Valuing People and Health Facilitation: The politics of ambiguity, leadership, and capital

Catherine Glynis Whitehead

School of Nursing and Midwifery
University of Salford, Salford, UK

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Declaration

I, Catherine Glynis Whitehead, declare that this thesis and the work presented within it are my own and have been generated by solely me as a result of my own original research. Where other sources of information and literature have been used, they have been acknowledged.

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification from this or any other university or other institution of learning.

Abstract

The health needs of people with learning disabilities are greater that those of the general population and yet they have inadequate access to health services. In 2001 the British government published *Valuing People* which demanded better access to mainstream health services for people with learning disabilities, and in England the role of health facilitation was initiated as the principle means by which the health status of people with learning disabilities throughout England was to be improved.

This thesis reports on an investigation into the phenomenon of health facilitation within learning disability services in England. An eclectic methodology based on a phenomenological approach was employed to gain an understanding of the essential truths of health facilitation as experienced by health facilitators. Four research methods were utilised: a policy analysis; a Delphi study; a series of semi-structured interviews; and a reference group. Data revealed: a degree of insecurity amongst health facilitators in relation to themselves and their roles; a lack of leadership at all levels; the inadequacy of management and support available; concern as to the quality of health action plans; and the slow and limited progress achieved.

The thesis notes that *Valuing People* (2001) had been received as a creative and innovative policy in its development and approach. However, its: vagueness towards the health facilitation role; deficiency in providing appropriate leadership; and the lack of investment in terms of health facilitator capital were found to have been detrimental to the progression of health facilitation.

Valuing People (2001) predicted an annual growth of one per cent within the severely learning disabled population. This, and the damning reports relating to the failure of mainstream health services, demonstrates the relevance of this research. This thesis contributes to the body of knowledge of health facilitation and learning disability and has significant implications for health service provision, good health, and social policy.

Chapter 1

Introduction

Introduction

This thesis explored health facilitation for people with learning disabilities in England. The context is that people with learning disabilities have some of the worst health outcomes of any group of people in the United Kingdom; evidence for which will be discussed in the literature review. Health facilitation has been one way that the United Kingdom government has tried to address such poor health outcomes. What follows is an introduction to myself as a researcher and my interest in the topic; a justification for the research; the aims of the study; and an outline of the thesis.

Researcher Background

My passion for learning disability and health issues stems from thirty years experience working as a nurse for people with learning disabilities. My introduction to people with learning disabilities occurred in the late 1970's when I embarked upon nurse training within a hospital for people with what was then termed mental sub-normality. Following qualification, the confines of endeavouring to provide people with ordinary life experiences within the bureaucracy of an institution became too frustrating and resulted in a move to working as a staff nurse within a community nursing team. Coming as I did from an institutional background, community work was something for which I found myself ill-prepared, to the point that for the first six months I felt that I had made the greatest mistake of my life. Community nursing in learning disability at that time was in its infancy: the first community nurse for the whole of the district having been appointed some three years previously; everybody was learning 'on the job'; and no official in-service training or induction programme was available. With the support of colleagues, and very tolerant clients and their families, I was able to adapt to meet the prevailing situation and my acclimatization occurred.

A twelve month period of time as the nurse in charge of a pre-school developmental unit gave me real insight and hands-on experience of working with babies and pre-school infants. This experience introduced me not only to the client group but also to a team of staff that had its own developmental and support needs. Having successfully met these challenges I was promoted to senior nurse within the local community nursing team, of which I was appointed manager after three years. Thus I became responsible for two additional teams providing day services to older learning disabled people, and a therapeutic horticultural service aimed at those people whose behaviours were deemed too challenging to be met within existing service provision. My experiences of working with people with learning disabilities have spanned the age and ability continuum and have provided an opportunity to gain first hand knowledge of the difficulties encountered in gaining access to generic services.

I didn't realise it at the time but all these experiences followed from the government White Paper *Better Services for the Mentally Handicapped* (1971). In summary this encouraged greater community provision for learning disabled people while at the same time demanding improved hospital services. It was to be thirty years before the next government White Paper for people with learning disabilities, *Valuing People* was published in 2001 and by this time the vast majority of long stay National Health Service provision had been closed and the White Paper was concerned primarily with improving community services. In the case of health services *Valuing People* found that,

> *When people with learning disabilities approached health care providers for assessment or treatment they often found difficulties in gaining access to the help they needed. The health needs of people with learning disabilities may not be recognised by doctors and care staff who have no experience of working with people who have difficulties in communication. Health outcomes for people with learning disabilities fall short when compared with outcomes for the non-disabled population* (p59).

And that,

> *Evidence of avoidable illness and premature death amongst people with learning disabilities is a major cause of concern for the Government* (p62).

My initial training was as a nurse and this, along with my subsequent experiences, inspired a fascination with health. Government policy rightly promoted choice and opportunity but, without good health, learning disabled people will not be able to make the most of the opportunities open to them. *Valuing People* had a chapter devoted to health and it is this chapter and its subsequent implementation that is the subject of this thesis.

Valuing People (2001) introduced two new concepts, health action plans and health facilitation. The first was relatively straightforward, but the second was a surprise as health facilitation had not previously been linked to people with learning disabilities. Chapter two of this thesis will examine the origins and background to health facilitation, whilst the remainder of the thesis will examine its implementation. Health facilitation was a new concept proposed as a means of improving the life chances, and health status, of people with learning disability throughout England. Some nine years have now elapsed since *Valuing People* was published. Judging from the Mencap report *Death by Indifference* (2007) there has been little improvement in the way that health services work with people with learning disabilities. Mencap presented stories of six people with a learning disability who were not looked after properly whilst in the care of the National Health Service and consequently died. The subsequent independent inquiry into access to healthcare for people with learning disabilities led by Sir Jonathan Michaels, *Health Care for All* (2008) found,

> *... high levels of health need are not currently being met and that there are risks inherent in the care system. People with learning disabilities appear to receive less effective care than they are entitled to receive, especially as they move from children's to adult services and discrimination is evident in access to and outcomes from services. Many of these problems concern basic shortcomings in the way that treatment is delivered that would be simple to remedy. However, there is also evidence of a significant level of avoidable suffering due to untreated ill health, and a high likelihood that avoidable deaths are occurring.* (The Michael's Report, 2008, p21).

To date very little investigation has been embarked upon as to how the practice of health facilitation has been interpreted and perceived by health facilitators in

the field. The fieldwork for this study took place across England during 2006/7. Scotland, Wales and Northern Ireland made their own provision in accordance with direction from their respective devolved parliaments and assemblies. Since then *Valuing People* (2001) has been updated in the form of *Valuing People Now: the Delivery Plan*, *'Making it happen for everyone',* (Department of Health, 2009) which confirmed that, despite the *Valuing People* document, health and healthcare for people with learning disabilities remains a low priority with access to, and provision of, appropriate treatment difficult to attain.

Justification for the research

Good health is an important constituent of a high quality of life. It has been suggested that life expectancy for people with a learning disability has increased over the past fifty years and will continue to do so in the years to come. Despite this, the life expectancy of people with learning disabilities continues to be lower than that of the rest of the general population. Moss and Turner (1995) discovered that the more severe the learning disability, the greater the possibility that an individual's life span would be short. It appeared that whilst life expectancy for people with learning disabilities had increased, fifty percent would be anticipated as dying before reaching the age of fifty, compared with only seventeen percent of the population as a whole. It is generally acknowledged that people with learning disabilities have much greater health needs, and access services less than the general population (*Signposts for Success*, NHS Executive,1998) . Their life expectancy is shorter and the most common causes of death are different from those of the rest of the population. In addition they are more likely to live unhealthy lifestyles; be in receipt of low incomes or benefits; be dependent upon carers or family members for their diet and participation in physical activities; and are more likely to have had poor experiences of health services (Mencap 2004).

Valuing People (2001) estimated that there were about two hundred and ten thousand people with severe or profound learning disabilities in England. Of these around sixty five thousand will be children and young people. It anticipated that one hundred and twenty thousand adults would be of working age, whilst twenty five thousand would be older people. In the case of people

with mild/moderate learning disabilities lower estimates suggest a prevalence rate of around twenty-five per hundred thousand per population that is some 1.2 million people in England. The prevalence of severe and profound learning disability is uniformly distributed across the country and socio-economic groups. Mild to moderate learning disability, however, has a link to poverty and rates are higher in deprived and urban areas. The number of people with severe and profound learning disabilities in some areas is affected by past funding and placement practices, especially the presence of old long-stay hospitals and people placed outside their original area of residence by funding authorities. *Valuing People* went on to say that the number of people with severe learning disabilities may increase by around one per cent per annum for the next fifteen years (*Valuing People*, 2001, p16), whilst in 2007 the Foundation for People with Learning Disabilities predicted that the number of adults with learning disabilities aged over sixty is predicted to increase by thirty six percent between 2001 and 2021.

A number of barriers to attaining and maintaining good health amongst people with learning disability have been identified. These include people with learning disabilities' capacity to understand information presented to them in a complex way, and their ability to calculate dangers and risks to their health. Some health professionals and possibly some family carers have lower expectations of what are acceptable standards of health for people with learning disabilities and make the assumption that illness is a feature of learning disability. This makes it difficult to obtain a diagnosis of illness due to the presence of a learning disability. Discriminatory practices, a lack of expertise amongst health professionals in communicating with, and understanding, people with learning disabilities, deficiency of service co-ordination and inadequate support to achieve and maintain good health are hurdles that people with learning disabilities have to face when attempting to navigate health care systems and services (Greenhalgh, 1994, and Meehanet al, 1995).

In 2002, Rob Greig, the National Director of Implementation for *Valuing People*, responded to the *Improvement, Expansion and Reform* (2002) document by arguing that the health care of people with learning disabilities needed particular attention due to their vulnerability. Among the points he emphasised was that learning disabled people were less likely to receive regular health checks but when checks were carried out they tended to reveal high levels of unmet need. He also argued that there was evidence to suggest that regular health screening, along with co-operation between different health professionals, would improve the health of learning disabled people. In describing the uptake of services he drew attention to the fact that people with learning disabilities had an increased usage of medical and dental hospital services, but a reduced uptake of surgical specialities, hospital admissions, and reduced lengths of stay when compared to the general population. It is therefore clear that that there is a problem with health care for people with learning disabilities within mainstream services in terms of access and subsequent health outcomes. This fact underpins this thesis and will be explored in-depth later.

Broad Aim of the Study

The primary focus of this research was to investigate the phenomenon of health facilitation from the perspective of health facilitators in order to gain insight into the health facilitators' experience of its implementation and process; its impact upon them as practitioners; and to provide an indication of the essential requirements of effective health facilitation. Additionally, the thesis integrates health facilitation into the broader world of social policy and learning disability in that it explores, through the experiences of health facilitators, how health facilitation has functioned in relation to the New Labour values of devolved decision making and increased rights asserted within the key principles of *Valuing People* (2001), rights, independence, choice and inclusion.

Health facilitation as it relates to people with learning disabilities has not hitherto been subjected to rigorous scrutiny. Some previous studies have been conducted on concepts that bear some similarities to health facilitation involving other client groups, for example, service co-ordination (Illback and. Neil, 1995), and care co-ordination (Gow et al, 1999). This research took an approach

based on phenomenological methods of enquiry to explore, interpret and gain an understanding of the health facilitators' perspective of health facilitation at a particular point in its history as opposed to attempting to arrive at a definitive explanation of health facilitation. Such an approach acknowledged that reality is subjective, multiple and complex, and that an understanding of reality cannot be achieved simply by observing it without endeavouring to comprehend the underlying perceptions and interpretations that the individual imposes. Health facilitation for people with learning disabilities had, up to the point at which this research commenced, undergone very little in the way of scrutiny and none at all from the perspective of the health facilitators themselves.

Valuing People: A New Strategy for Learning Disability for the 21st Century (2001) was eagerly anticipated as it was the first White Paper aimed at people with learning disabilities for thirty years. It was a valiant document in that it adopted a different perspective on the delivery of services to what it acknowledged as a very vulnerable group of people. *Valuing People* was a radical document in that it was not only a vehicle for New Labour's ideological reforms of the welfare state, but had innovatively involved people with learning disabilities and their carers in designing the content of policy. A summary of *Valuing People* will follow later in the literature review.

Structure of the Thesis

Chapter two will present a literature review which places health facilitation within the contexts of history, politics, health, and learning disability; revealing characteristics of its role, function and the attributes of its practitioners.

Chapter three will offer: the background and rationale to the choice of an eclectic phenomenological approach of enquiry into the *Valuing People* (2001) concept of health facilitation; the ethical issues considered; and a description of the data collection and analysis methods employed.

Chapter four is the first of two chapters that will proffer a combination of research results and their analysis. This chapter looks at the first two methods employed, that is, a policy analysis and a Delphi Study.

The results and analysis of the final two data gathering methods, semi-structured interviews and a reference group meeting will be presented within chapter five.

What emerges from these two chapters will be an account of health facilitation for people with learning disabilities as experienced by participating health facilitators. The most persistent themes to emerge from analysis were: ambiguity; a lack of leadership; and a lack of power and assets which can best be explained within the theoretical concept of capital.

Chapter six will present an in-depth and balanced exploration of the enduring aspects arising from the point by point analysis of the research findings; provide a considered understanding of the research topic and the issues raised; and will connect with the literature review and relevant theory where appropriate.

Chapter seven will: recapitulate and reflect on the research design and process; consider how this research and its findings might affect future research; connect with the current situation; and finally reflect on the assumptions and views of the researcher and how they have been affected as a result of the learning that has occurred as a result of this research.

Conclusion

This introduction has furnished information for the reader as to the origins, background, and justification for this research. In choosing to explore the *Valuing People* (2001) concept of health facilitation for people with learning disabilities from the perspective of health facilitators, a viewpoint that, until now, has received little attention or been subjected to rigorous scrutiny, it is anticipated that it will make a valuable contribution to the body of knowledge, and enhance the practice of health facilitation.

Chapter 2

Literature Review

Introduction

This chapter contains the literature review comprising six main elements. After outlining the search strategies employed in this review of literature it will proceed to: provide a brief commentary of the *Valuing People* (2001) White Paper; explore the origins of health facilitation; examine the concept of health facilitation within generic health care contexts; identify models of facilitation; categorise elements of the facilitator role; and investigate health facilitation as it relates to learning disability. This will provide a background to the subject as well as an explanation of published material.

The chapter begins with an outline of the search strategies employed to obtain the literature for the review, followed by a brief summary of the *Valuing People* document.

Search Strategies

A search of electronic databases was undertaken using a 'Population; Intervention; Comparison; and Outcome' (PICO) formulation. The search was conducted in three stages in order to locate authoritative articles and studies on the Valuing People White Paper; facilitation and health care in general and on health facilitation and learning disability in particular.

Stage 1: The Valuing People White Paper (2001)

Population: People with learning disability.

Intervention: The *Valuing People* policy (2001).

Comparison: Learning disability policy previous to 2001.

Outcome: Opinion as to efficacy.

Key words: Valuing People; Analysis; Evaluation; Critique; Scrutiny; Investigation; Assessment; Appraisal; Review; Assessment.

Stage Two: Facilitation in General

Population: Primary care patients.

Intervention: Facilitation.

Comparison: No facilitation.

Outcome: Change in practice.

Key words: Primary Care, Facilitat(*), and Change.

Stage Three: Health facilitation and Learning Disability

Population: People with learning disabilities.

Intervention: Health facilitation.

Comparison: No health facilitation.

Outcome: Change in practice.

Key words: Health Facilitat(*), Learning Disability, Change

The Boolean operator 'AND' was used in all instances to allow for the amalgamation of keywords.

Several data-bases were searched, including Ovid Medline, British Nursing Index, Cumulative Index of Nursing and Allied Health Literature, Swetswise, Ingenta, Blackwell-Synergy, British Medical Journal On-line, Sage Journals On-line, and Emerald Full-Text. This produced thirty research studies and thirteen journal articles. Twenty-seven research studies were selected for inclusion in this literature review on the basis that they were relevant, well researched and had credibility (Table1). Additional supporting material was drawn upon as and when appropriate (Table 2).

The White Paper

Before looking at the literature regarding *Valuing People* it is important to be clear about the document itself. The White Paper, *Valuing People*: *A New Strategy for Learning Disability in the 21st Century* (2001), was a much anticipated piece of documentation as it was the first to be produced since the White Paper *Better Services for the Mentally Handicapped* (1971), which

advocated the closure of long stay hospitals for people with learning disabilities and the development of services within the general community. *Valuing People*, whilst acknowledging the progress made in bringing an end to institutional care, clearly stated that much more needed to be done if people with learning disabilities were to enjoy satisfying and rewarding lives. In looking at the future of services for people with learning disabilities it took something of a revolutionary approach. Rather than merely advocating improvements within the existing public and specialist services, it required that mainstream service providers in pursuit of an equitable society meet their responsibilities to this vulnerable group of people. Several areas of concern were highlighted: disabled children and young people; choice and control; supporting carers; the leading of fulfilling lives encompassing issues of housing and employment; and improving health for people with learning disabilities.

Whilst relating primarily to adults *Valuing People* (2001) did outline its concerns and expectations for children and young people with learning disabilities. It conceded that they faced many impediments to full and satisfying lives. The list was long and included: a lack of support in practical and financial terms; insufficient information; inadequate and poorly co-ordinated services; delays in obtaining medical opinions; low expectations of abilities; lack of opportunities for play, leisure and sporting activities; poor access to good quality National Health Services; and finally, inadequately organised transition from child to adult services. The document made explicit the desire that children with learning disabilities should increase their life enhancing potential and benefit from the opportunities available to all children from educational, health and social services.

Valuing People (2001) proposed that support to families be increased via making Improvements to the co-ordination of care packages by health and social services. Several financial measures were suggested as a way of reducing the amount of stress experienced by families, such as: the continued support of the Diana Children's Community Nursing Services; developing parent partnership services; funding a National Information Centre for families with disabled children; the financing of a New Opportunities Fund and the Sure Star

Scheme to increase access to play, leisure, culture and sporting activities; and making direct payments available to parents of disabled children. The Special Educational Needs Programme of Action and the Departments for Education and Employment, Health, and the Disability Rights Commission were charged with developing good practice guidance on identifying special educational needs; involving children in educational decision-making processes; producing inclusion codes; developing attainment measures; and working with other agencies to share good practice and co-ordinate service provision. *Valuing People* emphasised the importance of children's health and the need for treatment/therapy being provided in such a way as to cause the minimum of disruption to education. It went on to stress the commitment made within the *National Health Service Plan* (2000) to increase the numbers of therapists and health professionals available to school children with disabilities, and the fact that the Department for Education and Employment was sponsoring a network of eleven Special Educational Needs Regional Partnerships across England to guarantee flawless child centred services for disabled children. Very little was known at that time about children receiving services from residential schools and homes. The National Care Standards Commission was tasked to register children's homes, including those homes for disabled children currently registered as care homes, and to inspect the welfare of children in all schools and Further Education colleges with boarding provision.

Valuing People (2001) conceded that children with disabilities needed help to develop into full and active members of society, and clarified the existing policies and funding streams via which it was predicted they would be able to access educational opportunities, help and advice, and therefore, ease the transition from childhood to adulthood. Support for families was also noted as being essential, as was enabling families to make informed choices about the type of support and services needed. With regard to quality measures, *Valuing People* (2001) proposed that the Quality Protects Programme should give new priority to children with learning disabilities and provide a more flexible type of home based support to families better designed to meet their needs.

This next section, focusing on adults, presents what *Valuing People (*2001) sees as *essential prerequisites for good health* (p59), that is, the four underlying key principles of inclusion, choice and control, rights and independence. The first principle to be deliberated upon is that of inclusion: meaning to be part of the mainstream of society by, going to work, using local housing, health, leisure, and transport services, and being fully included in all aspects of the local community. The *Mental Health and Social Exclusion Report* (2004) supported the need to promote people's rights to access services and facilities and identified the obstacles to inclusion as being, negative attitudes, stigma and discrimination. Partnership Boards were the means by which *Valuing People* saw inclusion being attained by the development of effective and collaborative working relationships towards long-term strategic change, not only the design, management and delivery of services, but also in culture and practice so that people with learning disabilities could lead the lives to which they aspired.

The second of *Valuing People's* (2001) key principles to be considered here is that of choice. Many aspects of daily life had been found to be beyond the control of people with learning disabilities, despite the fact that most could make their own choices and decisions. *Valuing People* (2001) gave notice of its plan to issue guidance on person-centred planning approaches, and its intention to develop direct payments and advocacy schemes, thus enabling people with learning disabilities to have the maximum possible choice and control over their lives. The development of advocacy was thought to be vital and to this end *Valuing People* made it known that one point three million pounds per year, over a three year period, had been earmarked to develop both a National Citizen Advocacy Network and to promote self advocacy. As well as choices appertaining to the individual, *Valuing People* contained a clear statement of intent regarding the involvement of people with learning disabilities in policy development and implementation at national and operational levels regarding issues affecting their lives.

Valuing People (2001) conceded that people with learning disabilities had been on the periphery of society, estimating that less than ten percent were in paid employment. Such a position could no longer be tolerated and it promised to

review current day service provision so that it could be aligned with the desire of people with learning disabilities to take up real and meaningful work, albeit in some cases with support. Partnership Boards were charged to develop links with supported employment schemes, and training and education providers to extend the opportunities available.

In relation to housing issues *Valuing People* (2001) made a commitment to close any long stay hospitals still open with residents being helped to move to more apposite accommodation. The range and amount of choice and control available to people with learning disabilities in the key area of housing was to be increased and legislation was promised to ensure that housing authorities provided improved advice and guidance regarding housing and support issues.

Addressing the third key principle of rights, the government committed itself to ensuring that people with learning disabilities were to have equal access to civil rights and challenging discrimination. The proposals put forward were to encompass the current legislation conferring rights on all citizens, for example, the Human Rights Act (1998), the Disability Discrimination Act (1995), the Race Relations Act (1976), the Race Relations (Amendment) Act (2000), and the Sex Discrimination Act (1975). The Disability Rights Commission that had been established by the government in 2000 to combat discrimination against disabled people had a remit to: enable people with learning disabilities to gain full access to their legal rights; ensure that their needs and views were integral to the Commission's work; and to promote the egalitarian entitlement of people requiring intensive health care support because of the complexity of their disability or the challenges they presented. The vital role of carers and their need to have confidence in the support services was .acknowledged in *Valuing People.* Their support needs were outlined in guidance issued by The Department of Health to local councils on implementing legislation, together with a leaflet entitled *The Carers Guide.* A carer's assessment was to be available to all carers; and person-centred plans were to address needs and preferences of the person with learning disabilities and their carers.

The fourth of the key principles to be considered is that of independence. People with learning disabilities have complained that they often felt

insignificant, needy, reliant on others, and overlooked by society. *Valuing People* (2001) made clear that, whilst some people with learning disabilities may be more able than others, the assumption should be one of independence rather than dependence, and that independence did not mean having to do things unaided. *Valuing People* acknowledged that specialist resources may be required by some, and declared its intention to make additional funding available to improve and expand community equipment services. Also noted was the fact that many people with learning disabilities were unable to move towards independent living and therefore remained with their families, often leaving only as a result of a crisis such as illness or death of a carer. *Valuing People* made it known that it wished to see more in the way of forward planning in relation to independent living for people with learning disabilities so that carers did not face continuing uncertainty in old age, and that sons and daughters could gain greater independence from parents. To promote this move towards independent living, agencies responsible for mainstream housing, education, employment and leisure would be fully included in local planning and commissioning. The National Care Standards Commission was given responsibility to ensure that all regulated care services should be delivered to national minimum standards.

Valuing People (2001) recognised that quality assurance within learning disability services were generally weak, rendering people vulnerable to mistreatment; lack of representation particularly of minority ethnic groups; and confusing and prohibitive complaints procedures. *Valuing People* sought to ensure the quality of service provision and recommended that all services should be based upon researched evidence and governed by quality assurance frameworks with a local service user focus. Echoed within *Valuing People* (2001) were the concerns expressed in recent years about the quality of services available to people with learning disabilities; for example, the deficits and underperformance of service providers, and inconsistency in commitment to learning disability services by local authorities and health authorities. To redress this balance the policy endorsed quality measures that included eleven objectives, forty-two sub-objectives and a series of proposed performance indicators. These objectives and sub-objectives were intended to clarify

expectations, and provide both direction and a basis for assessing progress. There were two types of objectives within the White Paper. The first dealt with outcomes for people and the second was systems based. Relevant to this thesis is the health related objective of *enabling people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, with additional support where necessary* (p125). This was supported by three sub-objectives: reducing the health inequalities experienced by people with learning disabilities; enabling mainstream National Health Services, with support from specialist learning disability staff, to meet the general and specialist health needs of people with learning disabilities; and promoting the development of evidence based National Health Service specialised learning disability services delivered with a focus on the whole person (p126). Alongside the *Valuing People* objectives was a set of ten performance indicators that provided a means of measuring whether or not agencies and authorities were performing as per expectations. Disappointingly, *Valuing People* (2001) did not contain a performance indicator specific to good health. The reason given for this was that National Health Service performance indicators were not client group specific. The government's aspiration to raise standards was based on the premise that providing good services would naturally lead to the acquisition of rights, increased independence, greater choices, and ultimately social inclusion for people with learning disabilities.

