourse. As Bogdan and Taylor (1989 – cited in Rapley 2004) put it.... " [T]he definition of a person is to be found in the relationship between the definer and the defined, not determined either by the personal characteristics or the abstract meanings attached to the group of which the person is a part" (page 31).

The idea of people with learning disabilities as potentially active agents in managing and monitoring their own health was notable at that descriptive stage by its absence in the texts. We came closest in **'Hart'** where part of the argument is constructed with reference to the authors own qualitative research – although even here, the voice of people with learning disabilities is still not actually heard, and we are left to wonder about the nature of the questions asked and answers given. Overall, however, people with learning disabilities are assumed throughout to be a largely passive group whose health problems are distinct from the rest of the 'non-disabled' population.

Here, in this second 'interpretative' phase of analysis we can see this process taken to another level however. The overriding image and identity of people with learning difficulties constructed in these texts is one of a vulnerable group in need of specialist health care support to help them avoid mental and physical health breakdown. Their vulnerability is presented as 'constitutional' and pervasive at a biological level, and great use is made of biological concepts. French (1994) argues that 'vulnerability' is a key concept used by health professionals to justify 'specialist' treatment and services, with an implicitly paternalistic role inferred in relation to a client group unable to manage such things for themselves. In this stage of our analysis we can see exactly this process being played out, and, despite claims to be leaving behind a bio-medical conceptualisation of learning disability, a biomedical discourse is nonetheless powerfully invoked to establish the facticity of such a claim. Most of the texts slip at some point into the technical language of bio-medicine, listing and classifying physical and psychological conditions and illnesses to which people with learning disabilities are especially prone. At times this process comes perilously close to the pathologising tendency of bio-medical conceptualisations of learning disability inherent in the 'medical model'. The concept of 'homeostasis', for example, is taken out of its usual biological frame of reference, and applied to psychological, and even social aspects of health in a clear illustration of what Gestaldo (1997) has described as an extension of 'bio-power' out 'beyond the clinic'.

What then lies beneath this 'biologisation' of the health of people with learning disabilities, and its implication of constitutional vulnerability? To answer this, we need to move onto the third and final phase of our analysis, in which we will attempt to explain why the discourse of health embodied in these texts has emerged at this time, and in this form.

CHAPTER 7

Data Analysis 3 – Explaining the Discourse of Health

Introduction:

In this chapter we will move onto our third and final stage of analysis in which we will explore the questions of why the discourse of health in learning disability nursing textbooks has emerged in the form that it has, and at this particular time. We will begin by returning to look at the texts, and the textbooks in which they are situated, in chronological order, summarising the findings of earlier stages of analysis, and exploring how these relate to ideological and policy developments in the UK welfare state over the period of their publication. This will allow us to draw some overall conclusions, and to link up once again with the historical narrative begun in Chapter 2, thereby bringing the story up of the profession up to date, and revealing how the emergent discourse of health can be placed within that larger narrative.

To begin with then, we will return to look at the text books, and the texts within them that constitute the discourse of health, and explore how, in their form and rhetorical function, they can be related to the changing ideological and policy context within which the learning disability nursing profession has found itself operating in the 'post *Continuing the Commitment* era'.

Returning to the Texts:

Starting with the first book, *Learning Disabilities* (Gates, 1997) containing the **'Vernon 1'** text, we saw that the contents of this book strongly echoes the agenda set out in *'Continuing the Commitment'*. The placing of the chapter on 'Health' at the beginning of the core 'Section 2' of the book, for instance, implies a pre-eminent position for this concept as *the* key area for professional orientation. This book is, it will be remembered, the first edition of the *Learning Disability* textbook to include a specific chapter on 'health', and to promote it as a specific area of focus for the profession. In the **'Vernon 1'** text itself, we saw the earliest construction of the three major themes which run through all the subsequent texts, albeit with varying degrees of emphasis. The identification with a holistic and humanistic model of health for example, is given major emphasis in **'Vernon 1'**, working to construct a conceptualisation of health broad enough to allow professional intervention that doesn't focus purely on responding to the presence of illness, but which is 'promotional' and 'educational' in nature. This fits strongly with the health promotion agenda that was being proposed at that time in *The Health of the Nation: A Strategy for People with Learning Disabilities* (DoH 1995). Key sub-themes within the health promotion and health education agendas are also emphasised, including helping people with learning disabilities to achieve 'independence' and to 'maximise their individual potential'; both powerful themes in a free-market oriented political culture, emphasising individuality and personal responsibility, such as that promoted by the Conservative governments which had set out the policy agenda for the welfare state and community care contexts.

The role of the learning disability nurse in **'Vernon 1'** is constructed largely around the twin concepts of 'health surveillance' and 'health promotion', with the central purpose being presented as helping people with learning disabilities overcome 'obstacles to health' that they face. The obstacles they face are depicted as intrinsic, in the form of biological, psychological and social functioning deficits. Strong biomedical, psychological and sociological forms of 'empiricist repertoire' are drawn upon to establish the 'reality' of these deficits, and the vulnerability to which they give rise. The use of empiricist repertoires works strongly to establish the 'facticity' of the problem, setting up by implication too, an imperative for the existence of a specialist profession to respond to this 'real' need. The concept of 'vulnerability' also works in a moralistic way however, conveying the implication that to not respond is, in effect, to abandon, a vulnerable group. All of this works rhetorically then to set up a powerful material and moral case for the existence of a specialist learning disability nursing profession.

In the Gates and Beacock (1998) book, *Dimensions of Learning Disability,* from which the next two texts **'Vernon 2'** and **'Wake'** are drawn, we saw that the stated purpose was, explicitly, to clarify the 'vital role' of learning disability nursing. In their introductory notes the editors stress the need for learning disability nurses to promote their 'unique knowledge and skills', an aim they seek to achieve by placing learning disability "...firmly on the health agenda", and focussing on what are described as the 'various dimensions influencing health and well-being'. These include 'biological, psychological, educational, cultural and spiritual, and political dimensions'. This book can be seen therefore to constitute a further, and broader, elaboration and consolidation of the discourse initiated in **'Vernon 1'**. A more 'offensive' action orientation is adopted in this book, however, with an explicit aim being to establish, and 'factualise', the notion of health as *the* central concept which should underpin care provision for people with learning disabilities. Nursing is presented as 'crucial' in this service provision, but it is also presented as needing to articulate its 'unique' role and identity further, and the editors of this book clearly identify themselves as taking on that task.