Other measures introduced by *Valuing People* (2001) in an attempt to raise standards concerned staff training and the criminal justice system. The needs of people with additional and complex needs are discussed within the text but no specific actions are outlined. In relation to staffing it has been estimated that when *Valuing People* was published some eighty three thousand people were employed in the learning disability workforce, of which three quarters were unqualified. *Valuing People* acknowledged the significant role played by staff in enhancing the quality of life for people with learning disability. It called for the development of workforce plans and introduced the Learning Disability Award Framework as the vehicle by which support staff would receive appropriate training. People with learning disabilities are known to encounter difficulties in

accessing and navigating the criminal justice system. In response, local councils were charged with developing policies and procedures for the protection of vulnerable adults taking into account the guidance to be made available concerning the use of physical intervention, and to gather data on the number of abusive incidents encountered.

Finally, the policy aimed to provide direction via a set of national objectives, targets and performance indicators, and financial support to agencies through new funding sources. A Learning Disability Development Fund of fifty million pounds was aimed towards the White Paper's priorities of modernising day services, long stay hospital closures, the development of supported living approaches for those people living with elderly carers, and local services for people with challenging behaviour. A central Implementation Support Fund of two point three million pounds was to be directed towards the development of advocacy service and national information and help lines.

Research Studies Reviewed

Study	Date	Title	Publication	Study Method
Harvey, Loftus-Hills, Ryecroft-Malone, Titchen, Kitson, McCormack, and Seers.	2002	Getting evidence into Practice: the role and function of facilitation.	Journal of Advanced Nursing	Concept analysis
Nagykaldi, Mold, Aspey.	2005	Practice Facilitators: A Review of the Literature.	Family Medicine	Systematic literature review
Lemelin, Hogg, and Baskerville.	2001	Evidence to action: a tailored multifaceted approach to changing family physician practice patterns and improving preventive care.	Canadian Medical Association Journal	Randomised controlled trial
Hogg, Lemelin, Graham, Grimshaw, Martin, Moore, Soto, O'Rourke	2007	Improving prevention in primary care: evaluating the effectiveness of outreach facilitation.	Family Practice	Randomised controlled trial
Dietric, O'Connor, Keller, Carney, Levy, Whaley.	1992	Cancer: improving early detection and prevention. A community practice randomised trial.	British Medical Journal	Randomised trial of two interventions.
Elwyn, Hocking	2000	Organisational Development in general practice: lessons from practice and professional development plans (PPDPs).	Family Practice	Project Work Evaluation
McGowan, Neville, Crombie, Clark, Warner	1997	The facilitator effect: results from a four-year follow up of children with asthma.	British Journal of General Practice	Follow up on an intervention and a control group after four years.
Tan, Wei & Lee-Partridge.	1999	Effects of facilitation and leadership on meeting outcomes in a group support system environment.	European Journal of Information Systems.	Experimental groups
Seifert, McDonald, Yukl.	2003	Effects of Multi-source Feedback and a Feedback facilitator on the Influence and Behaviour of Managers Towards Subordinates.	Journal of Applied Psychology	Experimental groups
Anson, Bostrom, & Wynne.	1995	An Experiment assessing group Support System sand Facilitator Effects on Meeting Outcomes.	Management Science	2 x 2 Factorial design

Fullard E., Fowler G., Gray M.	1984	Facilitating Prevention in Primary Care.	British Medical Journal	Proxy outcome measurement via patient records
Grabowsky, Farquar, Sunnarborg, and Bales	1997	Worldwide Efforts to improve Heart Health: A Follow-up to the Catalonia Declaration – Selected Programme Descriptions.	United States Department of Health and Human Services	Three year controlled trial
Warner and Ford.	1998	Mental health facilitators in primary care.	Nursing Standard	Postal questionnaire and telephone interviews
Bashir, Blizard, Bosanquet, Bosanquet, Mann, and Jenkins.	2000	The evaluation of a mental health facilitator in general practice: effects on recognition, management, and outcome of mental illness.	British Journal of General Practice	Systematically allocated control trial
Stetler, Legro, Rycroft-Malone, Bowman, Curran, Guihan, Hagedorn, Pineros, and Wallace.	2006	Role of 'external facilitation' in the implementation of research findings: a qualitative evaluation of facilitation experiences in the Veterans Health Administration.	Implementation Science	Reflective exploration via semi-structured interviews
Caan W. Lutchmiah J. Toocaram J. Thomson K.	2005	Health Facilitation in Primary Care.	Primary Health Care Research and Development	Multiple method: Interviews Shadowing Reflective diary Questionnaire Focus group
Thomson K., Gripton J, Lutchmiah J., Caan W.,	2007	Health facilitation in primary care seen from practice and education.	British Journal of Nursing	Multiple method: - Diaries - Shadowing - Questionnaires - Interviews
Mir G. Allgar V. Cottrell D. Heywood P. Evans J. Marshal J.	2007	Health Facilitation and Learning Disability.	Report - Leeds Institute of Health Sciences	Multiple method: Interviews Focus groups Shadowing Primary care records Data base analysis

Table 1

Additional Publications Reviewed

Author	Date	Title	Publication	Category
Kilcher. 2005	2005	The art of network facilitation.	National College of School Leadership,	Book
Burton M. Kagan C.	2006	Decoding Valuing People.	Disability and Society, Vol.21, (4), pp299-313	Article
Cumella S.	2008	New Public Management and Public Services for People With an Intellectual Disability: A review of the Implementation of Valuing People in England.	Journal of Policy and Practice in Intellectual Disabilities, Vol. 5, (3), pp 178-186	Article
Gates B.	2001	Valuing People: Long Awaited Strategy for people with Learning Disabilities for the Twenty-First Century in England.	Journal of Intellectual Disabilities,(2001), Vol.5, pp 203-207	Editorial
McNally S.	2004	Plus ça change: Progress achieved in services for people with an intellectual disability in England since the publication of Valuing People.	Journal of Learning Disabilities Vol. 8 (4) Pages 323-329	Editorial
Sooben R.D.	2004	Valuing People with Learning Disabilities in the Context of the Human Fertilisation and Embryology Act 1990: Social Policy and Legislative incompatibility.	Journal of Learning Disabilities Vol. 8 (2) pp107-111	Editorial
Department of Health	2001	Valuing People: A New Strategy for Learning Disability in the 21st Century.	Department of Health	White Paper

Table 2

Health Facilitation in Generic Contexts

Valuing People (2001) recommended the implementation of health facilitation for people with learning disabilities, although no indication of why this particular concept was considered valuable was provided. This next section traces the origins of facilitation within the context of health care in general. It began as a quality circle technique and has been extended to encompass a number of generic health care situations and environments. A variety of facilitation models will be discussed here, together with a description of the facilitation role and its efficacy as a method of improving health. As a concept, facilitation is a challenging notion to explain, not simply because of its evolutionary nature and the multiplicity and complexity of its components, but because much of it is concerned with process rather than outcome (Cook, 1994, Stetler et al, 2006). In simple terms facilitation has been described as *a technique by which one person makes things easier for others* (Harvey et al, 2002 p579). In reality the process of facilitation is far from simple in that it can occur at multiple levels; and involves making available to others the opportunities, means, and encouragement to analyse issues, learn from experience, work as a team to draw conclusions leading to the successful achievement of goals, and to take control and responsibility for service development (Bentley, 1994, Dismukes et al, 2000, Stetler et al, 2006). The rationale for using facilitation varies depending upon the context in which it is employed. Facilitation, as it is currently used in the health service can be seen to be broad, ranging from passive observation, to active intervention, to guidance, helping and supporting organisations to attain specific goals, and enabling practitioners and teams to analyse, reflect and change their attitudes, behaviour, and practices (Harvey et al, 2002, King, 2002).

The origins of facilitation go back to the work of Carl Rogers (1902 –1987) who developed the humanist concept of facilitation as a catalyst for change. Although Rogers worked primarily in the field of psychology and therapy his ideas regarding facilitation have been transferred to education, business and management arenas. Rogers expressed two major beliefs about facilitation. Firstly, the conviction that in relation to bringing about changes it was the

facilitator who could set the climate; elicit and clarify its purpose; make available support and resources; and deal with the emotions that arose as a result of the proposed modifications to practice. Secondly, Rogers believed there were three essential attitudinal qualities required of facilitators in order to bring about successful change: genuineness, acceptance and trust, and empathetic understanding. The most fundamental of the essential attitudinal qualities required by facilitators, genuineness, is the ability to enter into facilitation relationships without presenting a 'front' or a 'façade', thus enabling the facilitator to relate to others on a person-to-person basis and therefore enhancing the likelihood of being effective.

To be effective facilitators need to accept that others have worth in their own right and are fundamentally trustworthy. Such a facilitator is able to accept the trepidation and reluctance that may be present within organisations expected to embrace new concepts and approaches. The third, and final, essential quality of empathetic understanding occurs when facilitators have a sensitive awareness to practitioner perceptions of the proposed changes and the ability to comprehend practitioner reactions from the inside, (Rogers, 1969, Zimring, 1994).

The term facilitator began to be widely used in conjunction with quality circles in the nineteen seventies. Quality circles consisted of small groups of people meeting together regularly, under the leadership of a facilitator, to identify problems, analyse causes, recommend solutions to management and, where possible, implement the solutions themselves (Hutchins, 2006). Within this context facilitators acted as catalysts, innovators, promoters and teachers. Some were also responsible for coordinating and directing quality circle activities in such a way as to ensure that they were smooth running, effective and self-sustainable (Talib and Ali, 2003). A number of large public sector organisations have successfully used facilitation to sustain continuous improvement for two decades. Using a case study approach Goh (1999), discovered that the appointment of a facilitator was crucial to the success of public enterprise and where little or no facilitation was available, entire

programmes had to be restarted up to three times before they could be launched effectively.

Facilitation within the National Health Service has a history extending over a quarter of a century. The first reference to facilitation in a health context was by a Dr Arnold Elliot, a general practitioner, who in 1981 led the way by visiting colleagues with the intention of offering practical advice and support in order to improve practice premises (Carroll et al, 1993). This was a move away from the traditional method of encouraging changes to practice by simply issuing policies with the expectation that practitioners would comply. This was followed in 1984 by the Oxford Heart Attack and Stroke Project under the direction of Elaine Fullard, who was the earliest known nurse facilitator. Fullard later progressed to develop the National Facilitator Development Project. A training officer was appointed to the programme in 1986 to cater for the educational needs of increasing numbers of facilitators (sixty one in 1988), with an additional training officer based in the north of England some two years later (Astrop,1988). Rapid growth in the numbers of facilitators was highlighted in 1992 when the Association of Primary Health Care Facilitators commissioned a survey throughout the country. This found two hundred and twenty nine facilitators in post at that point (Cook, 1994), and in 1996 the National Project found that the number had doubled to four hundred and fifty six. Facilitation has developed and been employed within a variety of health care contexts in both the United Kingdom and abroad, for example: preventative medicine (Fullard et al, 1984), audit (Carroll et al, 1993), primary health care (Eliasson et al, 1998), health promotion, health education, mental health (Warner and Ford, 1998), cancer (Dietrich et al, 1992), and asthma (McGowan et al, 1997). Facilitation may be viewed as a continuum, with a task-orientated approach at one end, and a more holistic approach at the other (Figure 1).

Facilitation Continuum

An uninterrupted series of elements that blend into each other so gradually and seamlessly that it is impossible to say where one becomes the next (Encarta 2008).

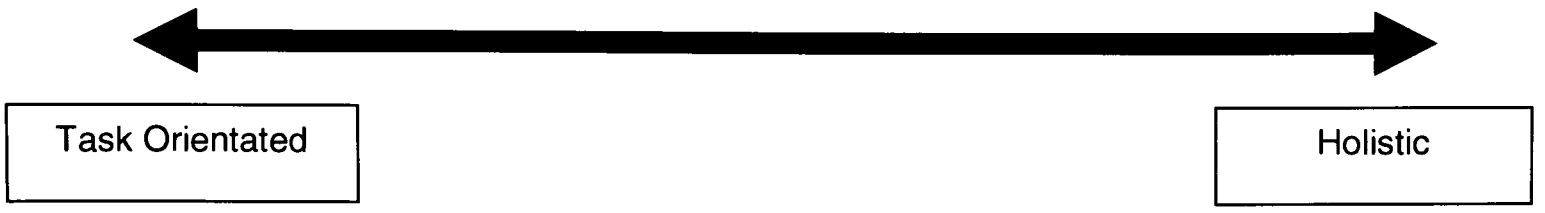

Figure 1

The concept analysis undertaken by Harvey et al (2002), confirmed this view, suggesting that an extensive division could be made between a facilitation model concerned with doing for others, and an approach whose priority is on enabling others. The doing role is likely to be practical and task driven with a focus on administrating, supporting and taking on specific tasks where necessary. In contrast, the enabling facilitator role was more likely to be developmental in nature, seeking to explore and release the inherent potential of individuals. In reality, many approaches contain elements of both these characteristics (Harvey et al, 2002). Scrutiny of the studies selected for this review revealed a variation regarding whether facilitators were drawn from within or without organisations, and in the number of sites a facilitator may operate in at one time, for example, externally, internally, or via outreach.

The Oxford Heart Attack and Stroke Project followed in the wake of a report from the Royal College of General Practitioners in which it was suggested that about half of all strokes and a quarter of all deaths from coronary heart disease in people under seventy were probably preventable by the application of existing knowledge (Royal College of General Practitioners, 1981). This project, under the direction of Elaine Fullard, hailed the role of the facilitator as the means by which general practitioners were enabled to organise their practices in order to provide preventative medicine. This venture acknowledged the difficulties arising from resource and capacity constraints in general practice. It offered interested practices: the services of a facilitator to support: objective setting; recruitment; more effective use of resources; training in prevention methods; exploiting opportunistic contacts with at-risk individuals;

developing systems and procedures; and regular liaison. Equally important was the condition that the facilitator did not see patients in his/her own right. The emphasis at all times was in enabling and empowering practitioners to change working practices. The results of the project were found to be both encouraging and cost effective (Fullard et al, 1984).

Facilitation Models

The External Facilitation Model

The Oxford Heart Attack and Stroke Project is an example of external facilitation involving the introduction of a facilitator from outside the organisation or team. Such a model is valuable where there is disagreement and conflict within a team or when it comprises practitioners from diverse backgrounds. Other advantages of this model are the inherent support and encouragement of the facilitator through: clarification of issues and goals; challenging the status quo; focusing on data collection and evaluation; and providing information and connections. The one main disadvantage with this approach is the possibility of facilitators being seen as intrusive by the established workforce (Wilson and Karlin, 2005, Elwyn and Hocking, 2000).

The Internal Facilitation Model

This model is based upon using an existing member of the organisation as a facilitator to establish a shared vision of what needs to happen and to work towards enabling practitioners to see themselves as true partners in the facilitation process. It is useful in developing a sense of ownership of the vision within the organisation by encouraging collaborative developmental activities. The advantage with this model is that the internal facilitator will have a shared understanding and an appreciation of the particular contexts and challenges faced by practice teams. The main disadvantage to this approach is that internal facilitators can find it difficult to be both a facilitator and a participant at the same time (Wilson and Karlin, 2005). An example of internal facilitation was evident in Snelgrove-Clarke and Scott-Findlay's (2005) clinical trial in which facilitation was used as a strategy for increasing nurses' use of guidelines appropriate to foetal health surveillance among low risk women in labour. A

facilitator from within the organisation supported nurses in a learning through action approach. The study concluded that behaviour could not be changed simply through presenting research evidence alone without additional supportive intervention, that is to say, facilitation.

The Outreach Facilitation Model

This is a flexible, tailored, multifaceted, support process, provided by an individual to a number of sites at the same time. It aims to maximise processes and results from individuals and groups delivering primary care services by providing: practice performance assessment; feedback, and consensus building towards goal setting and implementation; clinical, technical and practical advice; organizational resources; and encouragement to face and move through the challenges associated with practice change.

This multi-faceted approach has been seen as offering promise for improving preventative care in diverse practice environments (Hogg et al, 2005). It differs from the external model in that one facilitator, after a period of training, would work with as many as eight practices simultaneously (Hogg, et al, 2007). Outreach facilitation was employed in a study carried out in Canada (Lemelin et al, 2001). This study looked at changing physician practice patterns and improving preventive care using outreach facilitation as a catalyst for change. Three nurse facilitators were observed working with up to eight primary care practices each. It found that facilitators following a multifaceted approach significantly improved the preventive care performance of primary care physicians. It concluded that facilitation was more likely to change physicians' behaviour than traditional methods such as update courses.

The Facilitator Role

That a facilitator is a catalyst for change appears to be readily accepted (McGowan et al, 1997, Carroll et al, 1993). Lemelin et al (2001) pointed out that facilitators were pivotal in helping individuals and teams understand what they need and in successfully bringing about changes to practice. Table 3 outlines the role of the facilitator as it emerged during this literature review. Differences of opinion as to the character of facilitation were apparent. The role as outlined

in the Oxford Project emphasised that the facilitator did not see patients other than when demonstrating skills.

Facilitation Role

Study or Article	Responsibilities
Stetler (2006)	Provide reassurance and encouragement.
Lemelin et al 2001 p759	Take baseline performance rates prior to intervention. Develop practice policy. Assist in the setting of goals and desirable levels of performance. Assisting in the writing and implementation of development plans. Developing and adapting tools and strategies to implement plan. Monitor progress. Conduct performance feedback to measure the effect of changes made.
Fullard et al (1984) p1586	Help general practitioners to recruit new personnel or to enhance the skills of existing staff. Establish systems and processes. Liaise with members of the primary care team. Devise audit systems.
Cook (1994) p434	Introduce new projects and services from proposal through to evaluation. Health promotion. Teamwork. Training. Advisor.
Astrop (1988) pp311-312.	Cross pollination of ideas. Setting objectives. Discussion. Recruitment/utilisation of personnel. Provide training. Help with developing or supplying resources. Help to establish systems. Liaison. Set up audit systems.
(Nagykaldi, Mold and Aspey 2005 p583	Enhance documentation. Improve office systems. Implement technology. Promote preventative care. Be a resource. Assist with the implementation of guidelines. Provide education. Participate in clinical research thus bridging the gap between research and practice. Generate a positive attitude towards change. Raise awareness. Increase practice knowledge. Strengthen partnerships. Help with consensus building.
King J., (2002) S37	Plan objectives. Make sense of the meaning of what is going on. Confront difficult issues. Handle emotions. Help the group/team to structure itself and actively work together. Create a climate of personal value, integrity and respect.
Garbowski & Farquhar (1987) p49	Acquaint general practitioners, nurses and other staff with the potential to reduce risk factors. Provide guidance and tools. Conduct baseline and follow up audits to measure progress.

Table 3

It was evident that the facilitator was regarded as a motivator here whilst the primary care team did the actual work. Also noticeable was the variety of levels on which facilitators operated, working both vertically with individual primary care teams, and horizontally with the district wide services, and moving between different agencies. Nagykaldi et al's (2005) study differed from the Oxford Project approach in that it did include clinical interventions as part of the facilitation role.

A concept analysis of facilitation undertaken by Harvey et al in 2002, critically reviewed research literature and seminal texts in order to establish the conceptual clarity and maturity of facilitation in relation to its role in the implementation of evidence based practice. This review involved an analysis of ninety-five pieces of health care literature relating to implementing evidence-based practice involving a facilitator. Numerous interpretations of the facilitator role in practice were revealed, ranging from hands on in assisting change, to complex and multifaceted variations. In an operational sense, therefore, this study found that the facilitator's role was dependent upon interpretation of the facilitation concept. In summarising the literature of facilitator roles, the authors felt that there was a broad distinction between a facilitator role concerned with doing for others and a role concentrating on enabling others. The conclusion drawn is that the review was unable to find enough explicit descriptions or rigorous evaluations of the concept of facilitation within the studies analysed to provide a definitive account of the health facilitation role, and that what did exist were multiple perspectives and interpretations of the role.

Several studies and articles identified the knowledge, skills and attributes required for effective facilitation. The essential knowledge requirements, according to Cook (1994), included knowledge of group development, group management, change processes, statistics, research, and audit. To this list can be added the knowledge prerequisites recognised by Elwyn and Hocking (2000) of organisational learning theories and practices, working knowledge of the roles of professionals in primary care, and National Health Service policies and frameworks. Flexibility was seen as a crucial attribute of facilitators necessitating the ability to possess and draw upon a 'toolkit' of skills relevant to

the circumstances and context in which they operate, for example: training, management, empowering others to rely on their own resources, analysis and interpretation, goal setting and action planning, and Inter-personal and communication skills (Astrop, 1988, Elwyn and Hocking (2000), Tan et al, 1999, Seifert et al, 2003, McCormack et al, 2002, Harvey et al, (2002).

Miles et al (1988), suggested that effective facilitators had a range of styles, which they defined as *skills which are largely natural, even perhaps out of the agent's awareness or control* (p 191*),* and that they demonstrated the skills of initiative, calmness, tenacity, and energy. Other personal attributes required for effective facilitation involved rapport and relationship building; motivating others towards the belief that the gains to be had from facilitation are worthy of the effort and cost involved; diplomacy; and the possession of a pioneering spirit.

> *One of the most challenging aspects of the facilitator role is the opportunity for 'shuttle diplomacy'. Primary care is not yet an entirely homogenous entity; it is an interconnected network of different professionals, employed and managed by, and accountable to a range of different bodies,* (Cook, 1994 p 435).

It has been suggested that facilitation has a distinct role with a number of potentially crucial behaviours and activities (Lemelin et al, 2006) that are demanding and requiring considerable skill (King, 2002). However, little firm evidence as to the mix and relative importance of the different skills needed for successful performance of the facilitator role are available, and there is little clarity and consensus about how facilitation skills are developed and refined (Harvey et al, 2002,).

Effectiveness of Facilitator Intervention

The value of facilitation as an effective intervention was endorsed in a number of the studies reviewed. The presence of a facilitator providing face-to-face communication and using a range of enabling techniques was found to have made some impact on changing clinical and organisational practice (Harvey et al, 2002). That facilitation was a significant factor in bringing about change and improvement was evident in the literature review undertaken by Nagykaldi et al

(2005) who found it to be influential in increasing the rate of diabetic foot and eye examinations, establishing office systems and detection interventions and preventive services. There were also considerable improvements to be found in the screening of haemoglobin disorders; physician diagnosis and practice patterns; relationships and communication; and in the provision of professional education. Similarly, a study examining the long-term effect of facilitator intervention on the management of children with asthma (McGowan et al (1997) revealed that a short term change in primary care asthma management had lead to reduced hospital service use, in contrast to the findings of Dietrich et al (1992), and Elwyn et al (2000) that traditional methods of changing practice, such as the distribution of guidelines, were ineffective in common with other passive approaches such as mailings and didactic educational events.

The fact that a competent, supportive facilitator intervention resulted in increased behavioural changes was evident in Seifert et al's (2003) experimental group study exploring how facilitation could influence the behaviour of managers towards their subordinates. Anson et al's (1995) investigation into the effects of facilitators on meeting outcomes was able to determine that facilitators had significantly influenced cohesion and process outcomes. This study speculated that the quality of the facilitator themselves could have a significant impact on the effectiveness of the facilitation available, and suggested that a higher quality facilitator could considerably improve outcomes compared to no facilitator input at all, whereas a lower quality facilitator may have little effect. The majority of facilitators featured in the studies reviewed had been drawn from nursing or health care backgrounds. Bashir et al (2000), whilst evaluating the effect of a mental health facilitator in general practice, established that non-specialist facilitators had been able to improve the ability of doctors to recognise mental illness. Unfortunately, this study was not able to demonstrate any improvement resulting from facilitator intervention in either the management of mental illness by general practitioners, or in outcomes for patients.

Several studies had encountered difficulties with facilitation. Harvey et al (2002) highlighted the fact that facilitation had been conceptualised and applied

differently, thus making it difficult to draw meaningful conclusions about the efficacy of the facilitator role, and that it was impossible to isolate which, if any, dimensions of the concept were effective in promoting and supporting change. Although some studies demonstrated that facilitation as an intervention could result in better care, Nagykaldi (2005) established that the effect did not last following facilitator withdrawal. Facilitation had in some instances proved to be an arduous task resulting in only modest changes to practice. Lemelin et al's (2001) randomised control trial established only modest changes resulting from facilitation and demonstrated that even the small improvements made required a large effort in terms of facilitator time and resources. Some of the reasons speculated upon as to the limited improvements made by facilitation were noted as being: the difference in the type and number of interventions undertaken; the facilitation context and workload; the incapacity of individual practices to change due to organisational conflicts; issues of power and status; inclusion and exclusion in decision-making processes; systems not open to challenge; a lack of motivation and commitment; and other health service changes taking place simultaneously (Hogg et al, 2007, and Elwyn and Hocking, 2000).

Changing prevailing practice had been found to be something of a complex activity, which was often difficult to sustain. McGowan et al (1997) in their work on childhood asthma found that changes seen in consultation patterns, prescriptions and reduced hospital admissions during the facilitation intervention year did not persist in subsequent years. This was attributed to either a decline in enthusiasm, or to other priorities subsequently taking precedence, diverting attention from childhood asthma issues.

Health Facilitation and Learning Disability

This next section explores health facilitation within a learning disability context. Two articles, three editorials and three research studies met the search criteria. The articles and editorials take a different perspective on the *Valuing People* (2001) concept of health facilitation. The article *Decoding Valuing People* (Burton and Kagan, 2006) aimed to decipher *Valuing People* in terms of ideologies in human services and New Labour policy. Whilst in *New Public Management and Public Services for People with an Intellectual Disability: A*

review of the Implementation of Valuing People in England, Cumella (2008) explored whether or not the document conformed to this particular political ideology.