An example of how the discourse of health is being elaborated upon still further in Gates and Beacock (1998) can be seen in the organisation of the books contents, where, as in Gates (1997) health is given a prescient place, although the contents list in this book covers a considerably broader range of topics and issues. In the foreword John Turnball, one of the authors of the *Continuing the Commitment* document identifies 'health' as the central concept in the field. This statement, written by the then 'chief' learning disability nurse, obviously provides a significant official endorsement for the book itself, and the project of identifying 'health' as the central organising concept, both for the learning disability field generally, and the learning disability nursing profession in particular. Turnball also directly links this focus to the policy agenda established by the *'Better Services'* White Paper (DoHSS 1971), and thus as part of the 'progressive' ideological project officially initiated in that document, of integrating people with learning disabilities into mainstream society. Subsequently, in their own preface, the editors state that "… [C]entral to this book is the idea that one way to understand learning disability is to portray it as a complex state of health…" a 'state' comprised of the various dimensions that are identified in the contents, and which the book is designed to 'allow people to explore'. The section on health in particular is presented as an attempt to articulate "…the role of the nurse in bringing about health maintenance and/or gain," as advocated by 'leading nurse theorists'. The preface concludes with what can be seen as a rhetorically 'offensive' assertion that…. "[T]his is clearly a book that attempts to place learning disabilities firmly back on the agenda of health." Thus we can see a clear rhetorical assertion of the project underpinning this book; to reclaim learning disability for the 'health' agenda, with the clear implication that the reason this is necessary is to avoid the 'dangerous' and 'inaccurate' division of the health and social care agendas. The editors are thus asserting that their emphasis on health is actually a defence of people with learning disabilities from the potential 'dangers' of the policy direction initiated by the *NHS and Community Care Act* 1990. The Gates and Beacock (1998) book can be seen then, in this light, to be an overt attempt by leading academics within the learning disability nursing profession in the immediate post *Continuing the Commitment* era to place health back at the centre of the learning disability agenda in defiance of a political shift away from such an emphasis.

The brief introduction in the book to the two chapters in this book analysed in this study presents health as a 'fundamental' and 'elemental' concept, establishing it as the foundation upon which all that follows is constructed. Of the two chapters themselves, **'Vernon 2'** is constructed primarily around a detailed and elaborate exploration of models and theories of health, with the biomedical and humanistic models in particular being presented as the most relevant. These models are both identified as being 'scientific' and 'rationalistic', the implication being that this is a condition for being considered seriously. The subsequent discussion then sets out a case for choosing the humanistic over the biomedical as the model of choice, to avoid the 'oppressive' role and legacy of the latter in the history of services, and because if its overemphasis on deficit and impairment. This can be seen as a further elaboration of the argument made in **'Vernon 1'**, which firmly seeks to establish a distance between a humanistic model of health and the oppressive institutional history of services. Support for this argument is drawn in the text from Maslow, a major theorist of humanistic psychology, and O'Brien, one of the main American theorists of Normalisation philosophy. This can be seen as a process of authoritative validation and consensus building, used to construct a rational and empirically founded basis for the case being made, whilst at the same time establishing a moral congruence with the influential normalisation agenda.

The rest of **'Vernon 2'** involves a discussion of physiological and psychological aspects of health, constructed around the concept of 'homeostasis'. Health is described as an issue of 'achieving and maintaining balance', with people with learning disabilities presented as vulnerable to disruptions of a healthy equilibrium. Homeostasis is used in relation to psychological and social, as well as physiological aspects of health. The necessary response to this is set up as 'carers' who understand these concepts and the problems people with learning disabilities face, and who are able to work to restore and maintain balance in all aspects of people's lives.

We saw also how **'Wake'** picks up the theme of homeostasis in the following chapter. Here, the emphasis is on 'threats to homeostasis' from the external environment, with social, economic and environmental factors all identified as important factors interacting with the physiological and psychological vulnerability of people with learning disabilities. One external factor identified as of particularly significance is the 'attitudes of service staff'. An 'inadequacy' of knowledge and awareness of the health problems and issues facing people with learning disabilities among generic health professionals is emphasised as a particular problem.

So we can see that the three major themes of the discourse originally established in **'Vernon 1'** are further elaborated and developed in these two texts. In **'Vernon 2'** the holistic and humanistic model of health is thoroughly and elaborately constructed as the most appropriate model to apply to people with learning disabilities. Subsequently, 'homeostasis' a key biological concept is used to give scientific weight to the construction of the vulnerability of people with learning disabilities to the development of both physiological and psychological health problems. This concept is taken up and used further in **'Wake'**, where the added problem of the lack of knowledge and awareness of generic health and social care staff is added as a factor exacerbating this vulnerability. Once again, a moral dimension is added in these texts, particularly with the assertion in **'Wake'** that it should be the 'right' of people with learning disabilities to access specialist, as well as generic health care. Thus, as in **'Vernon 1'** empiricist and moralist repertoires are drawn upon and used to lay strong claim to 'facticity' and 'moral' authority.

In the third book, Thompson and Mathias's (1998) *Standards and Learning Disability* we saw a different approach being taken to the presentation of the field of learning disability, even though it was produced at the same time as Gates and Beacock (1998). In this book health is presented as an 'aspect' of the lives of people with learning disabilities to which services need to 'respond', rather than as *the* fundamental concept upon which our understanding of learning disability needs to be based. In contrast to Gates (1997), and Gates and Beacock (1998), where 'health' is given centrality as a concept, health is here presented as just one among a range of issues that need to be addressed in order to support people with learning disabilities to live in the community.

The original edition of this book, *Standards and Mental Handicap* (1992) was published just after enactment of the *NHS and Community Care Act* (DOH 1990), and was constructed in response to that legislation. Indeed, that first edition advertised itself as a means for nursing and social work students (some of whom were undertaking 'joint' training in the learning disability field at that time) to make sense of the implications of that legislation, outlining, as stated in the cover notes; 'changes in policy, competencies required for those working in the field, requirements of professionals working in a multi-racial society, and continuing professional development'. Thus the focus of this book is more on explicating the nature and organisation of services, than on the nature of learning disability as such. Accordingly, much of the language and content is constructed using 'managerial' and 'consumerist' repertoires, reflecting the developing importance of those ideologies in the British welfare state during the 1980s. This emphasis continues in the 2nd edition of the book from which the, **'Barr'**, text is drawn. This edition, however, is explicitly constructed in response to more recent policy documents, particularly *The Health of the Nation: A Strategy for people with Learning Disabilities* (DoH 1995), and *Continuing the Commitment* (DoH 1995), with the topic of 'health' being presented as a new addition.

In **'Barr'**, it will be remembered, we saw another elaborate discussion of models and theories of health similar to those presented in **'Vernon 1'** and **'Vernon 2'**. Models of health based on the use of 'diagnostic tests' and 'measurement of ability' are rejected as problematic for people with learning disabilities in **'Barr'** because they are deemed to equate deficits in intellect and social functioning with ill health. So we can see that a medical model of health is rejected, and presented as likely to promote 'negative expectations' about the health of people with learning disabilities. Instead we see the presentation of 'positive' models of health, such as those of Naidoo and Wills (1994), and Seedhouse (1986), as those to which we need to aspire in working with this client group. Seedhouses' model in particular is cited with approval, because it allows people with learning disabilities to be thought of as healthy, regardless of the presence of physical or intellectual 'disabilities'.

The 'vulnerability' of people with learning disabilities to the development of health problems is implied, rather than specifically elaborated upon in **'Barr'**, but it is presented as an important factor necessitating the need for health promotion with this population. The rest of the text is constructed around an elaborate outline and discussion of various models of health promotion relating to people with learning disabilities, an emphasis that fits neatly, of course, with the agenda of *The Health of the Nation: A Strategy for People with Learning Disabilities* (DoH 1995), and which also echoes strongly the health promotion emphasis in the role of the learning disability nurse elaborated in *Continuing the Commitment* (DoH 1995).

The theme of the 'inadequacy' of generic health services looms large in **'Barr'**, with generic health promotion services and strategies, in particular, presented as largely inaccessible to, and thus unusable by, people with learning disabilities. Reasons presented for this are given as including certain characteristics of people with learning disabilities themselves, such as communication problems and 'challenging behaviours', and also the fact that generic health service staff lack the skills and awareness needed to develop and adapt health promotion strategies appropriately for this client group. A 'critical challenge' presented here is the need to overcome the assumption that generic health service staff may hold to that negative changes in behaviour and health are automatically linked to an individuals' learning disability. Learning disability nurses are presented as an important resource for generic services because of their specialist knowledge of health issues and problems faced by this group.