Moving on to the editorials being considered, in *Valuing People: Long Awaited Strategy for people with Learning Disabilities for the Twenty-First Century in England,* Gates (2001) welcomed *Valuing People* but also expressed his concerns regarding what he saw as its negative aspects, mainly issues of funding, its lack of realism, and the fact that its implementation was not compulsory. In the second editorial, *Plus ça change: Progress achieved in services for people with an intellectual disability in England since the publication of Valuing People,* McNally (2004) acknowledged the positive impact of *Valuing People* but, like Gates, was less complimentary about what he believes to be insufficient funding; the disparity between the *Valuing People* ideology and its reality in practice; and the incongruity arising from legislative measure not being fully supported by action from government. The third and final editorial, *Valuing People with Learning Disabilities in the Context of the Human Fertilisation and Embryology Act 1990: Social policy and Legislative Incompatibility*, (Sooben, 2004) focused on the conflicting messages contained within this piece of legislation and how it contrasted with the concept of 'valuing' existing within the *Valuing People* white paper. These three editorials have been included as they offer viewpoints that are, whilst undoubtedly expressing their own opinions, topic specific, stimulating, and emanate from authors respected in the subject.

The three research studies included in this literature review include, firstly, the work of Caan et al (2005) who undertook an examination of health facilitation in primary care, which described the appointment of a health facilitator to improve transition planning for young people with learning disabilities about to leave school. Secondly, the study carried out in by Mir et al (2007) that addressed *Valuing People's* (2001) health specific objectives as they emerged in Leeds. And finally Thomson et al's (2007) study into health facilitation in primary care as seen from a practice and education perspective.

The first of the articles to be considered here is Burton and Kagan's (2006) *Decoding Valuing People.* The authors argued that reading and understanding current government policy documents relating to people with disabilities could be both uncomfortable and difficult due to the fact that they contained incongruous aspects as they both maintained and challenged simultaneously the social processes that create inequalities and oppression in society. The authors' declared purpose was to decipher *Valuing People* in terms of the *ideologies in human services, and the current New Labour policy mix* (p299). The approach used to do this consisted of an analysis of three of *Valuing People's highly* emphasised concepts of: person-centred planning, direct payments, and employment, alongside the key principles of choice, rights, social inclusion and independence. In a brief summary of the changes that have occurred for people with learning disabilities over recent years, the authors draw attention to the fact that many changes had developed asymmetrically, with progressive practice existing alongside long-standing, outmoded approaches.

The restructuring of welfare and public services has featured prominently in the Labour Government's schema. In examining *Valuing People* (2001) as it related to key aspects of the New Labour government's policies, Burton and Kagan suggested that the policies of Thatcherism and New Labour bore many similarities and therefore New Labour's move towards social inclusion and individualised care arrangements was inevitable given that the social welfare model, introduced post Second World War, in which the state accepts total responsibility for the provision of comprehensive and universal welfare for its citizens, had proved too costly to maintain. The promotion of free market ideals and the endorsement of privatizing public services as a means of reducing public expenditure featured in the neo-liberal government of Margaret Thatcher in the eighties and nineties. This created a change of attitude from one of public and community good, towards one of individualism and individual responsibility. *Valuing People* was developed amidst a climate in which people with learning disabilities, their families, and professionals were striving to end discriminatory practices and move towards positions of acceptance, and putting the needs of people before the needs of services and systems in an attempt to

live ordinary lives. *Valuing People* presented person-centred planning as the means to achieve this. The authors however, whilst acknowledging person-centred planning as a worthy concept expressed doubts about its ability to lead to significant service reform describing it as *voluntaristic, individualistic and romantic* (p306).

The article accepted that getting people with learning disabilities into work went beyond the *Valuing People* (2001) agenda. Employment schemes helping people with disabilities to find work would seem to fit with the government's desire to promote the principle of independence and were in keeping with their policy to reduce the number welfare benefits. However, *Valuing People* accepted that for many people with learning disabilities employment would remain an aspiration and this suggested that the reality of work would entail the need for intensive support, whether paid or unpaid, if this were to be achieved. The authors pointed out the impracticality of this.

People with learning disabilities often need practical support to participate meaningfully in everyday activities. Essentially direct payments were seen as a way of furthering independence and enabling people to manage their own care flexibly by employing their own carers or personal assistants. Whilst acknowledging the potential benefits of such a scheme in terms of the freedom from service and professional control that it offered, Burton and Kagan drew attention to the downside to such systems as being the inevitable reduction in existing public service provision leading to a reliance on a poorly paid, non-unionised workforce without any regulation as to training and safety needs.

Burton and Kagan suggested an alternative approach to empowering people with learning disabilities that would involve an adequately funded public service with people with learning disabilities at its core, and employing approaches that encompassed *collective responsibility and participative governance, and which drew on experiments in deliberate democracy* (Burton and Kagan, 2006, p308). Whilst accepting and welcoming the focus of *Valuing People* (2001) on independence, choices, inclusion and rights, they questioned why these particular elements were chosen for inclusion and not others, and why they had

been viewed from one particular perspective as opposed to other positions. They proceeded to suggest that whilst stressing issues around discrimination and the right to vote *Valuing People* had been remiss in disregarding how people with learning disabilities could become politically active. As the authors saw it *Valuing People* (2001) tried to take on board *planned social change* (page 306), as in the instance of health care provision, where it promoted working at both an individual level by way of health action plans, and at a systems level via health facilitation. They suggested that such a social approach was likely to be more effective when made simultaneously at macro, meso, and micro levels as opposed to separately on two levels and regretted the fact that the *Valuing People* agenda was not connected to the National Service Framework programme.

Valuing People (2001) was deemed by Burton and Kagan as set firmly within the context of the New Labour government's ideology in relation to social policy. They found it to be contradictory and criticised its portrayal of people with learning disabilities and their possibilities for the future suggesting that this had been idealised and as such was unrealistic. They felt that the emphasis placed within *Valuing People* on the key principle of making choices without acknowledging the complexity of this as a process, the subsequent consequences of choice upon the self and others, and the challenge of enabling people with learning disabilities, were not recognised and considered sufficiently. They expressed dissatisfaction of V*aluing People,* finding it to be focused mainly on the more able and, to a large extent, more easily assimilated people with learning disabilities, to the detriment of those with severe and complex learning disabilities. Equally censured was the overly simplistic depiction of social inclusion, that is, as a sequence of individual experiences. This, they asserted, failed to encourage meaningful engagement and inclusion in the mainstream of society as a whole. They believed it to be both impracticable and unobtainable for most people with learning disability in that it would require a thorough evaluation of the level of support required and considerable additional financial investment.

The next article under consideration here is by Stuart Cumella, of the Birmingham University Medical School, whose background is in social work and social research. His 2008 article New Public Management and Public Services for People with an Intellectual Disability: A review of the Implementation of *Valuing People* in England offered a more recent viewpoint on the *Valuing People* (2001) policy. The article traced the influence of political ideologies upon public policy development from post World War Two universalism, based on the concepts of human rights, and equality of access to public services as expressed within Universal Declaration of Human Rights (1948) and the Council of Europe's European Convention of Human Rights (1950) drawn up in the aftermath of World War Two atrocities. With universalism came the assurance that public services would provide a minimum standard of human rights. This approach, underpinned by theories such as normalisation, Cumella believed, presented people with learning disabilities as being a stigmatised and oppressed group deserving of liberation (p179), calling for the development of offsetting and enabling services.

The consumerist ideology of the nineteen eighties and nineties, however, aimed to be client-centric and consumer driven whereby being a consumer of goods and services was considered to be both constructive and advantageous. Within such a framework government aspired to promote choice and competition, whilst at the same time reducing the role of public agencies as service providers. Through the new public management philosophy of the twenty first century the government aimed to modernise public sector services by calling for an increase in market approaches towards one of service provision. It envisaged greater cost effectiveness and changes to the role of public services from that of service provider and administrator towards a commissioning and management role leading to an increased amount of consumer choice. Characteristics of the new public management approach, according to Cumella, are evident within *Valuing People*; for example, the adoption of a critical perspective of existing services, and an approach to partnership working which he described as being one of arm's length interagency (p108). He gives an example of arm's length interagency working by describing how the Learning Disability Task Force were briefed to advise

government and set targets for local services to meet *Valuing People*'s generically worded objectives.

According to Cumella new public management favours the bringing together of differing agencies to create new joint agencies. He suggested that this served to blur responsibility for policy and may provide a cloak for the centralisation of power (p183) and bemoaned the fact that there had been no evaluation of either the Learning Disability Task Force or the Valuing People Support Team. In relation to the work of the Learning Disability Partnership Boards he painted a depressing picture: national policy initiatives prevailed; it was difficult to reconcile care management and person-centred planning; there was an element of rubber stamping; and plans produced were ill informed and unrealistic. He also noted the extent to which people with learning disabilities and their carers were compromised in terms of equality with other board members in that they were often excluded from decision-making processes and were not recompensed for their time or pecuniary losses as a result of attending meetings. In relation to *Valuing People*'s targets the inference within this article is that they clearly embrace new public management philosophy: the suggestion being that within a target driven culture those with lower political and managerial priority often lost out to those with more power and a higher profile, citing the failure to close many of the long-stay hospitals as an example. Cumella concluded that *Valuing People* was in essence political as it incorporated the crucial elements of new public management.

At the core of this article is the opinion that *Valuing People* (2001) missed many valuable opportunities, citing: a censorious approach to existing provision whilst making no attempt to grant people with learning disabilities any additional rights; introducing only minimal changes aimed at increasing opportunities concerning ease of access to, and more socially inclusive public services; existing school-based assessments needing to include an employment advisor merely being reiterated rather than being built upon; Partnership Boards only being expected to agree a framework for person-centred planning; that no specific mention was made of the number of health facilitators to be appointed and nor was there clear description of the role being one to lead towards systemic changes in

primary and secondary health care services; and, finally, that *Valuing People* failed to indicate any preferred models for residential accommodation. On considering its impact, some seven years after publication, Cumella conveyed his disappointment at the lack of availability of official statistics, information on trends, and of outcome focused research commissioned by the government: all of which would have assisted in establishing its influence on the lives of people with learning disabilities. These issues arose consistently within the interviews conducted whilst gathering data for this thesis, and which Cumella suggested was a feature of the New Public Management approach. Cumella's disillusionment was further expressed in relation to the vague and often insufficient information contained within *Valuing People*. He gave as examples: the emphasis on person-centred planning suggesting considerable confusion was created by also proposing new health action plans; the continuance of care management assessment processes; vocational plans; housing plans; and in some instances, communication plans. The limited research into health facilitation was acknowledged by Cumella, who drew attention to the tendency to focus upon individual facilitators working in individual practices identifying patients with intellectual disabilities as a means of removing barriers to health services and screening programmes. Whilst finding this useful, in his opinion, this did not fit with the model of health facilitation as portrayed within *Valuing People* in which a facilitator was to be responsible for a number of primary care practices. As a result he believed many primary care teams lacked an awareness of the help and support available from the specialist services. That health facilitation research is limited and focused mainly upon individual facilitators will be seen in the studies presented later in this review.

Several concerns regarding the funding of *Valuing People* (2001) were raised by Cumella. First and foremost, he noted that *Valuing People* omitted to mention the cost of implementing person-centred planning, and made no additional funding available to allow people's goals to be met. Also lamented was that in the intervening years no information had been published as to the extent to which devolved budgets had grown as a result of *Valuing People*, and that in reality English law excluded from the direct payment system those adults

who lacked the capacity to consent and presumed that this may have been an impediment for some people with learning disabilities.

Looking at both these papers it is evident that *Valuing People* (2001) and its underpinning philosophy was welcomed. Despite this there were reservations and concerns. Generally it was found to be confusing, vague, ambiguous, naïve in its approach to the complex issues of such things as inclusion and choices, contradictory and, in some respects unrealistic in its understanding and portrayal of people with learning disabilities. The main focus of *Valuing People* was thought to be towards the more able individuals with learning disabilities and, whilst raising people's hopes and desires was to be admired, it ran the risk of being viewed as being too optimistic and lacking in pragmatism. Particularly singled out for mention was the risk of those with profound and multiple learning disability being overlooked and marginalized, and the lack of thought given to the financial commitment required to support the *Valuing People* vision. In relation to the *Valuing People's* aspirations for the health and well being of people with learning disabilities regret was expressed at the fact that it had not been included in the National Service Framework Programme and therefore lacked a systematic approach and a degree of authority, thus leaving it open to interpretation, manipulation and disregard.

Presented next are three editorials, the first by Bob Gates, the second by Steve McNally, and the third by Roja Sooben. Gates' (2001) editorial provided a synopsis of the *Valuing People* (2001) and particularly welcomed its proposals to ensure quality. He found it difficult to be critical of the quality based agenda of *Valuing People* (2001) but suggested that it had failed to address the existing problems within services, which he said would not *evaporate* (p206). As an example of this he cited the presence of demoralisation amongst health and social care staff, suggesting that in order to value people with learning disabilities it was also necessary to value the staff employed to work with them. To this end he welcomed the introduction of a Health and Social Care strategy providing new opportunities for learning disability staff, including a Learning Disability Awards Framework, the development of leadership initiatives and local workforce planning.

The editorial recognised and expressed regard for *Valuing People's* commitment to older carers, but was disappointed to find this only amounted to a pledge to establish the numbers of people living with older carers. The presence within *Valuing People* of the *Good Health* chapter was well received in this editorial. This chapter identified the need to address issues relating to giving consent to treatment, and health facilitation planning, but Gates expressed reservations in relation to the prescriptive tone adopted by *Valuing People* and speculated as to whether the general population would happy or willing to accept similar levels of intervention.

Gates recommended caution concerning issues arising within *Valuing People* (2001). Gates stated that care was needed regarding the perception within *Valuing People* of people with learning disabilities as a homogenous group as this could result in the needs of people with profound and complex needs being overshadowed. Marginalisation was indeed a real threat because he pointed out that at least one section of the learning disability population had received no mention within *Valuing People,* these being those people in receipt of forensic services. Another cautionary note sounded by Gates was through reference to the no-mandatory status of *Valuing People* and the consequent risk of it being compromised. He reflected that there was a body of evidence to suggest that guidelines such as *Valuing People* tended to be ignored when localities were left free to interpret and implement and implied that they may be open to political manipulation, concluding that people with learning disabilities would have been better served via a National Service Framework.

Plus ça change: Progress achieved in services for people with an intellectual disability in England since the publication of Valuing People (2004) by Steve McNally appraised the gaps between the *Valuing People* policy and its implementation. Whilst appreciating *Valuing People's* (2001) encouragement of positive developments for people with learning disabilities and its emphasis on person-centred approaches, McNally expressed a number of concerns. He suggested a disparity existed between the ideology of *Valuing People* and the

reality of practice within services for people with learning disabilities; intimating that this gap, rather than reducing, continued to grow.

Among his concerns were, firstly, the financing of *Valuing People* and the sufficiency of the funding available to deliver the *Valuing People* vision. McNally suggested that financial constraints often resulted in the most vulnerable in society bearing the burden. He went on to questions the wisdom of allocating funds to enterprises lacking positive proof of their ability to work with people with learning disabilities towards achieving a position of empowerment. Secondly, on appraising Partnership Boards McNally lamented the public's lack of awareness and limited involvement in them, and cited Mencap's (2003) survey of Partnership Boards that found that only twenty seven percent of those audited were accessible to the public. He proceeded to criticise *Valuing People* for its vague objectives and lack of information as to how they should be met, preferring clearly stated outcomes and delivery expectations; citing, as one of his main concerns, the possibility of person-centred planning becoming a paper exercise unless great effort was made to make such philosophically based policy initiatives work in practice. He spoke of the practical difficulties of service delivery in a context in which governments pass enabling legislation unaccompanied by the obligation to provide the services needed to achieve this, preferring instead to leave this to the discretion of local authorities and agencies. As a result the services provided are often those that are available from the limited resources available rather than those that that would meet both assessed and expressed needs. He advocated instead for the development of a truly person-centred way of working that would involve open and honest debate between commissioners, service providers, people with learning disabilities and their families as to what is possible and achievable within prevailing financial constraints.

According to McNally systemic difficulties have the potential to form barriers preventing the successful implementation of *Valuing People* (2001). In particular he spoke of his anxiety that Community Learning Disability Teams may develop into bureaucratic structures, devoting time to issues of eligibility of referrals, administration, and subsequent channelling towards other

organisations rather than offering supportive interventions. McNally expressed his disappointment at the time taken for policies to become the norm. He stressed the fact that the concept of social inclusion was not new, having been evident since the nineteen nineties; and concluded that whilst *Valuing People* was to be commended, it would require practitioners to be both creative in approach and visionary in outlook if they were to be able to translate its proposals into action.

The third and final editorial presented as part of this literature review is that of Sooben (2004), who approached *Valuing People* (2001) from a somewhat different but interesting perspective. The editorial began with a positive acknowledgment of *Valuing People's* recognition of the devaluing experiences faced by people with learning disabilities and its commitment to overcome this via its four underpinning values of rights, independence, inclusion and choice, and the support of existing legislative frameworks. Then came the question echoed by many of the participants in this research: given that this was legislation already in existence but not applied, just how was *valuing itself to be achieved* (Sooben, 2004, p107)? This editorial highlighted the government's inconsistencies towards discrimination of people with learning disabilities. Sooben pointed out that not all existing legislation supported anti-discriminatory practices and cited the Human Fertilisation and Embryology Act (1990) as an example. This Act allows for the termination of a foetus up to twenty four weeks gestation unless there is a serious handicap when termination can take place at any time, even up to full term. How, he queried, could there be true valuing of people with learning disabilities when the state allowed for discrimination against them even before birth. Sooben went as far as to imply that negativity towards people with learning disabilities concerned more than merely a lack of awareness but in fact lay in deep seated beliefs of their lack of worth as human beings. Such discriminatory practices it was suggested had *underlying connotations of eugenics* (p110). Sooben suggested that the success of *Valuing People* (2001) would depend not only on the government's determination to improve service provision for people with learning disabilities but also *a consistent, unswerving and unbiased commitment made toward*

persons with learning disabilities, both at conception and beyond (Sooben, 2004, p108).

Moving on next to review research specifically related to health facilitation for people with learning disabilities proved to be problematic. Whilst speculation as to what health facilitation within the learning disability context should entail has been prolific, as evidenced by discussion undertaken at seminars, conferences, and within the Foundation of Learning Disabilities electronic forum, only three published research studies were identified via electronic database search. The three studies will be introduced here briefly after which they will be considered collectively. The first study, an examination of health facilitation for young people about to enter adult services and the work of a health facilitator employed specifically to improve transition planning for school leavers was the focus of Caan et al's study in 2005. The second undertaken by Mir et al (2007) was concerned with health facilitation in Leeds specifically around the *Valuing People* (2001) health related targets of people with learning disabilities being offered a health facilitator by Spring 2003; all being registered with a General Practitioner June 2004; and all people with a learning disability having a health action plan by 2005. The last of the three studies to be deliberated upon is that of Thomson et al (2007) which explored how health facilitation in primary care was viewed from the perspective of both practice and education as a means of improving both the identification of health needs and access to appropriate health care for people with learning disabilities.

These three studies all bore some similarities to each other: for example, each focussed on a single area of the country and used combinations of similar data gathering methods, that is, interviewing and shadowing, to which the Caan and Thomson studies added questionnaires and reflection, and the Mir et al and Thomson studies assembled and scrutinised information from records and databases. Thomson et al alone used field notes and an e-mail survey to gather additional data. All three studies were somewhat constrained by the fact that the population was studied for a very short period of time. Despite similarities, the studies differed in certain respects. The Caan and Thomson studies focused upon the work of just one facilitator practising in London

Boroughs; whilst Mir's research looked at the actions and outcomes of eight strategic facilitators and a learning disability team of thirty nurses acting as operational level facilitators practising in the city of Leeds. The size of the learning disability team in Mir's study was acknowledged as not being the norm amongst Learning Disability Teams; this large number arose as a result of re-deployment following the closure of a long stay hospital in the area.

A professional background in learning disability nursing was common amongst facilitators in all three studies. The studies by Caan et al (2005) and Thomson et al (2007) involved health facilitators undertaking both strategic and person-to-person work. Whereas Mir et al (2007) used a conceptual model of health facilitation making a clear distinction between the strategic and operational roles, with person-to-person work falling into the remit of those functioning at the operational level, for example, the learning disability nursing team. Several similarities were evident in relation to how health facilitators had approached the role. Both Caan et al and Thomson et al's studies emphasised the value of making a wide variety of contacts and undertaking preparatory work with other professionals. This was achieved via delivering presentations and holding awareness raising sessions. Mir et al's study also demonstrated the importance of this approach, which they felt lay at the operational facilitation level, leaving the strategic facilitator free to support appropriate and accessible mainstream service development.

Access to services was one of the main features in Chapter Six of *Valuing People* (2001) *Improving health for people with learning disabilities.* Caan et al (2005) and Thomson et al (2007) both reported progress in this area. That facilitators had helped to access adult services for young people in transition was evident in Caan et al's research in which the development of a signposting and referral system was highlighted. Thomson et al's study reported service improvements based on: opticians offering eye tests; the National Health Service Forum for Patient and Public involvement arranging customer care training for all staff regarding learning disability issues; Age Concern's foot-care service being extended to include people with learning disabilities; and

community dental services opening a Saturday morning (although segregated) clinic for people with learning disabilities.

That health facilitation could be challenging was confirmed by Thomson et al (2007) who found it to be demanding, initially unappreciated by other professionals, and requiring the post holder to be highly skilled. This study also commented on the limited involvement of General Practitioners, speculating that this was due perhaps to the rapid rate of change in general practice or possibly to the low priority given to people with learning disabilities in primary care. Mir et al (2007), in common with the studies exploring facilitation in generic health contexts, identified working across professional and non-professional boundaries at both service user and strategic planning levels as being particularly challenging to health facilitators. Potentially more difficult for facilitators in learning disability was the fact that when looking at the local learning disability team a lack of confidence was detected, resulting subsequently in a reluctance to accept health facilitation as a new way of working for the team.

Amongst other obstacles to successful health facilitation for people with learning disabilities, Mir et al (2007) found that Primary Care Trusts gave low priority to learning disability related targets. Consequently little attention was paid to the issues of appropriate management and clinical supervision arrangements, resulting in poor monitoring of performance and the achievements of outcomes. This study discovered that health facilitators had difficulty overcoming obvious gaps in service infrastructures; for example, the lack of central recording systems hindered the gathering of essential data for use within primary care. Also encountered was a significant level of confusion relating to the definition of learning disability amongst generic health professionals and their concerns about labelling people as having a learning disability. These were seen as being difficult issues for health facilitators to overcome, requiring skilled handling.

Mir et al (2007) made the point that *Valuing People* (2001) failed to identify the skills and experience needed for the health facilitator's role, and that training for

those in a health facilitation role ought to have been a necessary requirement, which unfortunately had not been made available via *Valuing People*.
As to who was best placed to undertake health facilitation on behalf of people with learning disabilities there was agreement between Mir et al (2007) and Caan et al (2005) that it should not be assumed to be learning disability nurses. Mir et al (2007) concluded that far from being well placed to take on the role of health facilitators as decreed by *Valuing People,* members of the learning disability nursing team were ill equipped and lacking in the required skills.

Caan et al (2005) suggested that whilst some backgrounds, such as social work or youth work, were unlikely to prepare a practitioner sufficiently for a health facilitator role, a clinical background was vital. However, having experience as a learning disability nurse was not a prerequisite for successful functioning as a health facilitator. All three studies agreed that there was a gap in the understanding of the long-term impact of developments on the health and well being of people with learning disabilities. Similarly, there was general agreement that health facilitation had a valuable part to play in initiating changes to address disparities in service provision, systems development, and improving access to services.

That there are different levels of health facilitation is apparent within both *Valuing People* (2001) and in the accompanying guidance notes *Action for health, health action plans and health facilitation detailed good practice guidance* (2002). Health action planning would fit well within the level of health facilitation undertaken with individuals. The research undertaken in Leeds (Mir et al 2007) found that families, carers, and individuals with learning disabilities did not understand health facilitation and health action planning. The findings also revealed a model of health action planning much in need of improvement, with some plans resembling assessments rather than person-centred plans. Health action plans had been offered to only a small number of people and an even smaller number from minority ethnic groups. Where health facilitators had implemented health action plans it was evident that a range of possible health issues had been explored. However, problems arose on withdrawal due to family members' inability, or reluctance, to implement the plans put in place by

health facilitators. Where the responsibility for health action plans had passed on to willing and capable health facilitators they proved to be very effective (Mir et al 2007).

At a strategic level much of the work carried out by health facilitators centred on overcoming mainstream services' apathy and disincentives to work with learning disability teams. For example, only a quarter of the General Practitioners had taken up the template developed by the Leeds research team intended to help them to identify their practice population and compile effective learning disability registers. Mir et al's (2007) examination of records showed that there were no significant differences between general practices in the quality of care patients received either before, or after, being offered health facilitation. However, the number of health checks, recordings of blood pressure, body mass index, height and weight, and medication reviews rose in practices that had identified their patients with learning disabilities.

Conclusion

Despite variations in performance, facilitation has materialised as a useful way of changing health service practice. The White Paper *Valuing People* (2001) proposed the role of health facilitator as a mean of overcoming the barriers encountered by people with learning disabilities when accessing health services. However, the White Paper did not provide a model of health facilitation nor did it refer to any of the evidence that was available about the implementation of health facilitation in mainstream health care settings. As demonstrated, facilitation is not a new concept within mainstream healthcare; however, its application to people with learning disability was only formally recognised for the first time in *Valuing People*. This formal recognition was a significant opportunity to change the way in which health services were delivered at all levels (Williamson et al 2004).