In **'Barr'** we saw how an 'empiricist repertoire' was drawn upon in relation to both the extensive discussions of models of health, and the presentation of various strategies of health promotion. A powerful 'moral repertoire' is also apparent, with a strong sense of 'social' and 'service' responsibility invoked for the health and welfare of this 'vulnerable' group. Thus, a failure to address this issue in the way advocated is presented, by implication, as a failure to meet these moral responsibilities.

We can see then, that, in the first four texts analysed, all produced in the period 1997/1998, the discourse of health is constructed in ways that elaborate upon themes first established in *Continuing the Commitment* (DoH 1995), and which align with the policy agenda set out in *The Health of the Nation: A Strategy for People with Learning Disabilities* (DoH 1995). The period after the publication of *the Health of the Nation: A Strategy for People with Learning Disabilities* (DoH 1995), and *Continuing the Commitment* (DoH 1995) saw a further series of policy statements and guidelines from the Department of Health, the NHS Executive, and other governing bodies in the NHS, as well as various health care professions, all aimed at improving practice and performance in responding to the health needs of people with learning disabilities. For example, in 1999 guidelines were circulated (NHSE 1999) which sought to highlight to GPs that, in a list of 2000 patients 40 would be likely to have a learning disability, eight of which could be expected to have severe learning disabilities. Such guidelines, issued alongside other initiatives which sought to make people with learning disabilities and their carers more aware of their own needs and rights, such as *The Patients Charter and You* (Hull and Holderness Community Health NHS Trust, 1995), *The OK Health Check* (Mathews, 1997), *Feeling Poorly* (Dodd and Brunker, 1998), *Getting Better* (Band, 1998), *The Healthy Way* (DoH, 1998), and the *Your Good Health* series (BILD, 1997), were being delivered against a wider policy backdrop which increasingly emphasised the rights of, and need for, people with learning disabilities to access generic health care services, rather than be cared for entirely within specialist service settings.

The emphasis on people with learning disabilities accessing generic health care services had been present in *The Health of the Nation; A Strategy for People with Learning Disabilities* (DoH, 1995), the last major policy statement relating to people with learning disabilities to emerge from the outgoing Conservative government. It was also emphasised strongly in *Signposts for Success in Commissioning and Providing Health Services for People with Learning Disabilities* (NHSE, 1998), the first major policy statement relating to people with learning disabilities to emerge under the auspices of the incoming 'New Labour' government elected in 1997. Despite this apparent continuity, this document marked, as we saw in chapter 3, the beginning of a subtle shift of ideological emphasis in policy, however, in that it gave greater recognition to the idea that the inadequacy of healthcare provision for people with learning disabilities was an issue of 'inequality', reflecting their status as a socially excluded group in society; something not explicitly acknowledged in the preceding Conservative health agenda.

This shift was reflected strongly also in the emphasis of the new White Paper, *Valuing People: A New Strategy for People with Learning Disabilities for the 21st Century* (DoH 2001), on 'integration' and the rights of people with learning disabilities. This document, the first White Paper relating to people with learning disabilities since *Better Services* (DHSS, 1971), can be seen as further pursuing the community care agenda initiated in that earlier document, whilst at the same time drawing services for people with learning disabilities into a broader policy agenda aimed at eradicating 'social exclusion'. Published a decade after *The NHS and Community Care Act* (DoH 1990), it can be seen also as an attempt to address some of the perceived shortcomings of community care policy, including inequalities and inadequacies in healthcare provision. The White Paper sets out an agenda dominated by the pursuit of the ideal of social integration, and based on four key principles of 'Rights', 'Independence', 'Choice', and 'Inclusion'. Included as a priority in this agenda are targets for health screening for people with learning disabilities, the universal registration of all people with learning disabilities with GPs, the development of 'Health Action Plans' for all people with learning disabilities by 2005, and the designation of 'health facilitators' to manage and monitor these developments. Learning disability nurses are specifically identified as the professional's best placed to take on this health facilitation role.

It is this agenda that provides the context for the **'Hart'** text in *Learning Disabilities: Towards: Integration* Gates (2003). It will be remembered that in the cover notes of this book we found a narrative which described the learning disability nursing profession as 'successfully negotiating change and uncertainty'. Learning disability nurses are described as having skills applicable in a variety of roles and settings within services, although the roles mentioned, which include 'care management' and 'assessment officers' might be seen as contentious, with other professions, such as social workers, laying jurisdictional claim to them as well. The book is organised in close relation to the '*Valuing People*' agenda, the most obvious difference from the previous books being that 'integration' has replaced 'health' as the fundamental concept around which it is constructed. Thus we can see that, as the integrationist agenda has become dominant 'health' has increasingly come to be addressed as an aspect of, rather that the central organising concept, in the learning disability field. This can be seen also, therefore, as the final demise of the attempt by learning disability nurse theorists to reclaim health as the foundational concept; an attempt which, as we saw, reached its zenith in Gates and Beacock (1998).

In the **'Hart'** text we saw a significant change of emphasis. 'Health' and 'health promotion' are both presented as important and valuable concepts in relation to people with learning disabilities, although there is no in-depth discussion of the meaning of health as in previous texts. Rather the dominant theme that is quickly established is that of the inadequacy of generic services, and particularly, the 'dissatisfaction' of people with learning disabilities about their treatment at the hands of generic health services. Indeed, the impression created is one of a looming crisis, as emphasis is given to the increased demands on the health service likely to be made by an ageing population of people with learning disabilities. The emphasis on the term 'dissatisfaction', however, represents a shift in the way this theme is presented. Whereas in earlier texts the 'inadequacy' argument had been made using an 'empiricist repertoire', with screening, survey and epidemiological evidence being cited to back the case, in **'Hart'** we see a 'consumerist repertoire' being drawn upon instead. Here, the voices of people with learning disabilities as consumers is given emphasis through the reportage of the authors own qualitative research on the experience of people with learning disabilities receiving health care. This works to construct a powerful critique of NHS provision for people with learning disabilities, given extra potency for apparently being validated by the views of the client group themselves. Thus a powerful variation of the 'facticity' of the problematisation of the response of generic health services is constructed, and the role of the learning disability nurse is constructed, as a result, almost entirely in relation to the issue of helping people with learning disabilities to access generic health care: the 'Health Facilitation' role. This role is worked up strongly in **'Hart'** , with a critical tone being adopted for learning disability nurses who may be reluctant to work in line with 'positive current ideologies'. Although there is clearly a very close echoing of policy developments in the way this argument is constructed, **'Hart'** does not invoke policy, so much as a 'moral imperative' to address 'essential' and 'unmet' health needs of people with learning disabilities.

Thus, we can see in **'Hart'** a similar rhetorical strategy to the other four texts in which a powerful mix of material and moral repertoires is invoked to assert the necessity for reconstructing role of the learning disability nurse as a 'health facilitator'. The emphasis varies - but the rhetorical strategy remains in unity with the previously published texts; a unity of strategy that suggests also a unity of rhetorical purpose. This unity of purpose can be identified as an attempt over the past decade, by those whose role it is to 'textualise' learning disability nursing through the medium of pedagogical texts, presenting the essential, 'state of the art' theory and knowledge of the profession, to establish, what Abbott (1998) has termed, a 'jursidictional claim' for the profession over the area of the 'health' of people with learning disabilities.

This then is the main explanatory conclusion of our analysis; that the emergence of the discourse of health in learning disability nursing textbooks at this time and in this form should be seen as an historically and politically determined event, representing a significant element in the learning disability nursing professions' response to external ideological and structural pressures, manifested through the developing policy agenda, that have come to threaten its existence over the past decade. Our analysis shows then that this discourse needs to be read as something more significant than a supposedly 'neutral mapping' of a material phenomena. Rather, these texts and the discourse they constitute, are acting to establish a strong 'jurisdictional claim', of over the areas of health related work with people with learning disabilities.

Abbott (1998) argues that, for a profession to be able to prosper and survive, its theorists need to be able to identify, and stake a legitimate claim to some area of work widely perceived to be of real instrumental value in the cultural and structural context in which it operates. Our analysis illustrates that it is exactly this kind of claim that the discourse of health in these texts has been developed to support. The claim has been made, sometimes explicitly, but predominantly by the subtle construction of what Potter (1998) has termed, 'category entitlement'; that is, an assertion of natural, or 'organic' epistemological rights over this particular area of work by virtue of the apparent 'natural fit' between this phenomena and the natural existential territory of nursing. In doing so the authors of these texts have replaced a jurisdictional claim for learning disability nursing based on vague historical precedent, with a much more powerful, particularised claim, based on strong, culturally embedded assumptions about the nature of modern nursing as a scientifically based, and morally motivated, 'health' focussed profession. We can see this even more clearly if we return to the historical narrative begun in Chapter 2, and see how the emergence of the discourse of health fits into the broader historical picture.

Situating The Discourse of Health in the Historical Narrative of Learning Disability Nursing:

We have seen then, that the origins of the discourse of health can be located in the *Continuing the Commitment* document (DoH, 1995) . Central to the purpose of the *Continuing the Commitment* project was the specification of those areas of work to which learning disability nurses could, and should, lay particular claim. We have also seen that the necessity and impetus for making these jurisdictional claims arose from market oriented changes in the organisation of the UK welfare state instigated by Conservative governments in the 1980s, particularly the *NHS and Community Care Act* (DoH 1990); changes which shifted the ground under the feet of the profession in a significant way.

For example, Social Service departments, in their new role as purchasers in the newly established 'quasi' market system, were directed to use the private and voluntary sector to provide services for people with learning disabilities that had previously been provided by the NHS. These non-NHS service providers were placed under no obligation to use learning disability nurses in the same roles, as the NHS. Although learning disability nurses, and the skills and knowledge they possessed, were (and still are) often sought after by these organisations, they nonetheless came to be seen as an expensive option compared with staff trained 'on the job' through newly emergent vocational training schemes such as National Vocational Qualifications (NVQs). This was an especially significant factor for service managers who now faced pressure to keep costs down to win and maintain service contracts.

These problems for the learning disability nursing profession were exacerbated still further by the strict division established in the community care system between 'health' and 'social' care. Much of the work done by learning disability nurses in the early days of the shift to community care came to be classified subsequently as 'social' rather than 'health' care. And, even where learning disability nurses were employed by 'social care' agencies to do work very similar to that which they had been performing previously in the NHS, they were not, under legislative restrictions, allowed to do so as a 'nurse'; a situation that led many to question the value of continuing to register as nurses at all (Turnball, 2004).

It was, as we saw in Chapter 2, in response to pressures such as these that the *Continuing the Commitment* project was instigated from within the Department of Health. The publication of that document marked, therefore, a significant moment in the history of the learning disability nursing profession, namely, the first comprehensive attempt in its roughly 100 year history to construct its own role and identity. Up to the advent of the shift to community care in the 1980s, the role and identity of the profession that evolved into learning disability nursing had been largely defined for it by the psycho-medical elites that dominated service institutions and planning, and who defined the phenomena known variously as 'mental deficiency', 'mental handicap' and 'mental retardation', via a discourse of pathology in which it was presented and responded to as a form of illness. As we saw in Chapter 2, the mid 20th century saw the undermining of this discourse, and the institutions built upon it, as psychiatric medicine was forced on the defensive across the western world by the emergence of radical critiques from which new discourses, built upon social scientific, educational theories, and political theory emerged. The normalisation philosophies of Nirje (1970) and Wolfensberger (1975), the influence of which swept across 'mental retardation' services in western Europe, north America and Australia from the late 1960s onwards, are an example. In the UK 'mental handicap', as it was by then known, was redefined as 'learning disability'; a term given official sanction for the first time in the *NHS and Community Care Act* (DoH 1990). As a result, the emphasis in the learning disability field shifted from a medical model built around concepts such as 'treatment' and 'care', to a psycho-social discourse emphasising concepts such as 'growth',' development' and 'empowerment'.

We also saw how, after some early resistance, many learning disability nurses came to embrace these developments, taking on ideas and concepts from developmental, humanistic and behavioural psychology as their essential knowledge base, and adopting Wolfensbergers' version of normalisation philosophy, subsequently renamed 'Social Role Valorisation' or 'SRV' (Wolfensberger, 1983), as a nursing model. What many learning disability nurses (amongst others) apparently failed to perceive, however, was that, what was at work in the emergence of community care policy was not a single, unified, progressive ideology sympathetic to the principles of normalisation philosophy, but a subtle interplay between competing ideologies struggling for dominance. Whereas advocates and theorists of normalisation philosophy emphasised arguments for the deinstitutionalisation of people with learning disabilities from an ideological platform of human rights, drawing upon evidence from the social and behavioural sciences to reinforce their case, the structural changes wrought in the UK welfare state during the 1980s were actually driven by a neo-conservative, or 'new right' ideological agenda, concerned primarily with promoting managerial and fiscal discipline, and the privatisation of services for people with long term care needs. This policy agenda was in line with a broader ideological programme determined to reduce the size and role of the state in welfare provision, and push responsibility for long term care onto the family wherever possible, whilst simultaneously expanding the role of the private and voluntary sector in service delivery (Drake, 1999).

The political and theoretical leadership of the learning disability nursing profession found themselves then, in the early 1990s, in the position of having to choose between a 'health', or a 'social care' orientated role. They then had to explicate that role and identity to a potentially sceptical audience of service managers and purchasers, and also to the profession itself, many of whom were occupied in roles that had changed only in setting, from large institutions to community based group homes, rather than in the nature of the work in which they engaged. That was what *Continuing the Commitment* set out to achieve, identifying the distinctive role of learning disability nurses as working to promote the 'health' of people with learning disabilities. The health focused emphasis of *Continuing the Commitment* can be seen, therefore, to be a politically driven attempt to align the role and identity of the learning disability nursing profession with the contemporary emphasis of the government of the days' health policy agenda for this client group.

Although the idea of health as a central concept in learning disability nursing had been raised in one or two earlier documents (e.g. All Wales Nursing Group 1992., RCN 1994), it was in *Continuing the Commitment* (DoH 1995) that the articulation of the role and identity of the learning disability nurse attached firmly to the concept of 'health', and aligned solidly with the wider nursing profession, properly emerged. There is a particularly strong assertion that the role of learning disability nurses should centre on 'health promotion', 'health education' and 'health surveillance'; the very roles specified as essential in *The Health of the Nation: A Strategy for People with Learning Disabilities* (DoH 1995).