This review has examined the literature relating to *Valuing People* (2001), health facilitation within primary care services in general, and health facilitation as it related to people with learning disabilities. An outline of the search strategy employed was provided, as was a definition and description of the

different models encountered within generic health care contexts. The brief account of *Valuing People* (2001) presented in this chapter has provided information as to the document's main areas of concern, amongst which was that of improving the health of people with learning disabilities. It also outlined the main impediments seen as needing to be overcome if people with learning disabilities were to lead full and satisfying lives, together with a battery of objectives and sub-objectives deemed necessary to achieve this.

The foundation of facilitation as a concept was explored briefly, tracing its origins to Carl Rogers, albeit not within a health setting. This task fell to the pioneering work of Dr. Arnold Elliot and the 'Oxford Heart Attack and Stroke Project' under the direction and Elaine Fullard, which began the process of rapid facilitator growth during the nineteen eighties and nineties. The role of the facilitator as a vehicle for change emerged throughout the literature review. However, it was apparent that whatever the model of facilitation employed, the facilitator role was dependent upon interpretation of the facilitation concept and the knowledge, skills, personal attributes and experience thought necessary to perform the role effectively. That facilitation could be a successful intercession was sanctioned in a number of the studies reviewed. It was demonstrated that the presence of a facilitator providing face-to-face communication and using a range of enabling techniques had made some impact on changing clinical and organisational practices. However, it was also evident from the papers studied that sustainability following the withdrawal of the facilitator could not be guaranteed.

Research into health facilitation and learning disability was found to be very sparse despite nine years having elapsed since *Valuing People* (2001) was published. The three studies with a learning disability focus included in this review found that although a professional background in learning disability nursing was the convention amongst facilitators, this was not without its problems in that learning disability nursing did not necessarily equate with the skills required of health facilitators. Different interpretations of health facilitation were evident, with some facilitators undertaking facilitation at more than one level, whilst others established clear distinctions between the strategic,

operational, and person-to-person work. That there had been difficulties encountered by health facilitators for people with learning disabilities was apparent: not only those that could be anticipated, for example, resistance to change; but also deficits in the competency and confidence levels of the facilitators themselves.

To date only limited research has been undertaken into health facilitation for people with learning disabilities, and there is an absence of research into health facilitation from the perspective of health facilitators themselves. Because of this gap in the literature there was a need to investigate and analyse the concept and experience of health facilitation further. The research focus of this thesis therefore is significant in that, whilst using some of the same sampling and data gathering methods as previous studies, many aspects of it differed considerably. For example, it has adopted a phenomenological design in order to explore health facilitation from the perspective of health facilitators, a viewpoint not previously explored in any great depth. It is representative of participants from across the whole of England, thus encompassing both urban and rural areas, rather than focusing on a specific geographical area, in order to obtain a broader picture of what was occurring nationwide. And finally, it was open to all health facilitators irrespective of their professional background, working at any level or any service context.

Chapter 3

Method

Introduction

Chapter three presents the background and rationale for the choice of an eclectic phenomenological approach of enquiry into the *Valuing People* (2001) concept of health facilitation. It will also address the ethical considerations associated with the research as they arise within the text. In terms of chronology the research was done by: policy analysis; a Delphi study; a series of semi-structured interviews; and, finally, a reference group meeting. This chapter will concern itself with describing these methods and their quality control mechanisms.

Theoretical Framework and Influences

Generically, qualitative research is *a situated activity that situates the observer in the world .... It consists of a set of interpretative, material practices that make the world real* (Denzin and Lincoln (2005 p3). Essentially, phenomenology is based upon Husserl's premise that knowledge depends on insight (Husserl, 1931). Thus, direct insight is to be acquired through the investigation and analysis of essences and general structures. It is termed *phenomenological* because it focuses on the phenomena of perceived experience. The goal, therefore, is to construct a text that is both strong and insightful, and a representation that brings to mind the phenomenon described. The result of a phenomenological enquiry is a text or story that gives insights into the phenomenon under study and associated meanings (Kleinman, 2004).

Phenomenology proposes a return to the origins of knowledge, by examining how the world first appears to our consciousness, thus demonstrating that the world is an experience which we live before it becomes an object which we know. Therefore, phenomenology studies aspects of human behaviour from the perspective of a person's own experience (Anderson and Worth, 1995) with the goal being to describe that human experience as it is lived (Merleau-Ponty,1964). Phenomenology comprises a number of schools of thought all of

which explore the world in slightly different ways. As a result of such diversity phenomenology cannot therefore claim to be an exact philosophy.

Descriptive phenomenology has been explained as being a descriptive analysis of the essence of pure consciousness (Husserl 1931). In phenomenology consciousness refers to *the totality of lived experiences that belong to a single person (*Giorgi, 1997, p236). One of the main characteristics of consciousness is its intentional nature, for example, one's thinking is *of* or *about* something. McIntyre and Smith (1989) described intentionality as being the fundamental property of consciousness and the principle theme of phenomenology. Essentially, Husserl's phenomenology is concerned with: gaining knowledge via observation of, and insight into, objective phenomena as a means of understand another's experience; stressing the need to look at the quality of those experiences; and placing great emphasis on consciousness (Husserl, 1917, Kruger, 1979). Phenomenological reduction is the fundamental resource that ensures a reliable description of a phenomenon, seen as essential for a rigorous foundation for both the natural and human sciences (Husserl, 1965). This is the process of defining the pure essence of a psychological phenomenon and can occur on three levels: the epoché, consists of setting aside (bracketing) all the beliefs, theories, and attitudes about oneself and the world which have so far been taken for granted; the eidetic, the goal of which is to find the basic components of a phenomena or its essences; and finally the transcendental which brackets the empirical subject as well as the world (Puliganfdla, 1970).

Interpretive phenomenology also referred to as hermeneutic or existential phenomenology has been described as being *concerned with meaning* (Van Manen, 1999, p79). Hermeneutics was the term originally applied to the deciphering and interpreting of the linguistics, the history and the context of ancient manuscripts. Hans-Georg Gadamer, a proponent of phenomenological hermeneutics, believed that knowledge emerges as we learn to question continually our prejudices, and amend our assumptions (Warnke, 1987). Phenomenologists such as Heidegger were concerned with the truth of what it means to 'be'. Heidegger considered understanding phenomena rather than

just their description to be the goal of phenomenology. He put forward the notions that: it was through language that 'being in the world' or 'Dasein' could be understood (Maggs-Rapport, 2001); understanding is impossible without some sort of pre-knowledge; human understanding is a form of interpretation; and there can be no interpretation that is free of knowledge. He saw the fundamental ontology (the meaning of being in general) as the ground upon which the human sciences could be constructed (Heidegger, 1962).

Heidegger developed the interpretative perspective based on the work of Husserl. Moustakas, (1994) articulated the commonalities of the two main schools of phenomenological thought. Whilst Husserl saw the value of scientific knowledge he argued that knowledge gained in the scientific way could not help us to understand the concerns of human beings as a person's experience is always the experience of something. From this, it follows that to research the human experience of health facilitation in learning disability services it was the experiencing *of* to which attention should be paid. This paradigm assumes that there are multiple interpretations of reality and that the goal of researchers working within this perspective is to understand how individuals construct their own reality within their social context (Berger and Luckmann, 1966).

With descriptive and interpretive phenomenology there are some commonalities in that they both: require researcher immersion in the phenomena to look for meanings and essences of experience rather than measurements and explanations; concentrate on a holistic experience; and obtain descriptions of experience through first-person accounts (Moustakas, 1994). All of which are integral to this research. However, the overall perspective of each tradition has some distinctive differences (Laverty, 2003). Both traditions may engage the keeping of a reflective diary but, whereas interpretive phenomenology would require the recording of any assumptions and interpretations that arise and the incorporation of these within the experience under consideration, a descriptive approach would advocate that any assumptions and biases identified by the researcher be set aside (bracketed) (Laverty, 2003). Within this research a descriptive approach to reflection has been applied. Also in keeping with the descriptive phenomenological ideal a literature review was undertaken only

when all the data had been gathered in order to ensure that data was as free as possible from unexamined presuppositions (Spiegelberg, 1975).

The primary goal of methodology in interpretive phenomenology is to recognize that every act of research is actually an act of interpretation (Cole & Avison, 2007). Interpretation is present within the policy analysis and to some extent the thematic analysis of participants' experiences. Similarly, in accordance with the interpretive tradition I have maintained a constantly questioning attitude in the search for any incomplete or incorrect understandings. This was achieved via participant validation and having the results and analysis checked by a third party.

A quantitative approach to the research was considered and rejected as a methodology as it did not allow for the how and what kind of questions which would enable one to focus on whole experiences gained through first person accounts obtained in ordinary everyday surroundings. Health facilitation, as experienced by health facilitators in the arena of learning disability, had yet to be subject to close scrutiny. A qualitative approach would be the better option, given that data would be gathered directly from participants, thus giving it a depth and richness that could be utilized at a future point in time in order to inform quantitative studies looking at possible comparisons, relationships between variables and issues of cause and effect.

The result of a search for a theoretical approach to this research was the choice of an eclectic model. This was important because of the need to merge aspects of the descriptive and interpretive threads pf phenomenology. This choice was liberating in that it enabled me to choose research methods that, whilst being consistent with a broad phenomenological approach, were practical in that they allowed me to give voice to the health facilitators and make sense of what they said.

Whilst undertaking this research a number of theoretical issues arose. These were essentially about power and authority and were expressed within interviews in a variety of ways. For example, several participants explained that

they had fancy titles but no tools or authority to do the job. The concept of power, capital and leadership will be explored in chapters 5 and 6 as findings from this research. These concepts became important as the data collection progressed. Chapters five and six demonstrate that health facilitators found themselves to be in an ambiguous situation in relation to power and control. The approach that I adopted was designed to allow issues to emerge rather than to be imposed upon the respondents. The analysis ensured that respondents' stories spoke for themselves. Theory was only used to articulate their narratives. The emergence of power will be explained in chapter seven.

Defining the term 'power' is a complex and contentious issue in that it has been interpreted as meaning coercion and domination (Masterson and Maslin-Prothero,1999); whilst others, for example, Foucault, identify the productive aspects of power (Foucault 1982). Consequently it is difficult to provide a consensus definition. Descriptions of power have developed over time from uncomplicated notions such as that of Bertrand Russell who believed power to be simply *the production of intended effects* (Russell 1938, p35), to Lukes' more complex view of power in which he suggests that power is multi-dimensional. Lukes asserted that power involves the capacity to: make decisions; manipulate the debate over the kinds of decisions that actually reach the stage of being made; and to shape public opinion so that it reflects the interests of the powerful (Lukes 2005). For the purpose of this research I would contend that power manifests itself within a hierarchy of sovereign, professional and personal power, each of which will be considered in turn.

The term 'sovereign power' applies to the power invested in the state to enable it to govern itself (Raven and French, 1958). Governments then use a process of delegation to implement and enforce their laws, the most prominent form of delegation being from the state government agencies (Lupia 2001). Government agencies delegate and empower agents to act on its behalf in the implementation of policy. Thus, health facilitators, charged with the task of improving access to mainstream services in England for people with learning disabilities are a crucial conduit regarding the effects of power (Gilbert 2003).

Professional power, defined by Flood and Richards (1978, p241) as having the ability *to affect the outcome of organizational decisions* comprises several aspects; for example, specialised knowledge and expertise, legitimacy, formal authority over the activities of others, resources or decisions (Handy 1993, Ibarra 1993). The knowledge and expertise required to be considered powerful usually arises from an individual's experience, education, seniority within an organisation, together with a proven ability to successfully navigate its processes, systems and culture. Professional power encompasses what is sometimes referred to as legitimate or positional power, in that it emanates from the authority delegated to the position held by an individual within a given organisation. That the position has importance is traditionally evidenced via the accoutrements of power and status such as grades, titles, and good quality office accommodation (Handy 1993) and the ability to reward or impose sanctions. As can be seen from the research of Lammers et al (2008) power acquired legitimately improves the likelihood of co-operation and success.

A means of enhancing and maintaining professional power is by membership of an appropriate professional body whose primary purpose is to promote and support the particular profession by protecting the interests of the professionals and by protecting the public. This is achieved by: setting standards for professional competence; producing regulatory frameworks and codes of conduct; taking disciplinary action against members where appropriate; advancing the professional knowledge of its members; and providing advice to government bodies, and undertaking lobbying activities in the interests of members in general and the profession as a whole (Yardley Honess 2010 and Hanlon 1998).

The final form of power considered here is that of personal power. This type of power is attributed to the individual rather than their role and is said to be developed over time in the context of relationships which may take time to develop but can be sustained over long periods (Davis et al, 1997). People possessing personal power could be said to have charisma or a sense of magnetism. This has several identified behavioural components which include vision, articulation skills, the ability to empower others, sensitivity to the

environment and needs of others, unconventionality, and risk taking (Conger 1989). Such skills enable individuals to make influential formal and informal connections with social groupings and networks which can have powerful effects on the level and efficiency of production (Helliwell and Putnam 2004).

Policy Analysis

Arriving at a precise description of what constitutes a policy analysis has been difficult, given that it is a vague concept with an uncertain identity (Prunty, 1985). However, for the purposes of this research it is defined as being concerned with two distinct but related activities: the contents of the policy and the process by which it was developed. It was equally difficult to find an appropriate tool by with which to assess and analyse the *Valuing People* (2001) document. There appears to be little consensus regarding the most appropriate items that should be contained within any critical appraisal tool (Katrak et al, 2004). Also, all other policy assessment tools considered were linked to either specific issues, such as, anti-discriminatory practice, bullying, or health or safety issues, or were designed to be used in specialised and restricted situations. In the year 2000 The Queensland Government of Australia developed a *Good Policy Content Framework* (Department of the Premier and Cabinet 2000), which took an overarching approach to government produced policies. Via this framework The Queensland Government set out the following list of criteria for what they believed to be good policy content that would steer government endeavours towards fruition.

1. What outcome statements were made?
2. What assumptions did the policy contain?
3. Was the policy linked to government direction?
4. Was due process observed?
5. Was there evidence of stakeholder involvement?
6. What were the political expectations?
7. What measures were in place to ensure efficiency and cost effectiveness?
8. How was the policy to be measured and evaluated?
9. Was the policy adequately funded?

10. What steps were to be taken to ensure accountability, lawfulness, and enforcement?
11. Was the policy historically informed and its ideas tested?

The framework appealed to me because it provided a systematic approach to examining a policy. Once it had been applied to *Valuing People* (2001) the advantages of the tool became clear. In particular it helped to identify the significant gaps within due process and stakeholder involvement. As this thesis will show, the overriding influence was that the policy was linked to government direction.

It has been suggested that critical policy analysis should scrutinise the relationship between the text, its development, and the processes involved in that development (Fairclough,1989), whilst viewing it as an outcome of both historical and political conditions (Gee et al, 1992). The criteria informing The Queensland Government of Australia *Good Policy Content* encompassed these issues.

It was anticipated that any policy analysis would benefit from the use of an analytical tool in order to reduce the risk of any personal bias. The Queensland Government of Australia's *Good Policy Content Framework* accepted that to some extent a policy's content would be determined by party politics, but that there are some aspects of public policy that go beyond this. Whilst the Queensland framework draws on an Australian context it is open to being applied to other government's policies and having been developed outside of the United Kingdom served to reduce the possibility of an inherent political bias. Whilst it is acknowledged that a policy analysis is never one hundred percent complete, rational, or correct, the descriptive analytical approach of the *Good Policy Content Framework* was an appropriate mechanism to employ as an analytical tool within this research.

Delphi Study

This method was adopted because it was imperative that the study was relevant to learning disability professionals, services, agencies, and ultimately people with learning disabilities themselves. The Delphi method of enquiry takes its name from the Delphi Oracles' skill of interpretation. It was developed as a research tool shortly after the end of the World War Two when confusion as to strategic planning requirements proliferated. In the mid nineteen sixties it developed as a means of assessing future trends and has been used widely in health research (Mays and Pope, 1999). It is considered a creative and innovative means of generating a research question (Robson, 2002) with much to commend it, including: the use of an expert panel; controlled anonymous feedback creating less pressure for members to conform than, for instance, in a physical group or committee; systematic refinement; the development of a consensus; and an easy and inexpensive access to a large number of experts who were geographically distant (Bowles, 1999). The application of the Delphi technique is considered as greatly benefiting the exploration of important issues relating to health, social, and public heath policy (Adler and Ziglio 1996). In this instance it facilitated communication amongst a group of experts geographically dispersed across England. As a data gathering technique the Delphi method had much to commend it; for example, it provided a cost effective forum in which it was possible to quickly generate a consensus of expert opinion in order to take advantage of a wealth of different perspectives on the nature and articulation of imperatives relating to health facilitation, and the health of people with learning disabilities from diverse perspectives.

A characteristic of the Delphi technique is the use of an expert panel to determine the extent of consensus about a specific issue (Jones and Hunter, 1995). For the purpose of this exercise the term expert was defined as being a skilled professional working within the area of either learning disability or health. The range from which the experts were drawn was deliberately extensive in order to secure as wide a perspective as possible. Potential contributors were identified on the basis of their position in terms of their ability to influence policy and/or practice; having recently published work on learning

disability and health issues or current health or learning disability practice. Participants were recruited by contacting individuals directly and via a recruitment campaign amongst learning disability Internet networks. In all forty three people meeting the expert criteria were invited to participate in the Delphi study and twenty two confirmed their willingness to contribute. The final list of contributors included academics, general practitioners, primary care professionals, consultant nurses (Learning Disability), community nurses, and members of the Valuing People Support Teams set up by the government with a brief to promote change at local and regional levels across the whole of England. Data was analysed by a systematic refinement in order to develop of a consensus of opinion.

Semi-structured Interviews

This section will focus on the most significant data gathering method employed within this research, that is, semi-structured interviews. It will outline how, having gained ethics committee authorization to proceed (Appendix 1), an outline research itinerary and an overall recruitment plan was devised. This involved: establishing inclusion and exclusion criteria; enlisting potential participants; selecting participants for the one-to-one interviews and reference group; and determining the measures to be taken to gain access to participants.

The nature of this research demanded a fairly small sample with particular characteristics in order to maximize the possibility of exploring the phenomenon of health facilitation in learning disability services. A purposive sample was employed to facilitate the selection of candidates meeting the specified inclusion criteria. The characteristic that informed the inclusion and exclusion criteria for the one-to-one semi-structured interviews was that participants needed to have worked as a health facilitator with, or on behalf of, people with learning disabilities on a whole or part time basis. This was to ensure that data gathered was from an experiential as opposed to purely intellectual base. Additionally participants needed to be practising in one of the Valuing People Support Team Regions in England (Figure 2), other than the region in which I, as the sole researcher, was based. Facilitators from this area were to be invited to participate in a reference group which will be discussed later in this chapter.

Valuing People Support Team Regions

1. North West
2. North East
3. Yorkshire and Humberside
4. West Midlands
5. East Midlands
6. South East
7. London
8. South
9. South West

Figure 2

Recruitment

The recruitment plan required the gaining of access to, and the engagement of, two participants from eight of the regional support teams set up to implement *Valuing People* (2001) other than that which covered my own area. The study participants were recruited by appeals to take part in the semi-structured interviews via letters to professional health and learning disability journals including *Learning Disability Practice, The Nursing Times, The Nursing Standard*, together with an appeal by way of the *Into The Mainstream* (www.intothemainstream.cswebsites.org) and the Learning disability Network (ldhealthnetwork@ldhealthnetwork.org.uk) internet *w*ebsites. Replies to the letters published in the health and learning disability press were very disappointing in that they failed to produce any response at all. The website appeal for participants produced a flurry of interest from potential contributors. However, only eight out of twenty people followed up the invitation to participate in the research. It was clearly going to be difficult to meet the selection requirement of two participants from each of the Valuing People Support Team Regions. In response to this situation it was necessary to broaden the scope of

the recruitment by conducting an Internet search of Learning Disability Teams across England. Sixty two such teams were identified, targeted and contacted via mail shot. In addition it was necessary to make a personal appeal for participants at the 2006 National Health Facilitation Network conference in Oxford. Both these methods proved to be successful in attracting a number of additional prospective participants. However, recruitment in the London area was particularly difficult as only one person asking to be considered as a participant met the inclusion criteria. Following discussion with my supervisor it was decided to relax the inclusion criteria. This would allow the acceptance of a participant who, although not currently practising as a health facilitator, had set up and evaluated a health facilitation project in the target area. All potential participants expressing an interest in taking part in the study were supplied with: an information pack consisting of an information sheet offering an invitation to be part of the proposed study; a consent form to be signed and returned; a data form to complete and return giving basic information, such as gender, age, ethnicity, occupational background, length of time spent in learning disability services, contact details, and whether health facilitation was the whole or only part of their role (Appendix 2).

Problems occurred that complicated the recruitment process resulting in considerable disruption to the research itinerary. Firstly, considerable delays were encountered in the length of time taken by participants in returning completed documentation. This necessitated the sending of follow up letters and/or telephone calls in order to re-establish the potential participants' continued interest in the study. Secondly, obtaining permission to interview from nominated personnel within the participant's employing authority was in some instances a challenge. When contacted all the individuals concerned were apologetic for the delays citing pressure of work and the need to prioritise.

Sample Selection and Access Plan

Having recruited a number of potential participants, selection was relatively easy to accomplish with the aid of a screening tool (Appendix 3). Accordingly, I was able to obtain a sample broad enough to include maximum variation in facilitator experiences, perspectives, and views (Table 4). Ultimately, a total

sample of sixteen semi- structured interview participants, comprising two participants from eight of the nine Valuing Support Team Regions across England was selected. It was anticipated that samples of this size would ensure a full and thorough exploration of the topic and would result in the production of data rich in-depth and detail.

As outlined in the information pack, out of respect for the agencies concerned and the health and safety of both the participants and myself, permission to interview from the employing agencies' permission was sought. The response to this was good, with the majority of permissions coming from the participants' senior managers, and the remainder from the Research and Development departments of the employing Trusts. Fourteen employing bodies were happy to grant permission based on the information received. Permission was refused by one agency on the grounds that their health facilitator's workload would not allow for their release, but I was given clearance to interview a member of the team that had been engaged to evaluate their local Health Facilitation Service. One potential participant objected to her employer being approached on the grounds that she was a registered nurse and therefore considered herself to be an autonomous practitioner not requiring anyone's permission to participate. She was not included in the final sample as to do so would be, I felt, ethically incorrect. Risk assessments were undertaken in respect of conducting interviews at venues chosen by the participants. These indicated any risks to be minimal.

The Interview Process

During the period between October 2005 and February 2006 sixteen semi-structured interviews were conducted across England. Preparations for interviews were aided by the use of a checklist adapted from Denscombe's *Good Research Guide* (1998) (Appendix 4). As a means of displaying respect for those being interviewed I endeavoured to present an impression of neutrality through avoiding giving expression to my own individuality and style by dressing smartly, but not lavishly, in bland but universal colours. In attending to my appearance in this way I was attempting to avoid annoying or upsetting anyone;

to fit with those being interviewed; and to convey a trustworthy, personable and professional presence (Denscombe 1998).

Sample Selected for One-to-one Interview

Male	2
Female	14
Age group: 20-30 31-40 41-50 51-60	 1 6 7 2
Number of years in learning disability services: 0-5 6-15 16-25 26-35	 2 3 5 6
Occupational backgrounds included combinations of: Care management Learning disability nurse Health promotion Manager Health visitor University lecturer Social work	 2 11 2 1 1 1 1
Member of a minority ethnic group? Yes No	 2 14
Involved in health facilitation: Full time As part of existing role	 10 6

Table 4

In keeping with the humanist foundation of the phenomenological research approach, I endeavoured to reduce the power imbalance between myself as the researcher, and the participants, by offering to conduct the semi-structured interviews in the participants' own localities and at venues of their choice. On reflection, I discovered that whilst this arrangement met the needs of the participants, it did have its disadvantages for me as a researcher. The venues chosen were not always ideal for interviewing purposes. Usually appropriate accommodation was accessed. However, in some instances a great deal of flexibility was required on my part as some participants chose to be interviewed

at venues not particularly conducive to such a focussed conversation; for example, in a Bistro, a large staff-dining hall next to a coca cola vending machine, in office space containing large grey metal boxes of equipment pertaining to computer systems that made varied and persistent noises. Such situations demanded a degree of adaptability to the environment in order to meet my needs regarding the interviews. Spare copies of the interview schedule and topic guide were available should participants require them. One main and one back up tape recorder, one with a conventional plug and one with an adapter; spare audio tapes; and an electrical extension lead were also to hand. Prior to meeting each participant, details of the interview were confirmed in writing and each participant was furnished with a copy of the topic guide that had been based on issues identified as of interest or concern to a number of learning disability professionals via a Delphi exercise. This enabled participants to give some prior thought to the issues to be covered during the interview and to allay any potential fears or anxieties they may have.

Each participant had furnished written acknowledgment of the willingness to participate in the study. Each interview commenced with introductions and a recapitulation of the purpose of the study, and the rights of the participants. Participants were asked whether they were still consenting to the interview with this being recorded on audio tape. In the interest of respect, openness and honesty, an explanation was given regarding the intention not to take field notes during the interview in order to avoid being distracted from what they were saying; preferring instead to complete a post interview comment sheet on which would be recorded my impressions of what had been said, or occurred during the interview. In addition, as soon as possible post interview, a research diary/reflection sheet would be completed to aid myself, as the researcher, focus upon any thoughts, feelings and behaviours arising during the interview process.

Carl Rogers (1980) placed great emphasis on establishing an environment conducive to good interviews, featuring empathy, congruence and unconditional positive regard. Building good rapport is frequently mentioned as an important part of the qualitative interview process leading to fuller and less constrained

disclosure (Irwin and Johnson, 2005). The initial stage of the interview in which consent, confidentiality, and the process of the interview were revisited was a means of achieving this as it gave the participants time to establish how they felt about being in the interview position. I sought to develop this further by providing some basic information about my background, my interest in the subject, and how the subjects included in the topic guide were determined. Then in the tradition of phenomenological research I asked the participants *to tell me a little about yourself, your background and the journey that has brought you to where you are today – acting as a whole or part time health facilitator.* I anticipated that this type of open question would enable the participant to settle down and relax into the interview. The aim, in accordance with a descriptive phenomenological research approach (Lopez and Willis 2004) was to ask open-ended, undefined questions, thus encouraging respondents to express their own perceptions in their own words. Closed questions were posed at times to prompt, probe, clarify, expand on particular issues, or to move the interviews on. This course of action was calculated to encapsulate the complex cognitive and behavioural process in which participants were engaged. As the end of each interview approached I posed the question, *Is there anything I haven't asked you during this interview that you had hoped that I would?* The reasons for this were twofold. I wanted to avoid the occurrence of the *hand on the door knob* phenomenon, whereby once the tape recorder is switched off the participants then embark on revealing some attention-grabbing material that cannot be recorded accurately. It was also a means of ensuring that participants ended the interview experience feeling fulfilled and empowered. This was a valuable technique, which was used effectively by a number of participants. As the interviews were brought to a close participants were thanked for their time and valuable contribution to the research.

Saturation point was reached after the thirteenth interview*. Three interviews were still outstanding at this point and the decision was made to continue with these as they had already been arranged. To cancel would cause some

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* Analysis is discussed later in this chapter.

disruption to participants' schedules and perhaps not being included in the study may have left them feeling somewhat dissatisfied and devalued.

Respondent Validation

Prior to commencing this research the intention had been to strengthen the validity of the study by obtaining written respondent validation from each of the interview participants. Despite the attractiveness of respondent validation, and after a great deal of careful consideration, this option was discarded on the grounds of its potential to be problematic in terms of the amount of time it would take to manage this task, and the problems experienced previously in obtaining the timely return of documentation. Alternatively a summary of issues as they arose during interview, together with feedback to the participants of my understanding of what had been said was implemented, giving each participant the opportunity to confirm or refute as they saw appropriate.

Method of Data Analysis - Semi-structured interviews

On completion of the interviews each audiotape was transcribed (Appendix 7) and checked three times to ensure accuracy prior to analysis. A random sample of transcripts was selected and scrutinised as a means of self-assessment, these were subsequently examined and verified by the study supervisor at the half-way point. Descriptive phenomenology aims to investigate the lived experiences of research participants and demands an approach to data analysis that identifies the structure of those experiences as they are articulated. Accordingly, data was analysed and recorded reporting what each participant said as accurately as possible so as to ensure the power of what was said remained with the participants rather than the researcher. An inductive approach to data analysis was employed in this study in the anticipation that through analysis and description of the data, new or greater acuity would be achieved from the association of the emergent elements, thus providing the basis for new descriptions (Gray, 2004). Inductive reasoning begins with observation and builds up ideas and more general statements (Bowling, 2002). Observation commenced with immersion into the raw data by listening to the audio tapes, reading through the transcripts, studying the

research diary and notes immediately following interviews in order to note the key ideas and recurrent themes. Inductive codes were derived from the initial reading of the data which was then broken down into smaller units to reveal their characteristic elements and structure. These codes served as a template for analysis and changed and developed during and after the data collection stage as the process of analysis progressed. This proved to be a useful procedure as it meant that the impressions made in the early stages of analysis were not allowed to remain, thus reducing the possibility of researcher bias. Each audio taped interview was transcribed and then listened to twice more to ensure accuracy of transcription. Each transcript was then subjected to the coding process three times in order to affirm consistency of coding. A random sample was taken for scrutiny by the study supervisor to verify both the accuracy and reliability of the coding procedure.

A vast amount of information was generated and needed to be managed adequately to enable the process of analysis to continue. This was achieved by taking advantage of Jennifer Attride-Stirling's (2001) approach to Thematic Network Analysis. Attride-Stirling developed this system of analysis in response to the lack of tools available to aid analysis of qualitative data, and as a means of creating greater transparency within the analytical process. This particular technique was founded upon the principles of Stephen Toulmin's argumentation theory (Toulmin, 1958). Toulmin's model was designed as a philosophical and abstract depiction of argumentation that may be used for analysing and evaluating the worth or strengths of an argument; thus providing a structured method for examining negotiation processes, and a means of analysing and, or, constructing the logic of an argument. Argumentation is concerned primarily with reaching conclusions through logical reasoning based on certain premises. The argumentation model was based around six inter-related components for analysing arguments: claims, or the conclusions behind the argument; data, or the evidence and underpinning the claim; warrants, which are the components of the argument that establish the logical connection between the data and the claim; backing, or the material that supports the warrant in the argument; rebuttal, which presents the exceptions or restrictions to the claim; and finally,

qualifier, which represents the relative strength of an argument (Osborne et al, 2004).

Attride-Stirling's (2001) thematic networks aim to explore the understanding or significance of an issue rather than to reconcile conflicting definitions of a problem. Toulmin, therefore, provided the background logic to her network system but not the final method. The technique of Thematic Network Analysis provides a practical and effective procedure for conducting an analysis in that it: enabled a methodical systemisation of textual data; facilitated the disclosure of each step in the analytical process; assisted in the organisation of the analysis and its presentation; and allowed a sensitive, insightful and rich exploration of the transcribed texts overt structures and underlying patterns (Attride-Stirling 2001). The decision to use Attride-Stirling's approach to thematic analysis was based upon the belief that it provided a simple, commonsensible, constructive, and methodical means of realising a deeper understanding of the participants' experiences of health facilitation.

Thematic analysis is a method of analysing data that is widely used in qualitative research. The absence of an unambiguous agreement about what this actually is and how it should be conducted (Attride-Stirling 2001) allows for flexibility in how it is applied in practice. This flexibility allowed for a degree of detailed coding of transcripts in order to deconstruct the experience of health facilitation prior to categorisation into basic, organisational and global themes. Such in-depth analysis permitted exploration of varied dimensions of the health facilitation experience of participants; the acquisition of insight into any underlying themes and patterns present; and led towards increased understanding of participant description, and a clear and robust methodology. This form of analysis involved the devising of an alternative-coding framework based upon the grouping together of the major themes arising from the inductive coding exercise already applied.

Each transcript was then dissected into text segments using the revised coding frame. This was repeated three times in all to ensure consistency. Themes were then extracted from the coded text segments. All the text segments were then examined and the frequent or significant themes were extracted and grouped together. The selected themes were then studied in greater depth, summarised, and condensed into manageable sets of noteworthy themes. These were then grouped around coherent groups of basic, organisational and ultimately global themes, from which non-hierarchical web-like structures of global themes were compiled (Figures 3 and 4). The analytical process progressed from this point towards providing a description of each network's content; supporting each description with text segments; and noting the underlying patterns that were beginning to surface. Finally, the inferences made in the network summaries were brought together with relevant theories to explore the significant themes.

The analytical process was supported by the use of computer software. Initially the NViVO qualitative analysis software had been considered as an aid to thematic network analysis but was rejected in favor of Microsoft Excel's software package due in main to the availability of training in its use and potential flexibility. It afforded a simple but systematic and transparent approach to data analysis characterized by the ease at which data could be managed and retrieved, and an explicit analytic process enabling the means of making links leading to new understandings of complex phenomena. It provided a means of cross checking the accuracy of coding.

From Codes to Global Themes

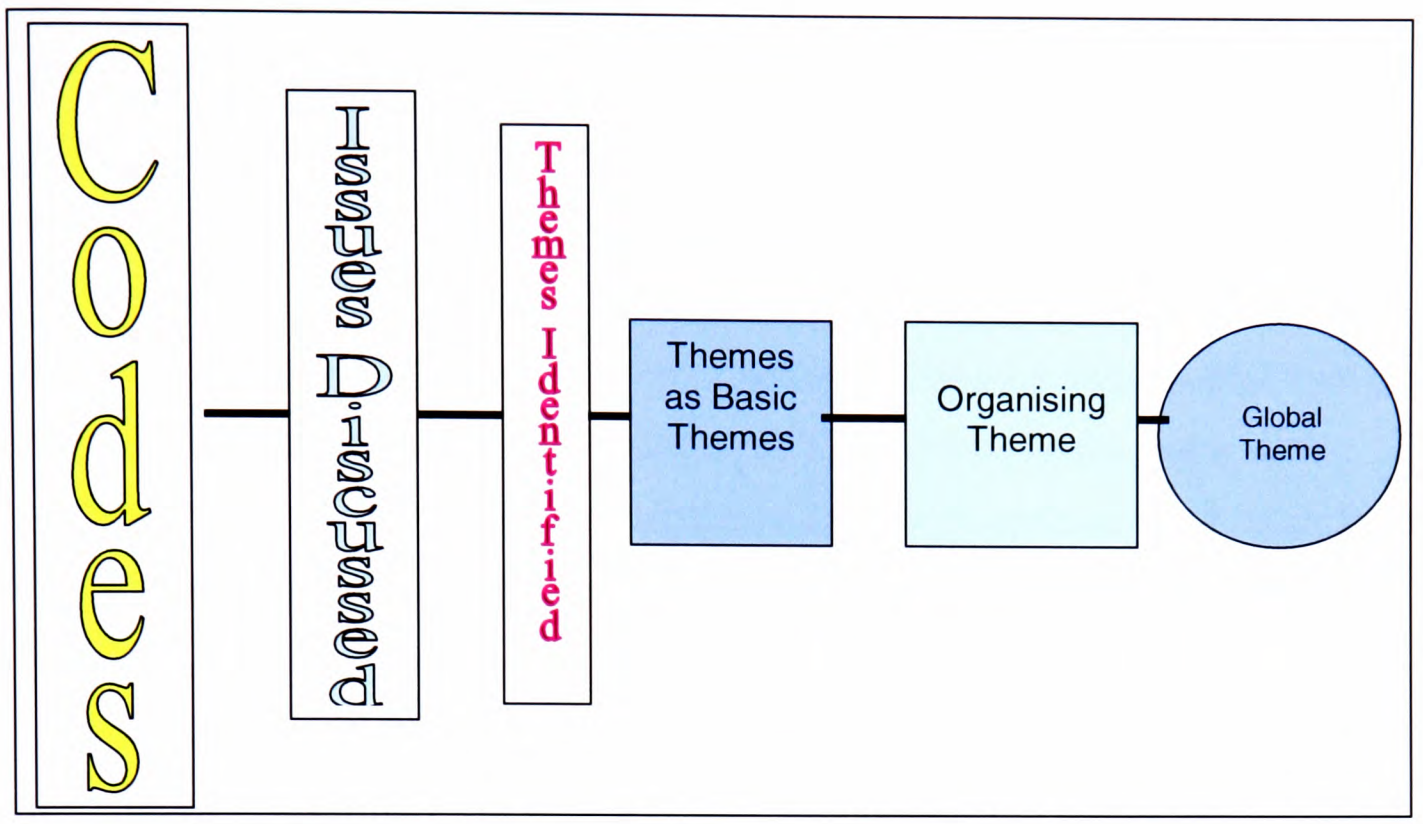

Figure 3

Graphic Representation of a Thematic Network

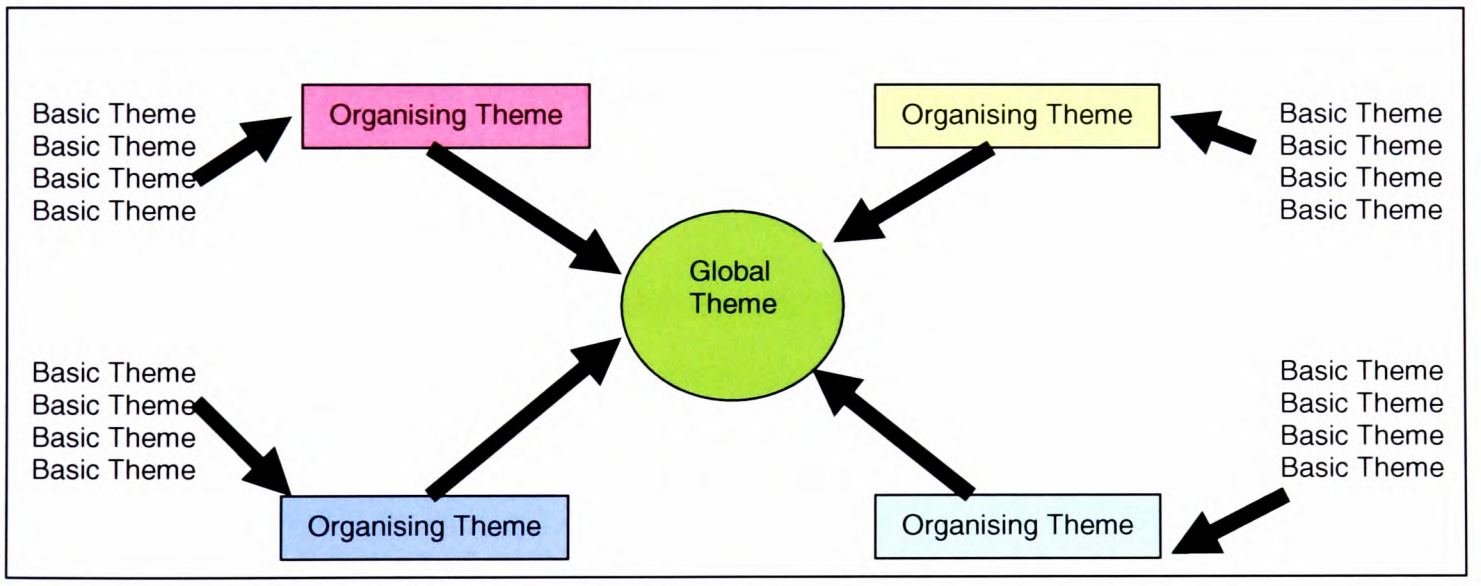

Figure 4

Reference Group

The fourth and final data gathering method employed in this research was that of holding a reference group meeting. Similar in many respects to a focus group in that members' opinions to a topic were elicited, it differed in that this reference group was recruited from a restricted rather than a wider population, and they were asked to consider their responses to the themes having emerged

from the semi-structured interviews as opposed to providing the themes for discussion themselves. The advantages of this approach being that it had a pre-established framework within which to work, thus making analysis of the results simpler (Bell, 1999). The reference group had a dual purpose: firstly, to ensure countrywide representation within the research as a whole; and secondly, to discern whether some of the themes arising from individual interviews applied to and impacted upon the reference group, and if so to allow for their broader and deeper exploration. Group interviews are a well-established approach used in qualitative research as they have been found to be a highly efficient technique for qualitative data collection, producing an increased amount and range of data because of the numbers of people involved. Such groups develop their own equilibrium due to the development of mutual restraints and ability to function in a different realm of social reality from that revealed by one-to-one interviews (Sim, 1998, Robinson, 1999, and Curtis and Redmond, 2007). Group interviews have several advantages over individual interviews; revealing as they do areas of agreement and disagreement leading to more meaningful insights due to participants' being able to challenging one another's views and the verification or refutation of data gained through other research methods, thereby enhancing the reliability of previous responses (Denscombe,1998).

Reference Group Recruitment and Selection

The inclusion criteria for the reference group included the need to have been a practising health facilitator with, or on behalf of, people with learning disabilities, either part the whole time, and to have been based in the one remaining Valuing People Support Team Region in England. Recruitment occurred by similar means to those used for the one-to-one interviews, that is, letters in journals and requests to electronic learning disability networks. Nine participants, one male and eight female ranging in age from forty to fifty five, two thirds of whom worked as facilitators on a full time basis, met the inclusion criteria and were subsequently invited to participate (Table 5).

Reference Group Sample Selected

Male	1
Female	8
Age range	40 – 55
Full time facilitators	3
Facilitators for whom health facilitation is part of their role	6

Table 5

The Reference Group Meeting

Following discussions with participants, a date and venue for the reference group meeting was agreed upon. However, on the day only six of the nine people attended. One participant could not attend due to unanticipated developments with a client, another had mixed up the date in their diary and one participant did not provide an explanation for absence. The reference group meeting was held at the halfway point of the semi-structured interviews with the interim findings forming the basis for discussion. The one hour meeting was taped throughout, using two tape recorders placed at different points in the room in an attempt to capture the often fast moving and chaotic discussion. This left the researcher free to take contemporaneous notes.

Method of Data Analysis – Reference Group

The data was analysed by expansion of the researcher's contemporaneous observations and annotation notes, supported by listening to audiotapes on three occasions. In order to reduce data to a manageable form the main thrust of the discussion was entered on to an inventory of points based on the meeting's topic guide (Appendix 6).

Conclusion

Chapter three provided an explanation of both the circumstances leading to, and a validation of, the use of an eclectic phenomenological approach to the subject of health facilitation as manifested within learning disability services. The most significant data gathering method for this study was that of semi-structured in-depth interviewing. The supplementary information sourced via

policy analysis, a Delphi study and a reference group, contributed towards ensuring both the quality and relevance of the information collected and has facilitated the development of a wider understanding of *Valuing People* (2001). This chapter addressed the research design employed to explore the concept of health facilitation within learning disability services as outlined in the *Valuing People* document. It went on to describe quality control and ethical considerations and how these were addressed. The techniques applied were in accordance with the phenomenological notion that any attempt to understand social reality has to be grounded in people's experiences of that social reality (Gray 2004). Consequently, the information gained was deep and wide ranging, exposing participants' impressions, experiences, views, language and opinions about health facilitation for people with learning disabilities. These results, together with their analysis, will be presented in chapters four and five.

Chapter 4

Results and Analysis – Policy Analysis and Delphi Study

Introduction

This next chapter is the first of two chapters that will present the results and an analysis of data gathered during research into health facilitation within learning disability services. The decision to present a combination of results and analysis together in the next two chapters may appear unconventional. Phenomenology is a still a developing science and is not demanding of unquestioning adherence to strictly defined techniques and procedures. Both the gathering and analysing of qualitative data is concerned with words and their interpretation. Given this fact, it felt logical to permit this overlap in order to see how they fit together, and to allow for the flexibility to remain open to any ideas, connections or patterns that might emerge (Miles and Huberman, 1984). This chapter, the first of two combining results and analysis, will concentrate on the first two data gathering methods employed and will consist of two parts. Part one will present an analysis of the *Valuing People* (2001) policy carried out with the aid of The Queensland Government of Australia's *Good Policy Content Framework* (Department of the Premier and Cabinet 2000)*;* whilst part two will portray the Delphi study.

Part One - Policy Analysis

The *Valuing People* (2001) policy introduced the concept of health facilitation for people with learning disabilities. For the purpose of this research an analysis of the *Valuing People* policy will contribute to understanding the context within which health facilitation was developed. The form of analysis undertaken involved a descriptive investigation using the Queensland Government of Australia's *Good Policy Content Framework* (2000). Whilst the focal point of the research is concentrated upon health facilitation, it has been necessary to take a broader view of *Valuing People* in order to place health facilitation within the contexts of evidence based policy making, history, theory, and New Labour government policy.

Historical context

As a document *Valuing People* (2001) was historically informed in that it referred to the fact that there had been a gap of some thirty years between its publication and the previous White Paper *Better Service for the Mentally Handicapped* (1971). *Better Services for the Mentally Handicapped* ploughed the furrow for change in services through focusing on: reducing the number of places in long stay hospitals; increasing community care provision; making a commitment to help people with learning disabilities to lead a normal life; and collaboration between health, social and other local services. *Better Services for the Mentally Handicapped* had an ambitious agenda and many of its aims were achieved. Very few large institutions remain today and there are no children in long-stay hospitals. Services in the community have expanded and developed and more people with learning disabilities are in work. There are active self-advocacy and citizen advocacy movements and the voices of people with learning disabilities are heard more clearly (Housing Options, 2008). *Valuing People* built upon the work of *Better Services for the Mentally Handicapped* by setting out a radical agenda in order to address improving the health of people with learning disabilities by requiring mainstream health services to accept their responsibility to be inclusive of people with learning disabilities. Close inspection reveals that *Valuing People* sits alongside an extensive body of social policy.

The impetus behind *Valuing People* (2001) arose due to the growing confidence of the advocacy movement amongst people with learning disabilities and their families, together with a growing recognition by the New Labour government that people with learning disabilities were amongst the most vulnerable and socially excluded in our society, with very few having jobs, their own homes, or a choice over who cared for them. Evidence was emerging that services for people with learning disabilities and their families were overlooked, poorly co-ordinated, planned and supported, and lack of effective partnership working was resulting in their health care needs being unmet.

Document Description

Valuing People (2001) was the government's plan for improving the lives of people with learning disabilities, their families and carers. It was applicable only to England as the responsibility for Scotland, Wales, and Northern Ireland had been devolved to the respective regional parliaments and assemblies. Since then *Valuing People Now: the Delivery Plan, 'Making it happen for everyone'* (2009) has been published. The focus of this research is upon the 2001 document written with help from people with learning disabilities, family carers, and people who work in services or other organisations for people with learning disabilities. It came with an easier to understand version and reports from, the service users' advisory group called *Nothing About us Without us* (2001), family carers *entitled Family Matters* (2001), and a report on learning difficulties and ethnicity. Its vision was clearly articulated as being to improve the lives of people with learning disabilities via *a commitment nationally and locally to strong principles, a firm value base and clear objectives for services. Each individual should have the support and opportunity to be the person he or she wants to be* (p24). Its four underpinning principles of rights, choice, independence, and inclusion were prominent and addressed throughout the text in an attempt to ensure that the vision was apparent in all its aspects. By highlighting the right of people to benefit from the Human Rights Act (1998), the Disability Discrimination Act (1995), the Race Relations Act (1976), the Race Relations (Amendment) Act (2000), and the Sex Discrimination Act (1975), the document placed *Valuing People* firmly within national and local legislative frameworks.

The vision of *Valuing People* (2001) was evident in its emphasis on developing networks and partnerships with people with learning disabilities, their carers, and other partner agencies. However, more detailed descriptions of what the key principles of rights, inclusion, choice and independence actually mean in practice would have been helpful. Indeed Sooben (2004), whilst commending the fact that the four key principles highlighted by *Valuing People* ensured a firm value base, expressed the belief that the document did not make clear explicitly how it anticipated the outcome of 'valuing' would be achieved. He puts forward

the theory that much of *Valuing People* was dependent upon existing government policies being made available to people with learning disabilities and wonders why this has not already happened given the presence of anti-discriminatory legislation, saying that, *the notion of valuing becomes less credible when one considers the continued discrimination and prejudices people with learning disabilities generally face regardless of nearly thirty years of relevant legislation* (Sooben, 2004, p107). In his opinion, *Valuing People* failed to understand the fundamental basis for prejudices in relation to people with learning disabilities and asked why it was that, *responsible professionals have not been influenced by the raft of pre-existing anti-discrimination legislation and what difference might Valuing People make to them?* (Sooben, 2004, p109). The *Valuing People* (2001) strategy described various ways of putting the vision into practice but placed a deal of reliance on people external to the learning disability services and unfortunately, for these people and organisations, learning disability may not be at the top of their agendas, thus compromising realisation of the vision.

Definition of learning disability

A definition of 'learning disability' was provided which was valuable in that it eradicated the confusion around what actually constituted a learning disability. The definition explained that a learning disability was, *a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), together with a reduced ability to cope independently (impaired social functioning)* (Valuing People, 2001, p14*).* It is also emphasized that these conditions needed to have started before adulthood, and are anticipated as having lasting effect on development. This definition made it very clear towards whom the document, and thus service development, was aimed, and for whom it was not; for example, the definition covered adults with autism who also had learning disabilities, but not those with a higher-level autistic spectrum disorder who may be of average or even above average intelligence, such as, some with Asperger's Syndrome. Learning disability does not include all those who have a learning difficulty, which is more broadly defined in education legislation (Department of Health, 2001).

Philosophical and Theoretical Context

Appearing within *Valuing People* (2001) are strong elements of both humanism and the social model of disability. The International Humanist and Ethical Union (2007), described humanism as being associated with beliefs of freedom, autonomy and the notion *that human beings are capable of making significant personal choices within the constraints imposed by heredity, personal history, and environment* (Elias & Merriam, 1980 p118). A comparison of the fundamentals of humanism and the underpinning principles of *Valuing People* demonstrate similarities between the two (Table 6). A noteworthy contributor to humanistic psychology is Carl Rogers who pioneered person-centred approaches to counselling and psychology. Given the prominence of person-centred principles within *Valuing People* and the fact that the four key principles of rights, independence, choice, and inclusion are central to the government's proposals, it seems safe to say that *Valuing People* sits comfortably within the 'humanist' philosophy in that it shares in its challenge to authority and the status quo.

Influential throughout *Valuing People* (2001) is ideology behind the social model of disability, which, rather than viewing the person with a disability as a problem, advocates for the removal of the disabling barriers to inclusion. Disabling barriers can be attitudinal, economic, and/or environmental in nature, serving to exclude people with disabilities from having the same level of opportunities to access services equally as well as non-disabled people (Joint Committee on the Draft Disability Discrimination Bill: First Report, 2004). The social model approach suggests that the disadvantages faced by disabled people are due to a complex form of institutional discrimination, as fundamental to society as sexism, racism or heterosexism. The disability movement believes the remedy to the problem of disability lies in changing society, not the person. Overcoming such barriers requires a move away from looking upon disabilities as simply a medical issue towards the restructuring of services and society, so that people with disabilities are not seen to be different but simply as being part of the normal diversity of the population. *Valuing People* confronted the issues of barriers, directly citing: language; racism; negative stereotypes; negative assumptions; insensitivity to issues of culture and language; limited choices;

and organisational and environmental structures. It makes apparent that these need to be challenged and changed in order that people with learning disabilities may participate fully in all aspects of society. *Valuing People* envisaged the introduction of health facilitation as the means by which the barriers to good health care faced by people with learning disabilities would be overcome.