That policy document, published contemporaneously with *Continuing the Commitment,* was the government of the days' response to a growing body of research in the 1980s and 1990s which appeared to show serious deficits in healthcare provision for people with learning disabilities living in the community. A number of research based reports described how the desired integration of people with learning disabilities into the use of generic, primary and other community health care services was either not happening, or happening only sporadically (e.g. Greenhaulgh, 1994, Mencap, 1997). For the political and theoretical leadership of the learning disability nursing profession this body of research provided both an important opportunity, and a legitimising rationale, and the health focussed role set out in *Continuing the Commitment* is presented thus, as a response to 'unmet health need', and the identification of 'additional risk' of health problems among people with learning disabilities. The texts under analysis in this study can be seen to constitute an elaboration, extension and consolidation of this rationale, constructing health as an issue of significant material and moral importance in service provision for people with learning disabilities, and, in doing so, laying the basis for a 'jurisdictional claim' over this area of work for learning disability nurses.

Conclusion:

In this Chapter we have completed the third and final phase of our analysis, which has involved exploring the questions 'why' the discourse of health analysed in these texts emerged at this time, and in the form in which it did. This exploration involved a summarising discussion of the findings of the earlier stages of analysis. We returned to look at the individual texts, and the textbooks in which they are situated, in their chronological order of publication, and explored how their form and content can be related to ideological and policy developments over the period of their publication. We then returned to link up with the historical narrative begun in Chapter 2 and concluded with an explanation of the way in which the emergence of the discourse of health was related to the strategy underlying the 'jurisdictional' struggles in which the profession was engaged during this period.

This explanatory phase of analysis then clarifies the primary purpose behind the emergance of the discourse of health in these texts, and the form in which it has been constructed. We can see that the primary task has been to elaborate upon, 'factualise', and give empirical and moral substance to the identification of health as the primary focus of the learning disability nursing profession that was set out in *Continuing the Commitment* (DoH 1995). At its most potent, this has taken the shape of a 'biologisation' of the health of people with learning disabilities in a form which comes close to the forms of 'pathologisation' of disability that are located as lying at the root of oppressive professional discourse identified by proponents of social model influenced critiques (Rapley, 2004). This tendency runs counter to more or less explcit claims within the texts to be creating a distance from an oppressive 'medical model' of health. The promotion of a 'humanistic' model of health that embraces the psychological and social domains of being is presented throughout as a shift towards a 'non-oppressive' model of health, distinct and distanced from a 'medical model'. Thus we see an uncritical stance taken towards 'non-medical models' of health that some commentators (e.g. Gestaldo, 1997) see as representative of a shift among health professions across the developed world, as they seek to reposition themselves in health care systems increasingly orientated towards preventative, rather than curative, interventions – evidenced by the growth of concepts such as 'health promotion' and 'health suviellance'. In the discourse of health analysed here we can see that the twin concepts of 'vulnerability' and 'pathology' still loom large however, and a good deal of the texts are given over to establishing the 'constitutional' vulnerability of people with learning disabilities in a way that constructs something very close to a 'pathologised identity' for them. Thus we can see that, even with a shift towards a 'non-medical' model of health, the 'biologisation' of the health of people with learning disabilities remains central in the construction of their particular vulnerability.

A social model of disability perspective might well interpret this as an attempt by theorists of the learning disability nursing profession to manitain their colonisation of the lives of people with learning diabilities, seeking legitimacy to maintain control over significant and intimate aspects of their lives by appealing to that most powerful, enduring and authoritative of repertoires – the discourse of biology; a version of what

Boyle (1999 – cited in Rapley 2004) describes as "…the appropriation of the language of medicine (with all the supposed scientificty that goes with it) …that the psy professions have assumed [to claim] authority over the management and control of those who, in one way or another, trouble the social order" (Page 43). An examination of this argument will form a significant part of our discuss of the findings of our analysis in the final chapter which follows.

CHAPTER 8

Discussion – Discourse and the Construction of Professional Identity in Learning Disability Nursing

Introduction:

In this chapter we will conclude our study by discussing the findings of our analysis in relation to relevant critical theory relating to the role and identity of the caring professions. We will begin by discussing some of the main critiques of those professions, paying particular attention to those emerging from theorists of the 'social model of disability' who have fundamentally challenged their nature and practice in relation to disabled people from a predominantly 'materialist' perspective. We will also refer to critiques made from 'idealist' perspectives, such as those that underpinned normalisation philosophy, before looking specifically at the work McKnight (1992) which combines 'materialist' and 'idealist' perspectives in a critique which, we feel, is particularly useful is seeking understand the discursive strategy adopted by leading theorists of the learning disability nursing profession analysed in this study. Finally, we will conclude with a discussion about the implications raised by this discussion about whether this profession can continue to contribute to the ongoing project of the emancipation of people with learning disabilities, and what it needs to do to achieve this. Firstly then, let us look at some of the main critiques of the caring professions that have emerged since the iconoclastic era of the 1960's.

Critiques of the Caring Professions:

As we saw in Chapter 1, the critique of the caring professions offered by theorists of the social model of disability can been seen as a relatively recent manifestation of a wave of critical theory applied to the role of health and social care professionals that emerged from the 1960s onwards. Although there are variations, a primary argument of social model theorists is that the caring professions are parasitic in nature, constructing bodies of knowledge and expertise based, not on the lived experience of disabled people, but on discourses derived predominantly from a bio-medical conceptualization of disability; discourses that contain assumptions equating disability with disease, deficit, tragedy and abnormality, amounting to an all embracing pathologisation (e.g. Oliver 1990, Morris, 1998, French and Swain 2001). This pathological conceptualisation of disability is then used to underpin forms of professional practice, or 'care', which deprive disabled people of control and influence over what happens to them, whilst at the same time holding up their entire lives for scrutiny as they are objectified as 'cases' (Gillman, Swain and Hayman 1997). Viewed from this perspective, the learning disability nursing profession can be characterized as part of an oppressive state response to the social construct of 'learning disability', playing a largely oppressive and controlling role in the lives of people with learning disabilities. In fact, it could even be argued that the profession is no more than a structural and institutional manifestation of a bio-medical discourse of learning disability in action.

One merit of this kind of critical perspective is the way it brings into view the ideological nature of professions, highlighting the fact that they are engaged in politically, as well as rationally motivated projects; a point emphasized heavily by social model theorists who see these professions as motivated by primarily material concerns. Oliver (1996), for example, in developing an argument similar to that of Johnson (1972), uses the concept of 'hegemony', drawn from the work of the Italian Marxist social theorist Antonio Gramsci, to describe the pervasive influence of the medical model of disability over health, welfare, and even educational service provision for disabled people. Oliver's argument is that 'medical hegemony' is an ideological manifestation of the 'creation of disablement' which he identifies as a feature of industrial societies. Underpinning this view is a materialist argument; that the caring professions, despite claims to the contrary, act in ways which serve their own material interests above and beyond any professed concern for their client groups.