Comparison between the Principles of Humanism and *Valuing People* (2001)

Fundamentals of modern Humanism as described in the Amsterdam Declaration (2002)	**Underpinning Principles of *Valuing People* (2001)**
Humanism: Is ethical in that it affirms the worth, dignity, and **autonomy of the individual** and the right of every human being to the greatest possible freedom compatible with the rights of others.	**Independence:** Promoting independence is a key aim for the Government's modernisation agenda. Nowhere is it of greater importance than for people with learning disabilities. ..... the starting presumption should be one of independence, rather than dependence, with public services providing the support needed to maximise this. Independence in this context does not mean doing everything unaided.
Humanism: Supports **democracy** and **human rights** and aims for the fullest possible development of every human being. It holds that democracy and human development are matters of right.	**Legal and Civil Rights:** The Government is committed to enforceable civil rights for disabled people in order to eradicate discrimination in society. People with learning disabilities will also receive the full protection of the law when necessary.
Humanism: Insists that **personal liberty** must be combined with social responsibility. Humanism recognises that reliable knowledge of the world and ourselves arises through a continuing process. Humanism emphasises an individual's uniqueness and freedom to choose a particular course of action.	**Choice:** We believe that everyone should be able to make choices. This includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day-to-day lives.
	Inclusion: Inclusion means enabling people with learning disabilities to do those ordinary things make use of mainstream services and be fully included in the local community.

Table 6

Health Facilitation

The focus of this thesis is health facilitation and its interpretation in practice. Health facilitation was not mentioned a great deal within *Valuing People* (2001), A content analysis of *Valuing People* (Tables 7 and 8) revealed that the term health facilitation occurred only once throughout the entire document, whilst the term health facilitator/s appeared on fourteen occasions. Health facilitation was described as a complementary task to be undertaken by specialist staff in addition to their clinical and therapeutic role and would involve working with primary care teams, community health professionals and staff concerned with delivering secondary health care (p63). Such a description, suggesting that health facilitation could simply be attached to an existing role, did little to convey it as a role of any great importance. This was reinforced by the fact that the combined terms of health facilitation/health facilitator occurred only fifteen times in all throughout the one hundred and forty two page *Valuing People* document. The fourteen references to health facilitator (Table 7) highlighted from where facilitators may be drawn; outlined the expectation that they would be available to support people with learning disabilities with the health action planning process; and access routes to appropriate physical and mental healthcare within both primary, and secondary health care services. In addition they were to be on hand to assist General Practitioners in identifying their learning disabled patients.

The implications for health facilitation within *Valuing People* (2001) were somewhat confusing in that the same term, health facilitation, was used for both the meeting of general health care needs of people with learning disabilities by the people providing their day to day care, as well as being used to describe specific tasks. These included: service design and development; overcoming barriers to access; facilitating the work of mainstream services; developing the capacity of services to support those with complex needs; complementing the work of local health promotion teams; working with primary care teams, community health professionals and staff involved in delivering secondary health care; and teaching and enabling a wide range of staff, including those who work in social services and the independent sector, to become more familiar with how to support people with learning disabilities to have their health

needs met. The level and intensity of these tasks makes apparent the need for a dedicated health facilitation role, as opposed to *Valuing People's* complementary notion.

Content Analysis of the Term Health Facilitator

Page no:	What Did *Valuing People* Say?	No.
6	Health facilitators will be appointed from each local community learning disability team to support people with learning disabilities in getting the health care they need.	1
27	*Valuing People* sets out a major programme to improve life chances for people with learning disabilities. The Government will enable all people with learning disabilities to have access to a health facilitator and to have a Health action plan.	1
61	Health facilitators to be identified for people with learning disabilities by Spring 2003.	1
63	Heading.	1
63	As the first point of contact, primary care is the place where many important decisions are made. But for many people with learning disabilities their encounter with the primary care team may be frustrating and difficult. In order to overcome these barriers staff from the local community learning disability team in each area will need to take on the role of health facilitators to support people with learning disabilities to access the health care they need from primary care and other NHS [National Health Service] services. This role might be taken up by any community learning disability team member, but learning disability nurses will be well placed to fulfil this role.	1
64	Health facilitators will help general practitioners and others in the primary care team to identify their patients with learning disabilities, in collaboration with colleagues from social services, education and health. Their task will be to facilitate, to advocate and to ensure that people with learning disabilities gain full access to the health care they need, whether from primary or secondary NHS [National Health Service] services. The role of the health facilitators should embrace mental as well as physical needs. The health facilitator role will be vital in helping people with learning disabilities navigate their way around the health service.	3
64	All people with learning disabilities should be registered with a general practitioner. We expect that all general practices, with support from the health facilitator and in partnership with specialist learning disability services, will have identified all people with a learning disability registered with the practice by June 2004. Progress in achieving this objective will be monitored by the Department of Health.	1
64	The Government expects each individual with a learning disability to be offered a personal Health action plan (HAP). Responsibility for ensuring completion of the HAP will rest with the health facilitator in partnership with primary care nurses and general practitioners. The HAP will form part of the person-centred plan. The HAP is an action plan and will include details of the need for health interventions, oral health and dental care, fitness and mobility, continence, vision, hearing, nutrition and emotional needs as well as details of medication taken, side effects, and records of any screening tests.	1

65	The Government expects all Learning Disability Partnership Boards to have agreed a framework for the introduction of Health action plans and to have ensured that there are clearly identified health facilitators for all people with learning disability by June 2003. All people with learning disabilities should have a HAP, [Health action plan] by June 2005.	1
65	Health facilitators will have primary responsibility for facilitating access to secondary health care. But by 2002 a Patient Advocacy and Liaison Service (PALS) will be established in every NHS [National Health Service] Trust. Individuals will then have an identifiable person they can turn to if they have a problem or need information while they are using hospital and other NHS services. Within the 130 or more NHS Trusts providing specialist health care for people with learning disabilities, PALS will have an especially important role for ensuring that people with learning disabilities can access the full range of NHS [National Health Service] provision. PALS will complement the work of the health facilitator.	2
118	Health facilitators identified by summer 2003	1
	Total Occurrences	**14**

Table 7

Content Analysis of the Term Health Facilitation

Page no:	**What Did *Valuing People* Say?**	**No.**
69	A health facilitation role; working with primary care teams, community health professionals and staff involved in delivering secondary health care	1
	Total Occurrences	1

Table 8

The Political Context

New Labour came to power following eighteen years of Conservative government and set out to implement reforms within the concepts of a third way and a whole systems approach. These theories, their values and ideas, are reflected within the *Valuing People* (2001) document. The 'third way' fell within the extremes of liberalism and conservatism and aimed to change the focus from the Conservative's competitive internal market approach towards a style of government that, whilst maintaining some elements of the internal market, was more centred upon partnership and collaboration. Niall Dickson (1999), in a speech to the Institute of Directors of Social Affairs explained the third way as

being something different and distinct both from liberal capitalism's unswerving belief in the merits of the free market and democratic socialism's demand management and obsession with the state. The third way, he suggested favoured growth, entrepreneurship, enterprise and wealth creation, whilst also advocating greater social justice through state control. The key elements of the third way are purported to include: a belief in the value of community; a commitment to equality of opportunity; an emphasis on responsibility; and a belief in accountability. The drive towards inclusion within *Valuing People* and its outlining of responsibilities towards people with learning disabilities would indicate an adherence to third way thinking. However, *Valuing People* lacked clarity and conviction where accountability was concerned as there were no indications of the sanctions for not meeting responsibilities. White Papers, such as *Valuing People*, are politically significant authoritative reports issued by governments as statements of policy on major issues, which outline their response to complex prevailing issues, and commitment to their alleviation. However, they lack the mandate and impact of documents with legal powers.

The Whole Systems Approach adopted by the New Labour Government was a system that aimed to engage stakeholders and bring systems into alignment in order to create sustainable results and organisational flexibility. To be successful this method requires that each individual element of the whole service not only needed to be effective in its own right, but also needed to connect efficiently with the other service components. Partnership working was therefore a crucial factor. The whole systems approach advocated the removal of unnecessary boundaries, and recognition of the independence and inter-connectedness between services in order to develop person-centered, needs-led and outcome based services (Asthana, 2003). The underlying principles highlighted as being essential if the whole systems approach was to be successful included: the need for fair access to consistently efficient, timely, accessible services of a consistently high quality; local responsibility for health care delivery set against new national standards; and partnership working that placed the needs of the patient at the centre of care processes. The government clearly associated *Valuing People* (2001) with the whole systems

approach, emphasising as it did that that when service reviews were undertaken that were to be looked at from a whole systems perspective, rather than considering particular services in isolation (p95). *Valuing People* decreed that professional structures should be appraised in order to encourage and promote inclusive working with staff from different fields and agencies (p110) to ensure that people with learning disabilities and their families had easy access to services from all agencies. Professional staff were to become a resource for the local implementation of the White Paper, promoting social inclusion for people with learning disabilities, and to be accountable for the outcome of their work to the local partnership arrangements, whilst at the same time ensuring the retention of appropriate professional accountabilities and support.

Other major initiatives of the New Labour government in general included their commitment to devolution, social inclusion and mainstreaming. Its staunch support of the political ideal of devolving power and responsibility to regional and local levels was reflected in *Valuing People* (2001) in the concept of local partnership and integrated commissioning boards with the responsibility to develop and implement joint investment plans and to oversee inter-agency planning and commissioning of integrated services. Social inclusion first entered British mainstream politics, in part, as a result of the *European Union's Lisbon Summit* (1996), which committed member states to adopt the promotion of social cohesion and inclusion as a strategic goal. Social inclusion then became a cornerstone of New Labour's social policy agenda. The Centre for Economic and Social Inclusion (2002) defined social inclusion as,

> *... ... the process by which efforts are made to ensure that everyone, regardless of their experiences and circumstances, can achieve their potential in life* (p1).

One of the methods anticipated as achieving this was the notion of mainstreaming, which is a concept championed in Britain by the Equal Opportunities Commission. Basically, this is a long-term process whereby policy makers take account and reflect the requirements of diverse populations within mainstream public policy frameworks. Public services have been directed towards providing value-based services that emphasize equality of all

and a move to deliver services in new and different ways and settings. Evidence of this can be found in the various policies and guidance documents emanating from government since 1997 (Table 9).

A Testing of Ideas

Evidence based policy making was championed by the New Labour government (Solesbury, 2001), and has much to commend it in that it provides justification for policy decisions in a climate of restricted resources and priority setting. It is suggestive of new concepts and approaches being introduced that are informed by both sound reasoning and the knowledge that they will work. The term itself is difficult to define as debate surrounds whether evidence based policies should be philosophically or practically grounded, how it should be gathered, and how it should be used (Dobrow et al 2004, Wells, 2007). What is clear is that evidence based policy was a theory championed by the New Labour government and is a concept referred to within *Valuing People* (2001). It could be speculated that, by involving people with learning disabilities and other interested parties in its development, *Valuing People* considered the expressed needs and values of the target population (Muir Gray, 2004) and can therefore be considered an evidence based policy. Policy however, is not formed from evidence alone. It is the outcome of political processes that are subject to a number of other influences such as *ideology, value judgments, financial stringency, economic theory, political expediency, and intellectual fashion* (Davis et al, 996 p865), power and authority (Solesbury, 2001). In the United Kingdom central government dominates the policy making process (Figure 5). However, in recent years, the experience of both individuals and groups has been recognised as being important to the planning and development of services (Baggott et al, 2005). *Valuing People* (2001) broke new ground in relation to learning disability policy making in that, for the first time, the government worked with and listened to the views of people with learning disabilities themselves. An advisory group was established which involved many meetings, conferences and consultations, together with individual representations from people with learning disabilities across the country resulting in a large number of people with learning disabilities directly contributing to the White Paper (Holman, 2001). A range of stakeholders

representing nine different categories were consulted and contributed to the *Valuing People* document (Tables 10 and 11).

Working Groups were formed around the topics of children, carers, health, supporting independence, workforce planning and training, and building partnerships. Consultation took the form of seven workshops across the country attended by almost one thousand people, together with themed seminars and web site contributions. The involvement of stakeholders opened up discussions around new ideas and introduced the elements of fairness and transparency to the proceedings, thus increasing public trust in the document's content. However, the transparency did not go far enough in that, whilst listing the names of those involved, no indication of each individual's background was made available. Thus making it very difficult to estimate the existence of any possible power struggles and unresolved tensions between different interest groups or whether the input provided might have been influenced by values/background. This lack of information makes it difficult to establish whether consultation adequately covered all key groups impacted upon by the policy or whether some were excluded and if so for what reason. Although the document summarised what people were asking for throughout the consultation process, no actual examples of the data produced by the working groups were supplied in either the body of the text or the appendices. Therefore, it is impossible to verify whether the results of the consultations bear a true resemblance to the published document. This is disappointing in light of the government's professed commitment to evidence based policy making and could leave it open to accusation of allowing politics and not evidence to drive policy. Policy is not always implemented because it represents the best ideas but rather because it fits within a particular policy window (West and Scott, 2000). Whilst such windows can be influenced by individuals and groups they can also be dependent on the whims of the political process. Throughout the document quotations from people with learning disabilities and other key stakeholders are presented. This helped to set the policy allowing the reader to see things from the perspective of the major personnel involved.

The V*aluing People* (2001) text revealed that working/advisory groups were consulted on emerging ideas via *papers prepared by their members on a range of subjects* (p136). How the groups were managed, however, is not clear. *Valuing People* failed to clarify whether groups were presented with, and encouraged to deliberate upon, competing values and policy options, or whether they were encouraged towards preference formation rather than preference assertion. Because the document lacked detail it is left open to speculation as to whether groups were: given access to balanced information and allowed an open agenda so that any recommendations emanating from the groups could be revised or expanded upon; allowed time to consider the issues effectively; a representative sample of those affected by the policy; and free from manipulation or coercion.

Political Context 'A'

Signposts for Success (1998)	This document provided a comprehensive developmental framework for commissioners and providers of services. It offered specific guidance points aimed at encouraging mainstream NHS services to become more responsive to the special circumstances and needs of people with learning disabilities. It also drew attention to the significant contribution that could be made by the NHS in helping people to live independently, and to the role of social care agencies in promoting the health and emotional well being of people with learning disabilities.
The Human Rights Act (1998)	Became part of British law in 1998, applies equally to people with learning disabilities. It spells out specifically that people with disabilities are not to be discriminated against (British Broadcasting Corporation 2005).
National Service Frameworks(1998)	Long term strategies for improving specific areas of health care. A systematic process of inauguration began in 1998. The National Service Standards identified key interventions for a defined service or care group. The areas covered included: ▪ Coronary Heart Disease. ▪ Older People. ▪ Long Term Conditions, ▪ Children. ▪ Cancer. ▪ Mental Health. ▪ Renal Services. ▪ Chronic Obstructive Pulmonary Disease. *Valuing People* (2001) stressed that the National Service Frameworks would apply as equally to people with learning disabilities as to other patients (Department of Health (2001 p 66).
Once a Day (1999)	Aimed at all members of the primary health care team, including general practitioners, practice nurses, health visitors, physiotherapists, receptionists, managerial and administrative staff and any others who work within and alongside the primary health care team. It was designed to stimulate discussion and action in order to make primary health care services more accessible and responsive to people with learning disabilities and to identify the points at which the involvement of the local specialist services may be helpful.

The New NHS: Modern, Dependable (1997)	Set out a vision in which communities work in partnership to plan and deliver healthcare services for the benefit of the community as a whole. It went on to explain that it expected the National Health Service to work locally with those providing social care, housing, education and employment in providing integrated care based on partnership, driven by targets. It set out three areas for action. 1. National standards and guidelines. National Service Frameworks. National Institute for Clinical Excellence. 2. A local drive for quality. Primary Care Groups. Explicit quality standards. A system of clinical governance. 3. A new organisation to tackle shortcomings. Commission for Health Improvement.
Information for Health' (1998)	Re-emphasised the messages requiring the setting up of Local Implementation Strategies between local organisations who had previously worked to their own agendas. One of the concerns expressed in the document was related to the mutual accessing of health and social care information/records by health and social care professionals. It expounded the need for the availability of accurate and reliable data if integrated care systems were to be supported. The principles behind 'Information for All' can be found within Valuing People in its bid to promote integrated professional working advocating for a reorganisation of professional and organisational structures to embrace the fields of housing, education, primary care, employment and leisure.
Doubly Disabled: Equality for disabled people in the new NHS Access to services (1999)	Recognised that National Health Service staff needed an increased awareness of, and response to, the needs of disabled people if it was to meet its responsibilities under the 1995 Disability Discrimination Act. It stressed the need for health service managers, Primary Care Groups and National Health Service Trusts to take seriously the needs of its disabled patients and to provide with a fair service. This document provided good practice guidance around the issues of: • Policy context. • Management and organisation. • Developing a local strategy. • The role of a Disability Services Adviser. • Approach and awareness, with a specific section relating to people with learning disabilities. • The environment. • Procedures.

	• Staff training.
Facing the Facts (1999)	The report identified huge inconsistencies in the support available to people with learning disabilities and their families. It gave three reasons for this. Firstly, the lack of clarity regarding the National Health Service's role and responsibility towards continuing care services for people with learning disabilities. Secondly, the insensitivity of health professionals as to how people with learning disabilities might experience health interventions. And finally, the divisions between existing service systems often resulted in access to health services significantly lacking consistency across the country. Facing the Facts (1999) envisaged change being implemented using generic measures such as 'Health Improvement and Modernisation Programmes'.
The Health Improvement and Modernisation Programmes	The Health Improvement and Modernisation Programme addressed the need for local strategies for improving health and health care and reducing inequalities in health. It brought together local priorities with the requirements of the National Priorities guidance. It set out the local contribution to be made towards the achievement of the national targets and objectives in 'Saving Lives: Our Healthier Nation (1999). Health Improvement Plans were expected to provide the means of addressing the health needs of people with learning disabilities so that they did not experience avoidable illness and premature death.
Modernising Government White Paper (1999)	It aimed to address how policies were devised, i.e. inclusive, joined up, strategic, and forward-looking, and service delivery, i.e. efficient and of a high quality in response to the needs of citizens rather than the convenience of the providers. The government's broad social policy agenda focuses on building up strong communities and developing high quality public services. It has placed great emphasis on improving health and well being through: prevention; effective treatment and support; breaking down barriers between services and promoting partnership working; raising the quality of services while maximizing value for money; updating structures to focus collaboration around local populations; and modernising support strategies for human resources, information, performance management, and regulation of both services and staff.
Saving Lives: Our Healthier Nation (1999)	Set out the government's strategy for health. It outlined how it intended to improve the health of the population as a whole and of the worst off in society in particular. It placed strong emphasis on partnership working; individuals being empowered to make informed decisions beneficial to their health, and the crucial role of primary health care staff in promoting good health in addition to treating people when they fall sick. All of which are strongly reflected within Valuing People.
The Special Educational Needs and Disability Act (2001)	Aimed to ensure that disabled students, including those with learning disabilities, are not treated less favourably than non-disabled students.

The Race Relations Amendment Act (2000)	This Act amended the previous Race Relations Act of 1976. It placed a duty on public authorities to promote race equality and eliminate unlawful racial discrimination (Johnson 2007). No secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse (2000) continued the government's theme of requiring local agencies to work together to protect vulnerable adults from abuse, by developing local multi-agency policies and procedures.
The 'Supporting People Programme' (2003)	This was the national government programme that provided a strategic framework and funding for housing related support. It offered vulnerable people the opportunity to improve their quality of life by supporting them to live more independently, maintain their housing and to provides housing-related support to prevent problems leading to hospitalisation, institutional care or homelessness. Supported housing providers were expected, amongst other things, to provide regular information on their tenants' progress in managing their health (Office of the Deputy Prime Minister 2004).The Care Standards Act (2000) amongst other things, established the National Care Standards Commission, an independent regulatory body for social care and private and voluntary healthcare services. It took over the regulation of these services from local councils and health authorities. It s aim was to ensure the quality of services and improve the level of protection for vulnerable people (Office of Public Sector Information 2000).
Modernising the Social Care Workforce	This was first national training strategy for England and was approved by the 'Training Organisation for Personal Social Services' England Board in April 2000 following public consultation and subsequently received ministerial endorsement. This was England's first comprehensive national training strategy to analyse the skill needs of people working in the social care sector in England and to propose an action plan to improve both the qualification base and the quality of training over the coming five years.
The Learning Disability Award Framework	This is a set of awards relevant to those who support people who have a learning disability. The awards are nationally recognised and provide a route for development and career progression.
National Vocational Qualification	Whilst the Learning Disability Awards Framework was designed to assist people to learn and gain knowledge and understanding, the National Vocational Qualifications are work-related, competence-based qualifications based on national occupational standards. They reflect the skills and knowledge needed to do a job effectively. Valuing People (2001) expected that by 2005 fifty per cent of front line staff would have achieved at least National Vocational Qualification, level two.
National Training Strategy	The broad aim was to improve the quality, and management, of social care provision to families, individuals and local communities, by encouraging a planned approach to workforce development. It draws together National Vocational Qualifications and post qualification training, spanning care workers in nursing homes and social services directors. As well as setting targets for training and qualifications, the five-year action plan aims to predict what future skills will be most in demand and how the government, employers, and employees should pay for the training. The government via *Valuing People*

	(2001) makes it clear that it is a government objective to ensure that social and health care staff supporting people with a learning disability are appropriately skilled, trained and qualified.
Health Act (1999)	Arrangements commonly referred to as Section 31 Health Act flexibilities provided an enabling framework so that money could be pooled between health bodies and health-related local authority services, and resources and management structures could be integrated. These arrangements allowed for the joining-up of commissioning for existing or new services and similarly for the development of provider arrangements
Joint Investment Plans	These were three year plans for the re-shaping services. They were a means of improving the content and delivery of services provided for a specific client groups and involved a variety of statutory services. Their main aim was to improve co-operation and joint working between statutory and voluntary agencies with concentration on including service users themselves in the planning process Joint Investment plans linked in to the government's commitment to establishing comprehensive and enforceable civil rights for disabled people in society (Jones and Waddington 2000). The objective of Joint Investment Plans for learning disability services was to promote the provision of integrated services that help adults with learning disabilities achieve and sustain maximum independence in their lives.
Partnership Working	Learning disability partnerships were developed within the context of the whole systems approach and the overall national policy framework for partnership. Local Strategic Partnerships are non-statutory, non-executive organisations. They were intended to be bodies that cut through all agencies and encompassed all sections of society, including people with learning disabilities. Their aim was to influence and bring together the provision of improved services from the public, private, business, voluntary and community sectors within their own localities; and to work towards creating empowered communities. It was anticipated that the Learning Disability Partnership Boards as outlined within Valuing People, would be located within this framework.

Table 9

When involving stakeholders in the policy making process it is inevitable that organisations will have brought their values, attitudes and ideals to the discussion. An internet search of stakeholders revealed a marked commonality of beliefs between the groups involved. What is not apparent is whether the fact that these organisations upheld government principles was the reason why they were chosen to participate or not.

Exactly what the criteria for inclusion in the consultation process were, and how contributors were recruited and selected was not apparent within *Valuing People* (2001). Several establishments represented in the groups had strong research connections. Whilst not wanting to doubt the integrity of those researchers participating in the working groups, the fact that The Department of Health intended to make two million pounds available for research projects starting in 2001/2002 could, consciously or sub-consciously, have influenced the contributions made. Six officials from the Department of Health's Disability Branch and only one from its Nursing Branch were named specifically in the document, whist twenty people were merely noted as being from the Department of Health with no indication of their background. From the information available in *Valuing People* it could be concluded that there was a bias towards ensuring input from health related personnel. This could account for the limited consideration given to health facilitators and the heath facilitation process within *Valuing People.* If this is the case it is regrettable given the emphasis it placed on inclusion.

Disappointingly, given the potential impact on mainstream health service delivery, there was no representation in the Health Working Group from the Royal Colleges of Nursing, General Practitioners, Physicians or Surgeons. Important stakeholders were omitted from the consultation process despite the assurance in *Modernising Government* (1999) that policies would be inclusive taking into account the needs and experience of all those likely to be affected by them. Such omissions bring into question the quality of evidence upon which *Valuing People* was based.