A weakness of these 'parasite' theories of the caring professions, however, is a failure either to recognise, or properly account for, the idealistic motivations of many who choose to work in these professions. Such critiques tend to either ignore, or bypass discussion of, the pursuit of idealistic and emancipatory practice by caring professionals, such as the role of medical professionals like Bank-Mikkelson (1980), Nirje (1970) and Wolfensberger (1972), in developing the normalisation philosophies that has underpinned the deinstitutionalisation movement in North America and Europe in recent decades for example. Similarly, analysis of the history of the learning disability nursing profession, such as that conducted by Mitchell (2000a., and 2002), shows that, although there have been episodes of reaction in defence of institutional and medicalised models of service provision, there have also been periods of progressive radicalism, in pursuit of those same ideals of normalisation philosophy in the 1980s, for example. The 'parasite' critique also tends to treat the caring professions as rather too homogenous, ignoring that fact, as Marks (1999) has pointed out, not all professions have the same degree of power and influence within society or service systems. Indeed, some, such as nurses, though they may receive a high degree of social approval, have relatively little power within service hierarchies. Indeed, Mitchell (2000b) has argued that learning disability nurses have often been as subject to, if not as seriously marginalised by, oppressive ideological systems as people with learning disabilities themselves; although such a claim might ring rather hollow to someone whose life has been lived out subject to institutional, and sometimes more direct forms of abuse at the hands of nurses!

One critique that has embraced this ‘idealist’ dimension in its analysis of the role of caring professions, however, is that developed by McKnight (1992). Writing in a North American context, McKnight identified the macroeconomic importance of the growth of ‘human services’ in post-industrial, societies where an increasingly large proportion of gross national product is related to, and reliant upon, their provision; so much so in his view that he describes them as ‘serviced societies’. A similar argument has indeed been advanced by Wolfensberger (1991). He says… “[T]his kind of society needs unproductive types of employment in order to circulate wealth, and one of these types of employment happens to be human services. ……..[T]he very service system that is supposed to be curative, therapeutic and habitational actually services the unconscious societal function of increasing, or at least maintaining a certain needed – and in our case large – percentage of the population in a state of dependency” (pp10-11). Echoing a critique of psychiatric medicine developed by Szaz (1977), Wolfensberger argues that human service professions thus actually ‘manufacture’ client groups in ‘need’ of care; client ‘need’ being defined by professionals requiring raw materials and markets in which to earn their living.

In its interpretation of the significance of material and economic influences then, this sort of critique is not dissimilar to that advanced by social model theorists such as Oliver. McKnight’s critique moves beyond economic determinism however, and introduces a ‘constructionist’ dimension, describing the construction of professional consciousness and its expression in ideologically and culturally authoritative linguistic forms, or discourses. These discourses undoubtedly serve a material purpose, acting as rhetorical weapons in, what Abbott (1998) has characterized as the ‘jurisdictional struggles’ engaged in by professions over ownership of particular areas of work. They also act, as we saw in the conclusion to the previous chapter, as important markers of cultural and ideological legitimacy within the wider social and political context.

To clarify this argument further, it is useful to illustrate the way McKnight (1992) explores the interplay of the material and the idealistic; and a particularly good illustration is his analysis of the use of the term ‘care’ by human service professions. ‘Care’, he asserts, is symbolic of the ‘expression of love’, and frequently underlies the individual and collective expression of values offered by human service professionals for choosing to do the work they do. McKnight points out that the use of such symbolism can serve to conceal underlying political and material interests. As he puts it, “…the politico-economic issues of services are hidden behind the mask of love” (p73). He is at pains also to point out that this 'mask' should not be viewed as a 'false face', however, and that he is not implying hypocrisy or conspiracy, and he continues… "[T]he modern servicer believes in his care and love, perhaps more than the serviced. The mask is the face" (p73). In this analysis then, can see then that such an emphasis on 'care' works powerfully to construct a link to wider culturally valued and authoritative moral discourses, and in this way a 'moral authority' is accrued by its use. However, the means by which 'care' is delivered by professions in service systems is elevated beyond the status of a purely moral project by the use of techniques and technologies, which are presented as the application of 'science' and 'scientific know how'.

Edwards (2001) has pointed out that 'science' is one of the most culturally and politically potent discourses of all, and one to which nursing has increasingly aligned itself in recent decades in order to gain cultural and political legitimacy. In the learning disability field specifically, Nunkoosing (2000) has identified how science provides the ideal model for the 'expertise' of the professional in relation to people with learning disabilities. Components of a scientific discourse include classification systems, description and categorization of affected individuals, diagnosis of their problems, and the knowledgeable, rational and skilled application of therapeutic responses. It is in the power of this scientific rationality, McKnight argues, that the control of caring professions over their clients becomes complete, as the power of the professional becomes that of the scientifically informed expert. The client, in contrast, is relegated in their capacity as a competent judge of their own condition and situation, and areas of their lives that they might otherwise address as citizens within the socio-political sphere become transformed into technical problems with technological fixes. Marks (1999) has called this process 'epistemic invalidation', where scientifically validated professional discourse is so privileged as to invalidate alternative accounts, especially those of a personal and subjective nature, which are deemed unscientific.

In this way, it has been suggested by Nunkoosing (2000), the lives of people with learning disabilities have become 'colonized' by the caring professions. McKnight (1992), advances a similar argument when he describes the effects of the way that the scientifically identified and categorized problem experienced by individuals become 'encoded' into a language comprehensible only to the professional expert and the expert community to which they belong. A major effect of this, he argues, is to mystify both the problem and its solution to the extent that client, or lay, evaluation becomes virtually impossible. It also means the potential for a dialogue with clients about service goals and outcomes is reduced in importance to a level which does not threaten the dominance and authority of the professional expert. This is particularly the case where the location of the clients 'problem' is the mind itself, as is the case with people with learning disabilities. The mind/brain is seen in western culture as the seat of the autonomous self, personal individuality, and, above all, rationality. This conceptualization of the self is a foundation of much of the western tradition of scientific psychology which, as Rose (1985) has shown, has traditionally been used to set the standards against which aberrations from behavioral normality are measured. From this perspective, the self is characterized as self-contained, self-reliant, unique, separate, consistent and private (Wetherell and Maybin, 1997). To experience impairment of the mind/brain, then, is to be seen to lose all, or at least, a critical part, of the self, and the consequent access to autonomy and independence that goes with it.

People with learning disabilities are still viewed, then, predominantly through a 'professional gaze' (to adapt a phrase from Foucault 1973) which constructs their identity, more or less unconsciously, according to the perspective of authoritative professional groups. The medium by which this construction occurs is authoritative, scientifically and politically legitimated discourses; a strong version of what Potter (1998) has described as the construction of 'facticity', which serves simultaneously to invalidate people with learning disabilities own attempts to name and speak their own lives and realities (Nunkoosing 2000).

So where does this place the discourse of health analyzed in this study, and should it be seen primarily as a part of a materially motivated attempt to defend the interests of the learning disability nursing profession? A 'McKnight style' analysis suggests that, although the 'material' interests of the profession may have been highly significant in governing the timing of the emergence of the discourse, as the leadership of the learning disability nursing profession sought to reposition it in response to structural and political changes in the UK welfare state, the 'idealistic' dimension should not be ignored or dismissed, and can be seen to be significant in shaping the way in which the discourse has been constructed. For instance, the elaborate definitional arguments aimed at promoting an alignment with a 'holistic/humanistic' model of health that is a major theme across the texts, suggests a particular concern to establish a distance from a medical, disease related model of health, and a pathological view of learning disability. Thus, it could be argued that, in form at least, the discourse can be seen as resisting, rather than promoting a pathological homogenization of people with learning disabilities. We have also seen, however, that such a view is based on a largely uncritical view of 'non-medical' models of health, portraying them as inherently non-oppressive.The assumption that this is the case underpins the promotion of this idea throughout the texts analysed in this study. As we noted in the conclusion of Chapter 7, however, the vulnerability of people with learning disabilities is nonetheless constructed with a strong emphasis on biological ideas and concepts - a process we described as 'biologisation'. We also noted that this process is most understandable as a strategy designed to give maximum weight to the claim of 'facticity' for the 'constitutional vulnerability' of people with learning disabilities, and that this could well be seen, from a social model of disability perspective, as an attempt by a profession whose 'natural dominion' over their client group has been brought into question, to maintain their position.

Nunkoosing (2000) has pointed out that in order to justify the existence of specialist health professions, the health of people with learning disabilities has to be presented as abnormally problematic in some way. This is achieved in this discourse, as we have seen, by the problematisation of health, firstly as an issue of vulnerability in people with learning disabilities, and, secondly as a problem in the inadequate response of generic health care services and professionals to this vulnerability. It is around these twin 'problematisations' that the case for a specialist nursing role is mainly constructed, with the focus placed on health education, health promotion, or 'health surveillance'; a peculiarly 'Foucaultian' term first used to describe the learning disability nursing role in the *Continuing the Commitment* (DoH, 1995) document itself.

This kind of shift to a health promotion/health education emphasis is not unique to learning disability nursing, however. Gestaldo (1997) has noted a widespread shift of emphasis across modern health care systems from a 'pathology' to a 'health' oriented focus, suggesting, that the emergence of this form of health discourse in learning disability nursing can be viewed as part of a wider trend in which the orientation of professional health work has shifted from diagnosing and curing illness to specifying the nature of health and healthy behaviour, and 'promoting' its adoption in target populations. Gestaldo goes on to differentiate between two types of health education, a 'traditional', paternalistic approach, where professional experts inform passive subjects how to behave to achieve and maintain health, and a 'radical' approach which focuses on the 'empowerment' of recipients, whereby health awareness and knowledge is developed in groups and individuals with the purpose of increasing informed choice and access to services. The discourse analysed in this study clearly appears to align with a radical, 'empowerment' based approach. Gestaldo goes onto point out, however, that health education is also linked to the construction of identity; 'healthy being' as opposed to 'unhealthy being'. Thus, even where an 'empowerment' model is promoted, this still represents the exercise of, what she describes as an 'external bio-power' via a pervasive, and colonising professional 'gaze', to paraphrase Foucault (1976), which reaches out into areas 'beyond the clinic'. Significantly, this means that what is healthy and/or unhealthy remains defined by professional experts; a situation close to that identified as pervasive in professionalised human service systems by McKnight (1992). Such a trend is certainly apparent in the discourse analysed in this study, centred as it is on a conceptualization of health that stretches beyond a medicalised 'response to pathology', reaching out 'beyond the clinic', to use Gestaldos' phrase, into the wider social sphere where the care of people with learning disabilities has been repositioned by community care policy. We can also say, however, that the 'biologisation' of the vulnerability of people with learning disabilities that is a significant part of the construction of the discourse of health in the texts analysed in this study, runs perilously close at times to pathologisation, despite claims of a shift away from a bio-medical conceptualisation of learning disability. The need to establish a biological basis to the vulnerability of people with learning disabilities appears then to remain a strong enough imperative to preclude the complete abandonment of a pathology based perspective.

It is also in the area of 'specialisation' that claims of professional jurisdiction are asserted and defended (Abbott 1998). The discourse of health identified in this study can be seen as just such a 'jurisdictional' claim, central to which is an assertion of the 'facticity' of health as a central issue in the lives of people; a claim based largely on reference to an emergent body of research such as that reviewed by Greenhaulgh (1994). This body of research claims to provide support for the argument that people with learning disabilities are more prone to developing physical and psychological health problems than the wider population. A variety of reasons for this are discussed by Greenhaulgh, including some factors relating to the underlying physiological causes of intellectual impairment itself, such as epilepsy and sensory impairments and their association with brain damage incurred perinataly, or as a result of childhood disease. Also, some conditions, or 'syndromes' as they are designated in medical literature, which cause learning disability have been identified as commonly resulting in particular health problems. For instance, heart defects, respiratory illness and early onset dementia in people with Downs' syndrome; and diabetes, weight and eating problems in people with Prada-Willi syndrome.

Health problems of a more general nature, unrelated to the specific nature or causation of learning disability itself, have also been identified as more common in people with learning disabilities too. In the studies reviewed by Greenhaulgh (1994) people with learning disabilities commonly face problems with teeth, feet, hair, diet, weight and continence, for example. Factors implicated in the under-reporting and poor detection rate of these kinds of problems include communication difficulties faced by people with learning disabilities themselves, such as where a person has poor, or even no, verbal communication, and they are reliant on care staff to pick up behavioural cues that may indicate a health problem. For this to occur care staff may need to know the person well, and be sensitive to idiosyncratic modes of communication. Lack of skills, knowledge and awareness relating to health issues among staff in social care settings has also, therefore, been implicated. Other studies, including that referred to in the **'Hart'** text analysed in this study, suggest that many people with learning disabilities continue to experience difficulty in accessing generic health care services, whether in hospital, or community and primary care, as a result of a mixture of ignorance, prejudice, and poorly organised health care environments (Mencap, 1997., Carter, 2000., Hart, 2003). The emphasis given to health in the *Valuing People* white paper (DoH, 2001) is itself, a reflection of the significance given to this body of research by the governmnet nad its advisors.

It can be suggested that, ironicasally, the emergence of such a body of research has only been made possible because of the demise of a pathological conceptualisation of learning disability. Though for much of the 20th century, many people with learning disabilities in the UK lived their lives under the close surveillance of the NHS, their frequent poor health often appears to have been perceived as 'part of the condition' by medical observers steeped in the idea that disability equates with ill health; one result being that actual causes of ill health, be they related to biological, or social-structural factors, were under researched and responded too. A more critical view, however, might argue that this new focus of research on the health of people with learning disabilities may actually represent a new opportunity for the 'colonisation' of their lives by specialist health professions disenfranchised by the demise of a pathological conceptualisation of learning disability (Nunkoosing, 2000). The evidence of this study tends, I would suggest, to support this argument - to some extent at least. The way the authors of these texts have sought to reconstruct the role and identity of learning disability nursing in line with a model of health explicitly distanced from a pathological conceptualisation of learning disability, and where the problem of health in people with learning disabilities is identified as one of vulnerability to social and structural inequities, as well as biological and psychological factors, can be seen as reflective of an idealistic and moral commitment to leave oppressive bio-medical models of health behind. We have already noted, however, that the 'spectre' of pathology, manifested in the overt 'biologisation' of the vulnerability of people with learning diabilities, continues to loom large in the discourse of health – suggesting that its authors feel a need to establish a biological basis to their jurisdictional claim.