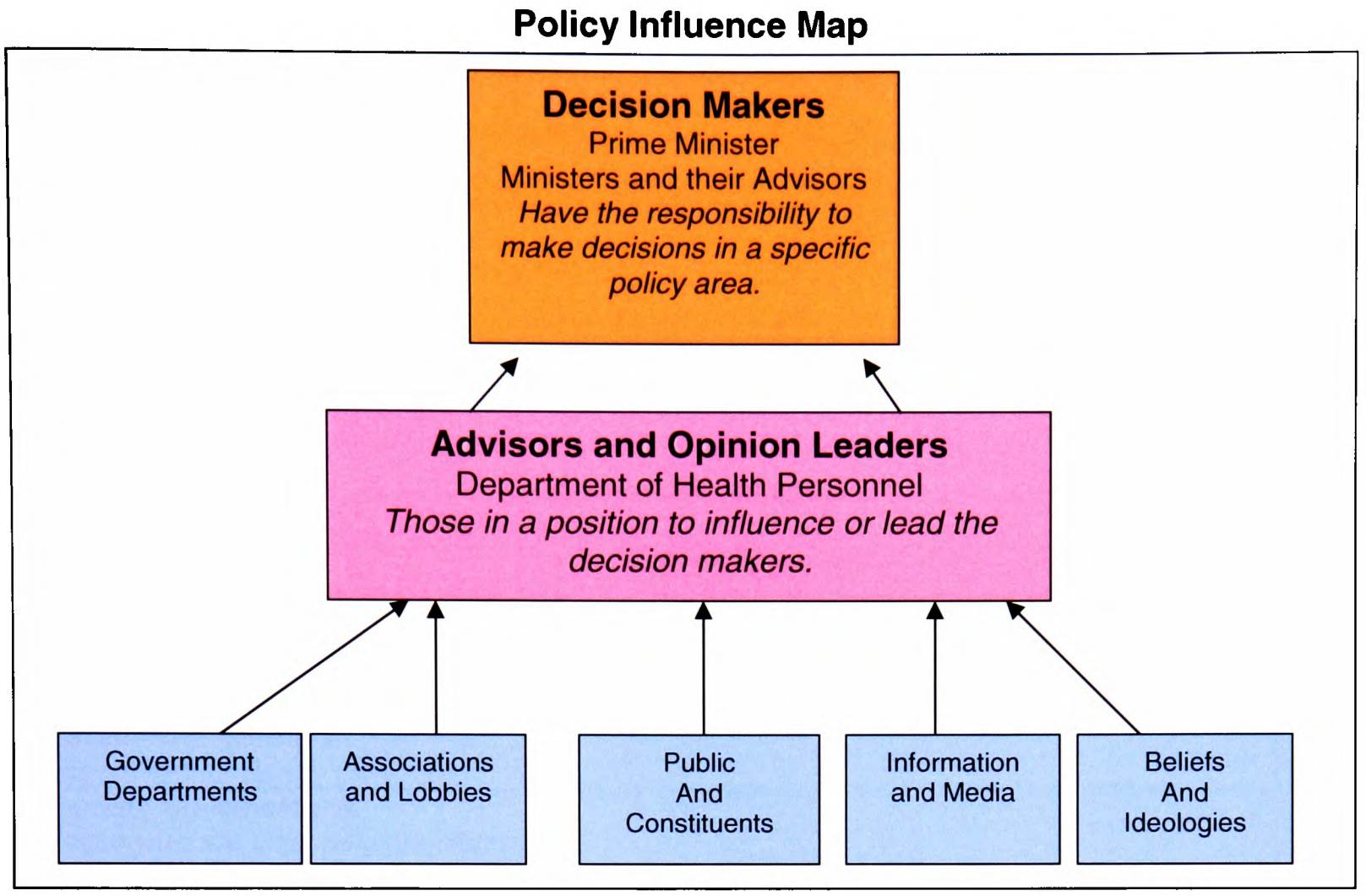

Figure 5

When looked at as a whole, however, it is possible to claim an evidence base for *Valuing People* (2001), drawing as it did upon specific pieces of research to support its proposals (Table 13) and in some instances made vague reference to the existence of others (Table 14). In addition, several research studies, reports and publications were commissioned by the government to accompany *Valuing People* (Table 12). Whilst endeavouring to illustrate that *Valuing People*'s foundations lay firmly within research-generated evidence no indication could be found within its text to demonstrate whether the research sources used were critically appraised making it difficult to assess the validity, results and relevance of the research studies cited. A search of *Valuing People* using the key words of research, studies, report and findings, revealed an acknowledgement of having utilised twelve relevant documents. The bibliography showed that thirty four publications were used to inform the development of *Valuing People*, supported by six working groups who had considered papers prepared by their members on a range of subjects. It is

interesting to note that none are specifically health related and the non-specific references made to research within *Valuing People* contained only two references to health issues. Documentation commissioned to sit alongside *Valuing People* demonstrated a lack of health specific texts. Such an omission must cast doubt on the importance afforded to health facilitation within this document as a whole.

Stakeholder Interest

Key Stakeholders: *Those who can significantly influence or who are important to the success of Valuing People.* Government ministers. Department of Health personnel.	**Area of Interest:** Political and ideological agendas. Working with decision makers.
Primary Stakeholders: *Those who are ultimately affected by Valuing People either positively or negatively.* Service Users. Carers. Health and Social Care Services. Health and Social Care Professional Bodies.	 Personal desires, experiences and ambitions. Personal desires, experiences and ambitions. Future configuration of services. The impact on the role of existing personnel.
Secondary Stakeholders: *All other individuals with a stake or an interest or intermediary role in Valuing People.* Pressure Groups. Advocacy Groups. Private and Voluntary Sector Service Providers. Universities and Research Institutes.	 Influencing the people who actually have the power to make decision. Protecting the personal and legal rights of individuals. Increasing the volume and quantity of the services they offer. Educating the workforce and undertaking research.

Table 10

Identified Stakeholders

Private and Voluntary Sector Stakeholders	Public Sector Stakeholders	Civil Society Stakeholders
Service Providers: Mencap. Norwood Ravenswood. Joseph Rowntree Foundation. **Professional Bodies:** Association of Directors of Social Services. Royal College of Nursing. Royal College of Psychiatrists. **Training Organisations:** TOPPS. Success in Shared Care. **Independent membership Bodies:** National Health Service Confederation. National Development Team and Council for Disabled Children.	**Named Government Departments:** Social Services. Social Security. Environment and Transport and The Regions. Education and Employment. **Local Authority Associations:** Local Government Association. Improvement and Development Agency.	**Pressure Groups:** People First. Mencap. Association for Residential Care. Afiya Trust. **Higher Education/Research Institutes:** Institute of Health Research. Lancaster University. Sheffield Hallam University. Norah Fry Institute. Joseph Rowntree Foundation. Community Care Development Centre, King's College, London University.

Table 11

The *Valuing People* (2001) chapter devoted to *Improving the Health of People with Learning Disabilities* was limited in that it cited from just one named document *Facing the Facts* (1999) in support of its proposals. *Facing the Facts* highlighted inconsistencies in service provision for people with learning disabilities across the country; the difficulties in gaining help to access services; and that the fact that the health needs of people with learning disabilities were not being recognised by doctors and care staff (p59). This chapter introduced the concepts of health facilitation and health action planning; but no evidence was presented to support these as positive, tried and tested interventions either within learning disabilities services, or in any other field of service delivery. At no point within the document are any pilot or feasibility studies relating to health facilitation referred to as having been carried out. Thus the opportunity to gain

credibility within both learning disability and mainstream health services, to establish the concepts as workable and realistic, to determine the skills and resources required, and provide a blueprint of good practice for others, was missed.

Future Orientated

In terms of being future orientated it was apparent that *Valuing People* (2001) was forward looking in its commitment to research (Table 15) and the development of an evidence based approach to service development and delivery. Two million pounds was allocated to the funding of a four year learning disability research scheme and improved standards were expected to result from better commissioning practices aimed at ensuring the provision of high quality, best value, and evidence based services. The Social Care Institute of Excellence was expected to contribute to and promote expertise.

Research, Studies, Reports Commissioned by Government to Accompany Valuing People (but not specifically to base *Valuing People* upon)

Research, Studies, Reports Commissioned by Government to Accompany *Valuing People* (but not specifically to base *Valuing People* upon).	**Undertaken By:**	**Date of Publication**
Nothing About Us Without Us.	The Service Users Advocacy Group.	March 2001.
Family matters, Counting Families In.	Family Carers Working Group.	March 2001.
Learning Difficulties and Ethnicity.	The Centre for Research in Primary Care, University of Leeds.	March 2001.

Table 12

Research Evidence Used to Support *Valuing People* (2001)

Research, Study, Report Produced by:	Topic Area	Valuing People Page Number
Centre for Research in Primary Care at the University of Leeds.	The needs of people with learning disabilities from minority ethnic communities.	20
Hester Adrian Research Centre, University of Manchester, 1999 -The Quality and Costs of Residential Supports for People with Learning Disabilities, Summary & Implications.	Social isolation. Differences in cost and benefits between dispersed housing, NHS residential campuses, and village communities.	20 71
Facing the Facts: Services for People with Learning Disabilities – A Policy Impact Study of Social Care and Health Services (Department of Health 1999).	Inconsistency in Service Provision. Reluctance to support people whose families make arrangements for them to live in village communities.	20 73
Swindon People First.	Direct Payments.	46
The London Learning Disability Strategic Framework.	Inconsistency in service provision.	20
Policy Consortium for Supported Employment.	Supported employment.	86
Moving into the Mainstream: The Report of a National Inspection of Services for Adults with Learning Disabilities (Department of Health 1998.	Short breaks.	21
Setting the Boundaries.	Exploitation. Sex Offences.	 24
Caring about Carers: the Report of the National Carers Strategy.	Benefit increases.	54
Mansell Committee Report.1993.	Development of specialist services. Commissioning specialist services.	67 103
Speaking up *for Justice* 1998	Youth Justice.	94
Youth Justice and Criminal Evidence Act 1999.	Youth Justice.	94

Table 13

Non-specific Reference to Research within Valuing People (2001)

Non-specific Reference to Research, Studies, Reports and Findings	Valuing People Page Number
Research has consistently shown: variable quality of community based services; concerns about shortfalls of provision in particular services; and varying degrees of commitment to learning disability services by local authorities and health authorities.	18
Recent research shows only 6% of people with learning disabilities having control over who they lived with and 1% over choice of carer.	19
There is a compelling body of evidence from research and inspection reports that disabled children and their families face many barriers to full participation in society.	30
Research findings show parents of disabled children would like: - Key workers to help co-ordinate services. - Early identification of impairments and early intervention. Simple accessible information about available services. Greater access to family support, short breaks and support.	31
Research has highlighted inadequate diagnosis and treatment of specific medical conditions, including heart disease, hypothyroidism and osteoporosis.	60
Studies of the management of people with challenging behaviour have shown over-dependence on the use of psychotropic drugs with poor outcomes as a consequence.	60
A study commissioned as part of the White Paper's development found 3,000 people living in 73 village and intentional communities.	73
Research has raised significant concerns about the quality of life enjoyed by people living in NHS residential campuses developed as a result of the contraction or closure of NHS hospitals.	75
Recent research suggests that family based early intervention for children with autistic spectrum disorders may result in improvements in skill and behaviour.	102
There is already a considerable amount of research activity on learning disability in the NHS.	115
Evidence suggests that the number of people with severe learning disabilities may increase by around 1% per annum for the next 15 years.	16
Various studies showed that housing design on its own does not guarantee positive outcomes.	71

Table 14

Measurability

Public policy is ultimately about achieving objectives. The *Valuing People* (2001) document followed a hierarchical model of presentation (Saaty, 1996) and in so doing was able to demonstrate the relationship between goal, objectives, sub-objectives, targets and performance indicators. In the forward to *Valuing People*, the then Prime Minister Tony Blair outlined the government's commitment to the goal of improving the life chances of people with learning disability. This goal was supported by six new targets, eleven objectives stating

the government's aims, and forty two more detailed sub-objectives; these in turn were supported by ten proposed and two already established performance indicators. Thus *Valuing People* provided the elements of direction, measurability and accountability. However, criticism has been aimed at the length of time allowed to meet the new targets as being unrealistic given that the pace of change can be slow. In an interview with Prasad (2003), Rob Greig* warned that to make a real difference to the lives of people with learning disabilities would take the best part of ten years and not the five allowed in the White Paper.

In relation to *Valuing People's* objective five, *Good Health,* which aimed to enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to consistently high standard, and with additional support where necessary (p 125), there were a number of sub-objectives. These set out the requirements that: health inequalities in the population of people with learning disabilities be reduced; mainstream National Health Services staff were to be enabled to meet the general and specialist health needs of people with learning disabilities; and that National Health Services were to develop specialised evidence based learning disability services focusing on the whole person (p126). Regrettably no performance indicators were outlined despite the strategy having introduced the two key elements of health action plans and health facilitation. Having no agreed framework for evaluation and little sense of accountability made this particular objective vulnerable. *Valuing People* placed a lot of emphasis on outcomes but there was vagueness about how to achieve them. Surprisingly, important key actions proposed in *Valuing People* were merely recommendations and not mandatory targets; unlike the National Service Frameworks, which had targets, clear standards and accountability. Unfortunately, without closely monitored and enforced targets and appropriate levels of resources being made a key priority the health aspects of *Valuing People* were destined to be at the mercy of good will.

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* Valuing People National Director

Funding

Inevitably social and economic policies are linked. In *Valuing People* (2001) the government made quite clear that it anticipated mainstream funding (Table 16) to be made available to provide services for people with learning disabilities. In addition it committed to financially supporting *Valuing People* initiatives via the Learning Disability Development and Implementation Support Funds. The Learning Disability Development Fund comprised fifty million pounds per annum from April 2002; twenty million pounds in capital and up to thirty million pounds in revenue from the release of health funding formerly attached to long-stay health provision. It was aimed at the policy's key priority areas and was to be made available as part of pooled funds under the Health Act (1999) flexibilities. The Implementation Support Fund (Table 17) consisted of two point three million pounds a year for the three years to fund new initiatives linked to support for key aspects of the new strategy. Finally, the designated function of The Learning Disability Development Fund was to support leadership initiatives, the modernisation of day services, the reprovision of long-stay hospitals, the development of supported living for people with challenging behaviour and the advancement of integrated health and social service facilities for young people with severe disabilities and complex needs. Despite *Valuing People*'s (2001) commitment towards a considerable financial investment, once again, no specific additional monies were made available for health initiatives such as the provision of health facilitators or for supporting primary care services to improve access to health services for people with learning disabilities. The danger being that this could create the impression that health objectives were not seen as being a priority for development by the government and allow health service providers to take a relaxed attitude towards the inclusion agenda.

The *Valuing People* (2001) agenda was ambitious and aspirational but doubts were expressed at the time of publication as to whether the finance and resources available were in fact adequate to deliver such a strategy, especially as they were very much dependent upon the release and reinvestment of existing resources (Robbins 2001). *Valuing People* itself admitted that it had been difficult to establish accurate information as to the prevalence of learning disability and that it had had relied on estimation: thus the government never

made an accurate assessment of how much *Valuing People* would cost to fully implement.

Future Research Planned

Planned Future Research (On publication of *Valuing People*).	**To Be Undertaken By:**	**Valuing People Page Number:**
Two million pound research initiative- People with learning disabilities: Services, Inclusion and Partnership.	No information provided.	8 114
To obtain a clear and comprehensive picture of current knowledge about the incidence, prevalence, and causes of autism and the strength of evidence that underpins the knowledge. Report to be submitted in the autumn of 2001.	Medical Research Council.	102
During 2001/2, there will be a national inspection of learning disability services in order to assess how well placed local councils will be to implement the new strategy. Findings from the inspection will be used to inform the work and priorities of the Implementation Support Team.	Social Service Inspectorate.	115
There will be a study of the links between supported employment and day services.	No information provided.	7

Table 15

Mainstream Funding Sources

Source	To Be Used For:
Quality Protects Programme.	Providing better support to children to facilitate involvement in play and leisure activities.
Schools Access Initiative.	Improve accessibility of mainstream schools.
Standards Fund Grant.	Improving provision for children with special educational needs.
Sure Start. The Children's Fund. Connexions.	Dealing with the social exclusion of disabled children.
The Family Fund Trust.	Reducing stress on families with severely disabled children.
New Opportunities Fund.	Quality play opportunities, including one-to-one support and adapted toys and equipment, and palliative care for children with life limiting illnesses.
The Carers Grant.	Ensure that carers can have breaks from caring when they need it.
Supporting People.	Enabling local authorities' flexibility in how they fund support services for vulnerable people.
Further, Higher, and Adult Education and Youth Services.	To improve accessibility for disabled students and learners.
The Adult basic Skills Strategy Unit.	Improving basic skills.

Table 16

The Implementation Support Fund

Money available:	To Be Used For:
£300,000	Increasing volunteering opportunities for citizen advocates. Expansion of advocacy services.
£5000,000	Establishment of a National Learning Disability Information Centre and Helpline. Person-centred planning Partnership working. A scoping study of the interface between employment and day services. Extending the Learning Disability Awards Framework.
£2 million	- Research.

Table 17

Leadership and Support

The government acknowledged that such a radical learning disability strategy as that outlined in *Valuing People* (2001) would need leadership and support if it were to be effective. To this end a series of supports were established. A National Director tasked with leading and managing a National Valuing People Implementation Support Team, informing and influencing policy development and delivery across government in order to ensure inclusion of the needs of people with learning disabilities in mainstream service development and the promotion of the profile and understanding of the *Valuing People* (2001) policy. The Director was supported in this by the *Valuing People* Support Team development workers based regionally. An inclusive Learning Disability Task force was formed by government to review progress made around the adult elements of *Valuing People* and to report this to the Minister along with proposals for what needed to be added or performed differently. The National Forum of People with Learning Disabilities meanwhile was put in place to provide a voice for people with learning disabilities and to be a point of contact that the government could consult in order to obtain a representative viewpoint. A National Forum of People with Learning Disabilities, supported by a network of regional forums, was created to elect members for the Task Force and participate in a range of national initiatives. The Disability Policy Branch at the Department of Health had responsibility for ensuring the management and continued development of the *Valuing People* policy by helping other government departments and the rest of the Department of Health to ensure the new policy initiatives were inclusive of the needs of people with learning disabilities. And finally, the Social Service Inspectorate, now known as The Commission for Social Care Improvement, was tasked to monitor the performance of Social Service Departments. In the National Health Service this role fell to the Commission for Health Improvement.

Part Two - The Delphi Study

A Delphi study involves having experts formulate solutions to problems, or offer opinions on a specified topic through several cycles of revision based on each other's feedback in an attempt to reach an end result that offers a better solution or opinion than any of the experts could have arrived at individually.

A Delphi study had much to offer as a data gathering method in that it provided an interactive communication structure between the researcher and a group of experts in a specific field. This enabled the generation of ideas and facilitated consensus among individuals who have special knowledge and supplied information upon which to base a topic guide for use within semi-structured interviews.

The rationale behind choosing to use a Delphi approach as a data gathering method was that it provided a means of establishing which issues relating to health facilitation were considered to be important from the perspective of a panel of experts in order to formulate the topic guide used in the semi-structured interviews. In practical terms it offered a transparent and democratic technique, which, because it was conducted via e-mail, was speedy, inexpensive and straight-forward to administer. It was attractive to participants in that they could contribute without having to leave their places of work and afforded them anonymity which left them free to contribute without being subject to the influences of conventionality, reputation, power or politics.

The panel of experts identified as potential participants were drawn from professionals working in, or allied to, learning disability services. They were recruited for their ability to influence policy and/or practice, having recently published work on learning disability and health issues, or the currency of their health or learning disability practice.

No data gathering method is without limitation and in the case of Delphi studies these are usually to be found in relation to issues regarding the status of

'experts'. In this research the recruitment of experts was ultimately limited to my own knowledge of significant people in the field of learning disabilities. This was mitigated by consultation with my supervisor and colleagues who were themselves expert in their practice. This consultation did identify a small number of new sources and also confirmed my initial selection of experts. With Delphi studies there is also the difficulty of maintaining adequate expert input at each phase of data gathering. Fortunately, in this instance, enough respondents were retained.

In the first round participants were asked to list the three issues they felt were worthy of being the subject of study. A statistical summary of group responses was prepared following each round of questioning, which was then used to develop the ensuing round of questioning. The summary was issued as feedback so that individuals, having an awareness of the overall responses of others, might, if they chose, revise their previous viewpoints. The twenty two contributors to round one identified fifty one issues grouped together under six headings: models of health facilitation; outcomes and outcome measures; client opinion and experience, links with person-centred planning; roles; and commissioning issues. These were then drafted, unedited and unattributed, and circulated to all participants (Table 18).

Round two required participants to study the circulated groupings and choose three statements/issues that they felt were worthy of an in-depth study, ranking them in order of priority (Table 19). Of the twenty two first round contributors, only fifteen people responded at round two. In the round two responses several contributors suggested that some of the possible topics from round one could be combined to form the basis of an interesting study (Table 20). This second round of the Delphi raised some interesting comments. Several people acknowledged that that they had not given much thought to examining the concepts of health facilitation and health action planning in terms of their effectiveness, preferring to assume that this would simply happen as a matter of course. They chose in practice to concern themselves more with issues of how health facilitation would manifest in their localities or, as in some instances,

were just coming to terms and getting on with the process of health facilitation without much in the way of deliberation.

In summary, the main issues arising centred around: the effects of health action planning; the process of facilitation including which models produced results; measuring health outcomes for individuals and the learning disabled community as a whole; how to influence the local health needs analysis, community profiling, and working with public health departments; and the issues of efficiency and cost effectiveness. As no strict rules exist as to what constitutes an optimum number of rounds for a Delphi study the two rounds of questioning employed were adequate to supply a consensus as to the prevailing issues upon which to inform a topic guide for use within the semi-structured interviews (Appendix 5).

Unedited and Unattributed First Round Responses

Heading	Number	Question/issue
Models of Health Facilitation	1	Which models of health facilitation bring the best results?
	2	In-depth look at facilitation roles at both levels, with some deeper reflection on models and effective work and results.
	3	What is actually happening? There has been a significant amount of research on health facilitation, but it has all looked at a single facilitator working with one or two practices (almost always with a strong commitment to better health care for people with a learning disability). The proposals in Valuing People are very different – a health facilitator will work with a great many practices, and attempt to meet a centrally imposed target. The effectiveness of this approach has not been evaluated. There is a danger that it will become a 'paper exercise'.
	4	An in-depth look at how the Department of Health's guidance has been implemented on the ground and how effective, leadership wise, those individuals in health facilitation posts have been in relation to change management both with primary care and specialist services.
	5	How health facilitators have: engaged with General practitioners; provided education to General practitioners and primary health care teams; provided appropriate education for carers'; and tackled issues of consent set against the need for invasive medical practices.
	6	What are the successful strategies for people when being supported to access the primary care team?

	7	How do the health outcomes achieved via health facilitation and health action planning compare with areas such as Wales where different approaches to achieving health gain for people with learning disabilities are employed?
	8	Are the ways in which health action plans are being implemented taking into account local circumstances?
Outcomes/outcome measures	9	How to measure outcomes and see health gain in individuals and communities.
	10	Explore how the members of the learning disability workforce can demonstrate with quality indicators that they can improve access to primary and acute care.
	11	Mainstreaming. Does this work improve mainstreaming or not?
	12	Health action plans. Have they proved to be a vehicle to engage with primary care?
	13	Tracking health action plans that detail the holistic needs of people with learning disability and then demonstrates that action has resulted in improvements in access and health assessment within primary care.
	14	What are the outcomes of health facilitation and health action plans? There's quite a lot around about the 'how', so it would be valuable to look at the 'what'.
	15	A study of health action planning outcomes, how have the services ensured that the actions have been met?
	16	What impact has any change had on the health of people with learning disability?
	17	What impact has health action planning had on the health of individuals, and on mainstream provision, attitudes, development etc?
	18	How many people with learning disabilities have actually had a health action plan?
	19	How are quality and outcomes for people being monitored?
	20	What is the nature of the link between Community Learning Disability Teams and Primary Health care Teams?
	21	How effective are health action plans?
	22	Has health facilitation helped people to access their rights, e.g. to health checks under the Care Standards regulations?
	23	Has health facilitation and health action planning increased people with learning disabilities understanding of health issues? Do they feel better about visiting the primary care team? Is it making a difference to access for people?
	24	Have General practitioners and primary care teams been adequately engaged?
Client Opinion and Experience	25	What is the perspective of people with learning disabilities and their families on health facilitation and health action planning?
	26	How will we know if people are being treated as equal citizens in relation to access and delivery of mainstream health care?

	27	What does the concept of health action planning mean to people with learning disabilities? Do they need help? Who do they think are best placed to help them?
	28	What is the experience of people with learning disabilities of going to the doctors and into hospital etcetera?
	29	How person-centred are health action plans? How is this being demonstrated?
	30	Who plans health action plans in reality?
	31	What has been the role of people with learning disabilities in the planning process – are they having an active involvement or are they passive recipients of the process?
	32	Has health facilitation increased the awareness of people with learning disabilities to their health?
	33	What does the concept of health action planning mean to people with learning disabilities? Do they need help?
	34	There is a hidden population of people with learning disabilities not known to services. How do they access health facilitation and health action planning?
Links with Person-centred Planning	35	The person-centred debate. Is this being confused with a plan of action for health and health screening, which are two different processes?
Roles	36	Who is taking the lead in health facilitation? Will it lead to more paper work and less 'hands on'? Will it result in deskilling for the professional taking on this role?
	37	Health facilitators, what do they do? Are they a better choice than specialist community nurses?
	38	The role of health facilitator, is it a role for anyone? Does the background of the facilitator affect the contribution they make?
	39	Who plans health action plans in reality?
	40	What are the perceptions of primary health care staff of the support they need/get from the specialist services.
	41	The responsibility for completing, reviewing and evaluating health action plans. Is anyone with a medical background checking them?
	42	How well prepared are health facilitators for their role?
	43	Who takes responsibility for completing, reviewing, and evaluating health action plans?
	44	
	45	
Commissioning Issues	46	How has the information gathered by health facilitators influenced the commissioning process?
	47	Are health checks cost effective? Is it more expensive to stay with a population of people with learning disabilities that is relatively unhealthy or do some proactive work and maintain a healthy population of learning disabled people?
	48	What has been the cost to general practice of implementing health facilitation and health action planning? Has it improved health and has it been cost effective in the long term?
	49	What are the resource implications of health

		facilitation and health action planning? Is the scope of this approach so great that it requires either the investment of huge amounts of resources or a dilution of principles?
	50	How has the information obtained around people with learning disabilities been fed into health needs analysis, community profiling, and public health departments?
	51	What impact has health action planning had on commissioning?