Conclusions:

That the health of people with learning disabilities is an issue of great significance is not in question. In its review of the progress of the *Valuing People* agenda (DoH, 2005) the continuing persistance of health inequalities affecting people with learning disabilities is highlighted. The picture emerging is that the NHS is addressing the health needs of this group only sporadically, a situation not helped by the fact that the health targets set out in *Valuing People* were not made compulsory. Too frequently they appear to have been given a low priority, and made easy to ignore or pay mere lip service to. The review also identifies the poor levels of data collection relating to the health of people with learning disabilities, and highlights the fact that addressing these needs has not often been specified in GP contracts, which means that Primary Care Trusts have had little leverage with which to exert pressure on them to take a lead. A number of changes are promised, including more money (though no figures are mentioned and this commitment remains vague); the setting of new targets for GPs; the development of specialist learning disability related knowledge input into commissioning; new standards for data collection and monitoring; and the tighter application of the Disability Discrimination Act (1995) to the NHS. There is evidently a lot of work to do to develop the competence and commitment of the NHS to getting things right for this section of the population – and thus, it can be argued, as indeed does **'Hart'**, that learning disability nursing could have a significant role to play in promoting an inclusive agenda in health. But does the discourse of health as consituted in these texts contribute to that process or not?

In a review of the sociology of the caring professions Abbott and Meerabeau (1998) have argued that the term 'professionalism' has multiple meanings. Professions are often looked at critically, but can also be viewed positively. For example, professionalism can be seen as a benchmark of performance, competence and moral quality. The 'professionalisation' argument in nursing has sought to emphasise such arguments. Similarly, Friedson (1994) has argued that 'professionalism' is itself an ideology, and that it naturally reflects wider socio-culturally embedded ideologies about the nature of professional competence, knowledge and morality. The 'textualisation' of nursing knowledge in authoritative textbooks can be seen to be a manifestation of this, in that it represents an attempt to establish both the empirical and moral foundation from which that profession promotes itself – the discourse of health identified and analysed in this study being an example of precisely this in the case of learning disability nursing. In Friedson's view, professions are, despite all the critiques, better than the alternatives, and are both necessary and desirable to maintain a 'decent' society.

A number of authors have advocated, however, the development of new kinds of professionalism which attempt to address and overcome the shortcomings of traditional, paternalistic forms of professionalism identified by critical theory. Stacey (1992) for example, argues for a 'new professionalism' focussed on the ideal of service, rather than expertise and control. Other authors have argued that such a change requires a shift in the relationship between professionals and their clients. Davies (1995) argues for a new form of professionalism in nursing, built on the construction of alliances with patients, clients and other health professionals via the medium of 'reflexive practice'. Likewise Williams (1993), who argues for a 'dialogue' based approach to the development of professional knowledge, drawing in particular from the experience of individual clients and client groups; a view that echoes the perspectives of the social model of disability, the political disability movement and the self advocacy movement for people with learning disabilities.

Leonard (1997) argues that the emancipatory project of the welfare state, the health and social care systems that comprise it, and the professions that inhabit it, can be rediscovered only by acknowledging the powerful role of discourse as a form of cultural production of identity and knowledge systems. In particular, there is a need to acknowledge and celebrate difference; a point emphasized also by social model theorists (e.g. Swain, French and Cameron, 2000). A starting point for this, Leonard argues, is to refrain from pathologising and homogenizing difference, a tendency deeply entrenched in the consciousness of many professions – and one reflected in the discourse analysed in this study - whose first impulse is often to objectify clients and conditions in line with the powerful cultural imperative to demonstrate the scientific foundation of their knowledge and practice. A concern of mine at the beginning of this study was that the emerging discourse of health in learning disability nursing textbooks might represent exactly such a process of pathologisation and homogenization, and as such, a potentially retrogressive step in the way that people with learning disabilities are conceptualized and responded to by the profession. My analysis in this study has done little to allay these fears. By constructing the discourse of health in the way that they have, learning disability nursing theorists could be argued to have taken up an opportunity to redefine the role and identity of the profession, encouraging it to work in a more useful and focused way with people with learning disabilities than has often been the case in past. On the other hand, the evidence in this study is that the tendencies to pathologise and homogenise noted by Leonard (1997) are still very strong.

The social model of disability has provided a critique of professions and professional practice which nurses cannot, and should not ignore. Whilst its argument that professionals are purely 'parasitic' on disabled people is, I would argue, an overstatement, it is important nonetheless to recognize the extent to which nursings' own material interests are intertwined with the maintenance of the service systems and power structures within which they work, and to ensure that these do not override the moral imperative to work in ways which contribute to the emancipation, rather than the oppression of their clients, both as individuals, and as minority groups in society. There is a need, therefore, to reconstruct the nursing role as part of an emancipatory and empowering project in the lives of the individuals we work with, and in alliance with people with learning disabilities as a social group. This can only be achieved by dropping the tendency to retreat into expert/professional monologues about people with learning disabilities, and to adopt instead a dialogue based approach in which they are encouraged to speak and name their own truth and reality – in relation to health as much as any other part of their lives. Anya Souza (with Ramcharan, 1997) for example reminds us that… "It takes a great deal of courage and strength to fight people who have the power to define who you are" (Page 14). She describes how such power has been used to frame and restrict her entire life, leading to a separation from the rest of society. The need to resist that separation, and to escape the separate 'special world' constructed within specialist services is a strong theme of her account. "I have rights…" she asserts "…to a job, to services when necessary, to a decent standard of living, to know about my medical problems, to speak my mind and to make choices and decisions…" (Page 14). Souza is emphatic in identifying this process of separation as 'disabling'. "The people who make the decision to separate people from society in this way do not see that the minute this separation starts is the minute they begin to make us disabled. They are disabling us in our rightful role in society. And the longer this separation lasts, the more the person comes to see themselves as separate" (Page 4). Goodley (2000) echoes this strongly in his assertion, based on his own research with 'self advocates', that… "The 'difference' of people with learning difficulties as being located in some biological deficit, individualises their very humanity: ripping them out of a social context, placing them in the realms of pathological curiosity" (Page 35). Such a view reminds us also of McKnights (1992) assertion that such separation takes peoples problems out of the realm of socio/political action, and recasts them instead as technical problems that can only be solved by specially trained experts wielding their scientifically validated tools and techniques. Science surely has it uses in the pursuit of health, and other goals, for people with learning disabilities. But it should give much greater priorty to seeking to address the problems that they identify for themselves, rather than constantly classifying and identifying them as *the* problem that needs to be addressed.

A practical example of this kind of approach would involve, for example, working with individuals with learning disabilities to construct joint narratives about their health; an approach which would help them to name and claim own experience, and help carers and supporters to perceive them, not merely as 'cases', but as 'subjects' with their own life story, experiences, hopes and aspirations. Such work can have a transforming effect on professional consciousness and practice, fostering something approaching what McGee and Menelascino (1991) described as 'a psychology of interdependence'. The research referred to earlier by Gillman et al (1997) is a good example of this kind of work in practice, as is the 'lifemapping' work of Grey and Ridden (1999), and the case studies described in my own work relating to people with learning disabilities and challenging behaviours (Goble, 2000). A hopeful sign that this message does appear to be seeping into the consciousness of leading theorists in the profession is the recent appearance of a new textbook aimed partly at student learning disability nurses, which explicitly, if not exclusively, grounds its approach in line with a social model of disability, and where experiential narratives of people with learning disabilities are given some prominence (Grant, Goward, Richardson and Ramcharan, 2005). The discourse of health in learning disability nursing does appear then, to be continuing to evolve, and the signs are promising that this may lead to a more emancipatory and empowering role for the profession in the lives of its client group. History in the learning disability field should have taught us to take nothing for granted however, and a commitment to the work of building alliances with people with learning disabilities must continue if the profession is to maintain its moral validity.

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