Table 18

Topics Commended for Comprehensive Study at Round 2

Topic Number	Number of Votes
17.	7
9.	4
1, 25, 48, 50.	3
2, 6, 16, 23, 29, 40, 46, 51.	2
3, 4, 5, 11, 15, 19, 21, 28, 30, 34, 37, 41, 47, 48.	1
7, 8, 10, 12, 13, 14, 18, 20, 22, 24, 26, 27, 31, 32, 33, 35, 36, 38, 39, 42, 43, 44, 45.	0

Table 19

Combination of Topics Made at Round 2

Question Numbers	Suggested Question
25 + 31	What is the perspective of people with learning disabilities and their families on health facilitation and health action planning and what has been the role of people with learning disabilities in the planning process – are they having an active involvement or are they passive recipients of the process?
50 +51	How has the information obtained around people with learning disabilities been fed into health needs analysis, community profiling, and public health departments? And what impact has health action planning had on commissioning?
17 + 19	What impact has health action planning had on the health of individuals and on mainstream provision – attitudes, development, and etcetera? And how are quality outcomes for people being monitored?
17 + 50	What impact has health action planning had on the health of individuals, mainstream provision – attitudes, development etcetera? And how has the information obtained around people with learning disability been fed into health needs analysis, community profiling and public health departments?
6 + 3	What is actually happening? There has been quite a significant amount of research on health facilitation, but it has all looked at a single facilitator working with one or two practices (almost always with a strong commitment to better health care for people with a learning disability). The proposals in Valuing People are very different - a health facilitator will work with a great many practices, and attempt to meet a centrally imposed target. The effectiveness of this approach has not been evaluated. There is a danger that it will become a 'paper exercise'. What are the successful strategies for people when being supported to access the primary care team?

Table 20

Conclusion

This chapter has presented the combined results and scrutiny of the *Valuing People* (2001) policy analysis undertaken with the aid of The Queensland Government of Australia's, *Good Policy Content Framework* (Department of the Premier and Cabinet 2000). It found that as a policy, *Valuing People* clearly articulated its vision, ideologies, values and beliefs. Apparent was the fact that by building as it did on the work of *Better Services for the Mentally Handicapped* (1971) it was historically based. It was theoretically and politically informed and sat alongside a wide-ranging body of social policy.

On the whole it was a creative and innovative policy in the method of its development and the fact that it looked beyond traditional boundaries, set crosscutting objectives and required joint working across government, private sector, and voluntary sector precincts. It afforded a degree of flexibility in that it allowed for interpretation to meet local needs but could also have been responsible for a degree of confusion surrounding its implementation. An example of this can be seen in relation to responsibility and accountability, two concepts afforded a good deal of prominence within *Valuing People* (2001). Learning disability Partnership Boards were charged with implementing *Valuing People* at local levels but *Valuing People* failed to make explicit how in practical terms this was to be achieved. Clearly the support of the Primary Care Trusts was needed if health facilitation was to be introduced successfully but responsibility and accountability for introducing, monitoring and measuring its outcomes within Primary Care Trusts was not made clear. Such lack of clarity did not bode well for health facilitation in terms of its credence within mainstream health services. Health facilitation and health action planning have been disparaged due to their not being part of a clear strategy aimed at influencing specific health determinants in the learning disabled population (Achiaga, 2006), and for having been integrated into health and social care strategies (Mencap 2004).

Evidence based policy was a theory championed by the New Labour government and is a concept often referred to within *Valuing People* (2001). *Valuing People* was based upon evidence gathered from a wide range of

sources, including research and stakeholder consultation. Although due to a lack of information as to critical appraisal methods used, the quality of the research utilised cannot be established and there are doubts as the inclusivity of the consultation process. In terms of health facilitation very limited evidence was presented to support its development. The policy analysis exposed another area within *Valuing People* that would have benefited from a more robust evidence base, that is, the funding of its innovations. Several references were made to funding implications and sources but having admitted to resorting to using an estimate of the number of people with learning disabilities in England due to a lack of information doubts exist as to the adequacy of the funding made available. Of particular concern to the *Valuing People's* health agenda was the fact that no specific funding was earmarked for the introduction of health facilitation.

In terms of its outlook *Valuing People* could be viewed as a forward looking policy in that it took a radical approach to service provision for people with learning disabilities in the twenty first century and was committed to commissioning future research (Table 15). But its policy outcomes were short in nature and it perhaps would have been better and more realistic if a longer term view had been taken. It could face criticism for its failure to look outward from England in order to take into account European, American and Australian developments, particularly in relation to health care.

The main issues arising from the data gathered via the Delphi study centred around: the effects of health action planning on the health of individuals and on mainstream health care provision; matters connected with how to do health facilitation, for example, which models produced the best results for people with learning disabilities; how to measure health outcomes for both individuals and the learning disabled community as a whole; how to influence the local health needs analysis, community profiling, and public health departments; and factors around efficiency and cost effectiveness.

Whether *Valuing People* will be seen as a having a robust policy is open to debate. It certainly was not guaranteed to work in practice from the onset given

that: there was a vagueness about the numbers of learning disabled people in the country; there was a need for guidance documents to accompany its publication but these were not published until a year later; there was an inability to predict the financial implications with any accuracy; and finally, the fact that as a White Paper it was not enforceable. These concerns all cast doubt on its ability to stand the test of time.

Chapter 5

Results and Analysis of Semi Structured Interviews and Reference Group: Health Facilitators and Health Facilitation Activities.

Introduction

The next chapter presents a combination of results and analysis from the first two global networks. It will focus will be upon information gained via the most significant data gathering method used in the research, semi-structured interviews. This will be supported by data gained from the reference group meeting, the findings of which will be woven into the text as appropriate.

Analysis of data gathered via the reference group was subjected to a tape, note and memory based scrutiny. Jennifer Attride-Stirling's (2001) thematic networks approach to the analysis of data generated within the semi-structured interviews revealed five global themes: the health facilitator, health facilitation activities, leadership, management, and quality (Figure 6). Each global theme will be explored in turn, and within each global theme organisational themes will be considered consecutively in conjunction with their constituent basic themes.

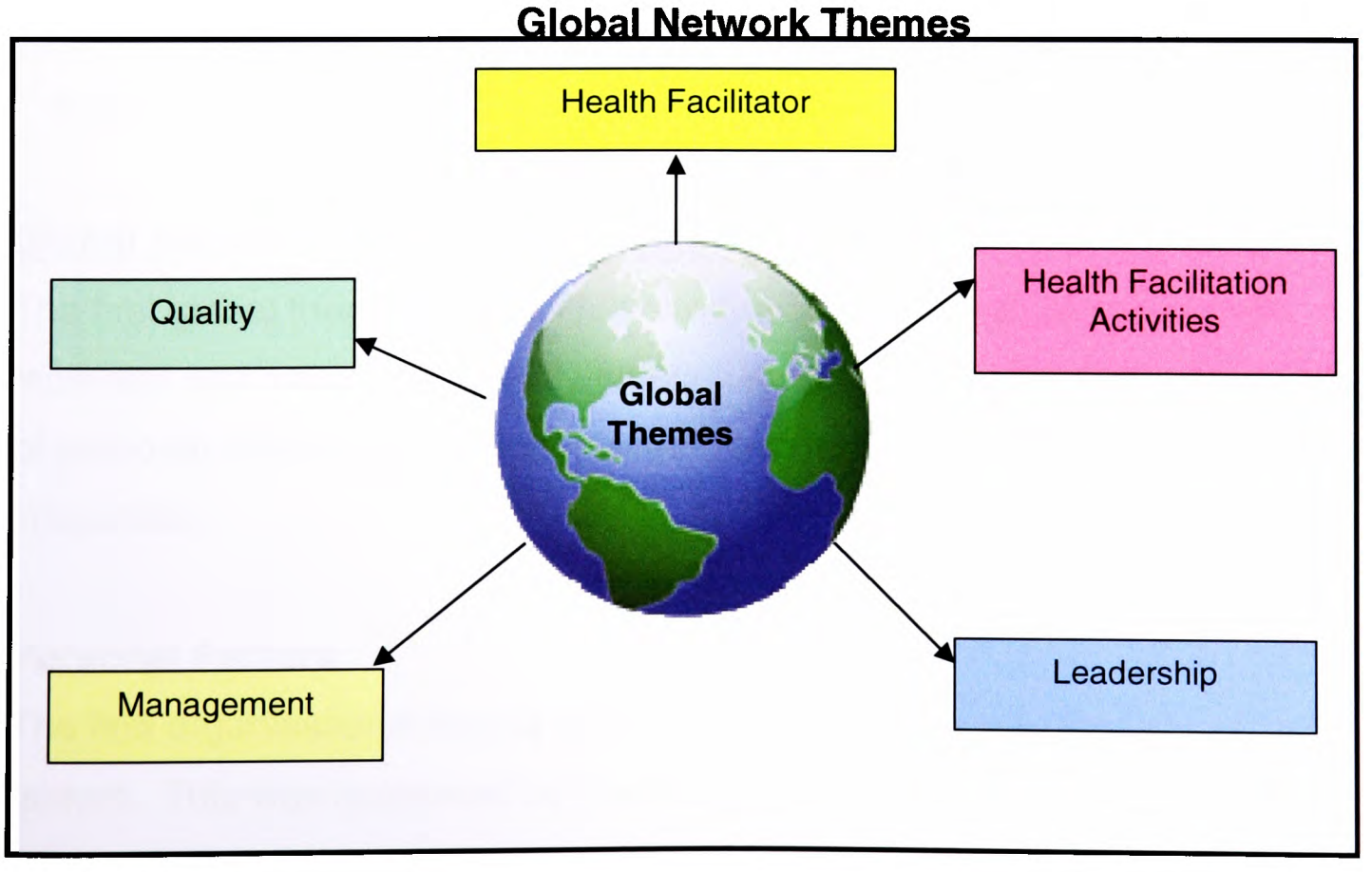

Figure 6

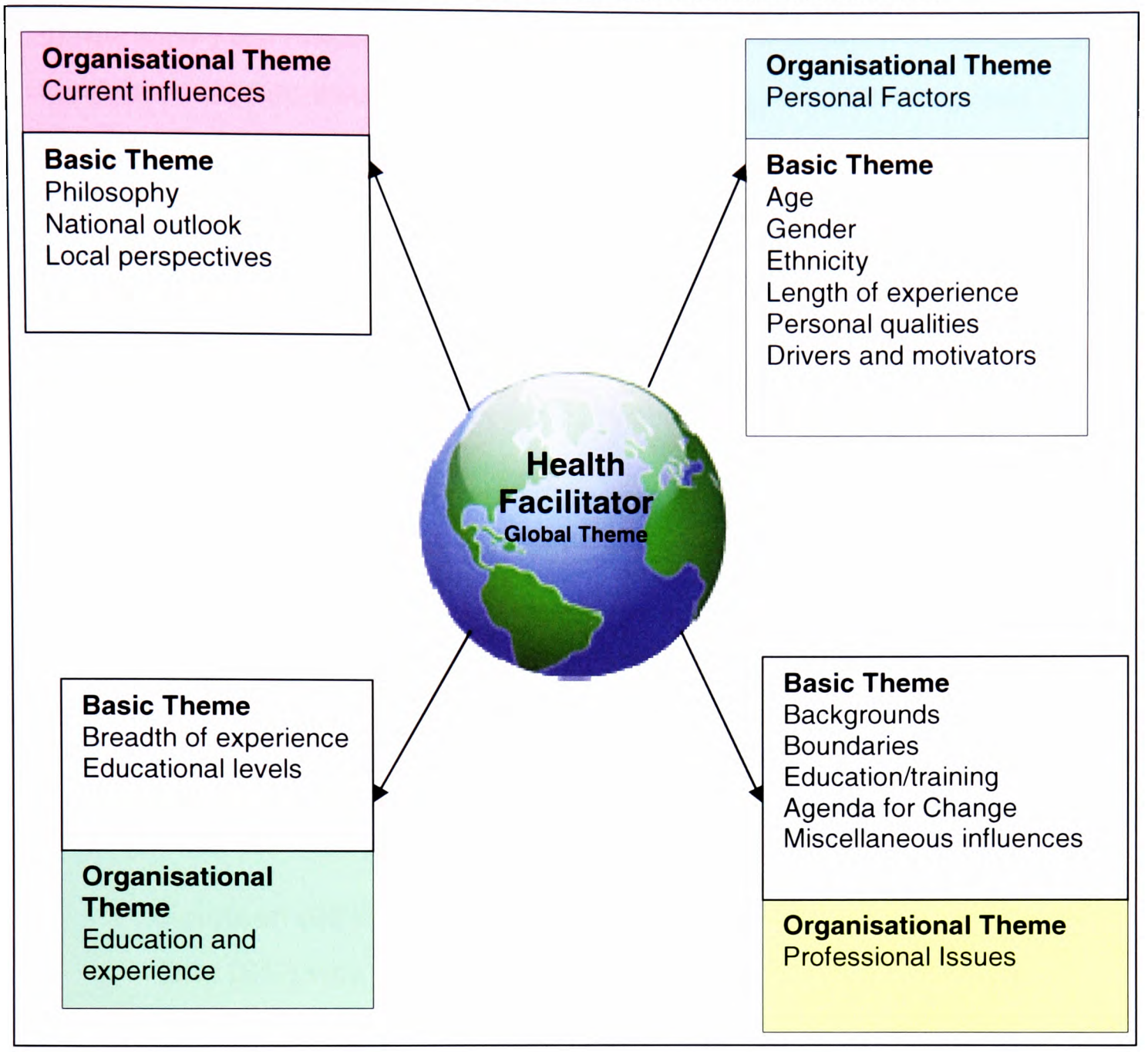

Figure 7

Global Network 1-The Health Facilitator

The first global theme (Figure 7) centred upon the person of each health facilitator and was subsequently categorised into the four organisational themes of personal factors, professional issues, education and experience, and current influences.

Personal Factors

The first organisational theme within this global theme was that of personal factors. This was supported by the basic themes of age, gender, ethnicity, length of experience, personal qualities, and drivers and motivators.

Age:

In relation to the first basic theme of age, over half of the participating health facilitators fell into the 41-60 categories (56.25%). The largest group represented in the sample were aged 41-50 (43.75%); 37.50% fell between ages 31-40; 12.50% fell into the 51-60 age banding; whilst the youngest participants ranged within the 20-30 age group and made up 6.25% of the sample. All members of the focus group were within the 41-50 age banding.

Gender:

The second basic theme of gender revealed that fourteen of the sample interviewed was female and two were male. The focus group consisted of 6 females and 1 male.

Ethnicity:

The ethnic background of interview participants was the focus of the third basic theme. Of the study's participants the ethnic composition was as follows:

- Fourteen (88%) were of white British origin.
- One (6%) was of white European origin.
- One (6%) was of Asian origin.

Length of Experience:

All the interviewees in the study were experienced in working with people with learning disabilities (Table 21). Of the sample only two participants had five or less years experience; two had between six and ten years experience; two had between eleven and fifteen years of experience; one person had sixteen to twenty years experience; three had accrued between twenty one and twenty five years experience; four had amassed between twenty six and thirty years; whilst two contributors had accumulated between thirty one and thirty five years of experience working with people with learning disabilities. All members of the focus group had between twenty to twenty five years experience. Age and length of service or experience has resulted in different approaches to health facilitation amongst facilitators. One health facilitator who had worked in learning disability services for many years thought that, not having seen or

experienced institutional style care, the more recently qualified facilitators did not have a full understanding of current values and concepts. She went on to cite the example of some recently qualified facilitators and their active involvement in physical health checks, electrocardiographs, taking and interpreting blood pressure and urine testing whilst wearing general nurses' uniforms.

> *The younger ones that are coming up now, because they didn't go through what we did, they don't realise what they're doing, and I think there's an element of experience in knowing what to take on, and knowing what to leave to other people.* (T2)

Length of Time in Learning Disability Services

Time band	%	Number
0-5.	13%	2
6 -10.	13%	2
11 - 15.	13%	2
16 - 20.	6%	1
21-25.	18%	3
26 - 30.	24%	4
31-35.	13%	2
Total years experience = 318.5		
Average years experience = 19.90		
Least - 4.50 years		
Highest = 34 years		

Table 21

Personal Qualities:

The basic theme of personal qualities brought to light those merits that participants felt were essential to the facilitator role: a commitment to, and belief in, what they are doing; assertiveness; strength of mind; radicalism; open mindedness; persuasiveness in negotiations; confidence; tenacity; self-motivation; self-direction; innovation; focussed, reflective, and critical thinking. One facilitator in describing her quality of single mindedness said,

> *I never loose my focus because I don't care what a tough time PCT's are having, at the end of the day my job is to make sure that they are going to meet the needs of people with a learning disability.* (T2)

Drivers and Motivators:

The final basic theme in this organisational network concentrated on what motivated and drove participants to take up a health facilitator role. Participants identified having a passion to achieve the best possible opportunities and experiences for the client group and a desire to look towards how primary care could be developed in terms of delivering good quality services in order to make real differences in the lives of people with learning disabilities, and in so doing to push the boundaries of health care for this vulnerable group of people.

> *I want to walk away thinking I did a good job, I really did make an impact, I've made a difference,, and that I've completed what I hoped I wanted to achieve.*(T8)

Some facilitators professed a fascination with health topics in general and in promoting good health amongst people with learning disabilities in particular. A number recalled having had negative experiences in the past when supporting or working on behalf of people with learning disabilities that had made them determined to work towards overcoming the overt and covert barriers existing within the health services.

> *I've been to GP's, sitting there with a service user with learning disabilities when the doctor wouldn't even get up and come round the table to look at this lady's legs which were weeping, you know.* (T1)

Professional Issues

The second organisational theme of professional issues was connected to the basic themes of background, boundaries, education, Agenda for Change, and miscellaneous issues.

Professional Background:

The first basic theme examined was the professional background of those participants interviewed. A variety of professional backgrounds were represented amongst participants: social services, public health, health visiting, general nursing, health promotion, management, and learning disability nursing;

the latter making up 56% of the interview sample. Some facilitators were qualified in more than one professional discipline. The majority of participants considered their backgrounds to have influenced the way in which they practised health facilitation.

> *I think mainly my learning disability background and public health background.* (T8)

> *I was a community nurse before I became a co-ordinator. The experience of that I think is what made me do what I do. I actually do believe the experience of the nurses lends itself to the role.* (T9)

Over half the facilitators interviewed, and all the focus group participants, were from a learning disability nursing background. Some facilitators believed this to have been beneficial but to others it had proved to be a limiting factor.

> *I think my biggest challenge probably has been the fact that as learning disability nurses we always feel that we lack something.* (T4)

Some recognised that their own extensive experience in working with people with learning disabilities could present a barrier to receiving health care that was inclusive, and that they may have been denying their mainstream health care colleagues the opportunity to develop skills in working with people with learning disabilities by being overprotective of them and the client group.

> *I was very protective and thought 'This is my population, I know best', and protected the mainstream. I think we've almost created this gap ourselves, you know, by thinking that as learning disability nurses, ... 'Is this our role?' So we filled in a lot of the gaps ourselves. So I think we did some damage there.* (T15)

Facilitators from learning disability nursing backgrounds believed that they brought dimensions to the health facilitation process that their non learning disability nursing colleagues did not. In their opinion these included their ability to communicate effectively with people with learning disabilities, take a holistic perspective, and to be reflective practitioners.

> *Being a [learning disability] nurse helps, I think. As nurses we're able to be a little more reflective and look at the bigger picture a bit more and put things together. We can pick up from what people are saying.* (T12)

This was not a view generally supported by the non-learning disability nurse trained health facilitators who felt that their background more than adequately equipped them to carry out the role of health facilitator.

> *Where I've come from academically, and being able to do research and that sort of thing, you know, I feel that I'm much better placed perhaps than some.* (T1)

> *My background has influenced how I'm implementing this. Because of the degree that I'm holding, which is health promotion, which is really about empowering and enabling individuals to take control of their health, and that's been what I've been trying to do I think, yeah. Health facilitation and Health action plans are just support aids for the person to take ownership of their own health.* (T11)

Professional Boundaries:

Professional boundaries were an issue that had proved to be problematic and prevalent. *Valuing People* (2001) suggested that whilst learning disability nurses would be well placed to fulfil the health facilitation role it did not exclude other professionals from taking up it up also. The health facilitators participating in this study were predominantly from a learning disability nursing background and felt that their background adequately equipped them to adopt the facilitator role. Indeed there had been occasions when a facilitator from outside a nursing background completely was greeted with surprise, for example,

> *I did meet up with another health facilitator a while ago; I think she was a bit surprised that, you know, that I wasn't from a nursing background.* (T1)

There had been instances when facilitators from a non-nursing background had felt disadvantaged.

> *I mean I do feel sometimes actually that because of some of the obstacles I have come across that yes it would be really useful if I was a nurse.* (T1)

The evidence would suggest that the learning disability nurses, in particular, were experiencing some difficulty in separating a clinical nursing role from that of health facilitation.

> *I'm a nurse by background and I find it hard to say 'No'.* (T8)

This was complicated further by the perceptions and assumptions of others, for example,

> *Their expectation is that you do know about epileptics, you work in learning disability you do know about asthma, you do know about diabetes, you know, because we've got the nurse title.* (T4)

One participant spoke of how the knowledge that she was a nurse had been a hindrance to her work.

> *I think one of the things I haven't done very well in is I think I'm still perceived as a nurse.* (T14)

In some instances health facilitators' job descriptions emphasised a clinical role.

> *In my job description, I have got that I can have a small case load of people with complex health care needs, and do their Health action plans.* (T6)

This scenario was reinforced by some Primary Care Trusts.

> *They want me to be, you know, doing the strategic stuff, but they want to know that I am doing one-to-one and having patient contact as well. They see that as a vital part of my role.* (T4)

Some facilitators had involved themselves in clinical work despite there being no expectation upon them to do so. The rationale for this was given as being a

necessity resulting from perceived gaps in primary care service provision; for example, lack of support from practice nurses due to a shortage of time, skills, commitment and enthusiasm to perform their duties with this client group.

> *The practice nurse won't do very much about these kinds of things.* (T10)

> *Practice nurses don't have the time to look through it in the same way as we do, and pick out other things, which, you know, as learning disability nurses, we are able to do 'cos we have the time and skills to do that but practice nurses, that's not what they do.* (T12)

However, that some health facilitators were involved in the process of planning for the changeover of responsibility from facilitator to primary care practitioners was apparent.

> *I am starting work on health screening clinics, that's for the GPs and practice nurses, and they can identify any health issues.* (T16)

Participants undertaking health facilitation roles from within an integrated team setting, whilst recognising the value of an integrated team approach, had reservations about their ability to carry out health facilitation meaningfully from within this environment and were fearful of their practice losing a health focus.

> *When they were in health, part of our role was very health focussed, it's not now.* (T8)

Agenda for Change:

At the time of the interviews the National Health Service was undertaking *Agenda for Change*, which was a new grading and pay system for all National Health Service staff, with the exception of doctors, dentists, and some senior managers. It covered more than one million people and brought into line pay scales and career progression arrangements across traditionally separate pay groups (Department of Health 2004). Health facilitators reported bandings of between grades five to seven, a fact that had been received with some degree of negativity.

> I *think going through the Agenda for Change is a nightmare.* (T4)

It's very hard, particularly at the moment, it's very, very difficult as you know because [of] the Agenda for Change. A lot of the bandings are coming back really low. (T14)

Education and Experience:

Health Facilitators' Prior Experiences

Health Facilitators' Prior Experiences (Sample size = 16)	Number
Challenging Behaviour	1
Respite	3
Agency/bank nursing	1
Community nursing	8
Institution	8
Day Service	2
Community Home	6
School	3
Voluntary service	2
Primary care team	1
Secondary care	1
Care management	2
Health promotion	1
Health Visiting	1
Advocate	1
Social service management	2
Nursing home	1
Adult Placement Scheme	1
Assessment unit	1

Table 22

Education and experience comprised the final basic theme in this organizational constellation. Table 22 demonstrates the variety of health facilitators' prior experiences gained both in the United Kingdom and abroad. Experiences covered all age groups and all levels of disability. This basic theme portrayed the breadth of health facilitators' experience and specialist knowledge, covering public health, health promotion, management, learning disability nursing and social work. The minimum educational qualification held by health facilitators was that of Higher Education Diploma, whilst all facilitators appointed specifically to strategic facilitation posts were educated to degree level and above. In all, nine facilitators were educated to Bachelor degree level, two to Master's degree level and one was pursuing a Doctorate. The elements of a higher education that had proved to be of particular value to the health facilitator role were an increased range of knowledge, critical thinking and research skills.

A degree equips you to draw on so many skills. I actually realised that, actually, all of the skills that I learnt I still use now in my day-to-day life. (T11)

Having a degree in Health and Social Care Management really opened doors for me in this job. (T1)

The degree definitely gave me a lot of knowledge to be able to, to carry out this role. (T16)

Miscellaneous Influences:

The final organisational theme within this network relates to miscellaneous influences acknowledged by participants as being significant in relation to how they practised health facilitation. Sustaining this organisational theme were the three basic themes of philosophy, the national outlook, and local perspectives.

Philosophy:

On a philosophical level the participants felt that the work of the advocacy movement had been an inspiration to them leading them to speak up for and support the right of people with learning disabilities to express their wishes and to make real choices in relation to getting their health care needs met and in taking a greater part in wider partnerships involved in policy and service development.

I kind of felt that it was about advocacy I mean the whole thing about health facilitation is really for me about advocacy. From the strategic sense down to the one-to-one level, and I think it was advocacy within the NHS. (T11)

... a 'Talk About Health Group', that you know, will meet on a regular basis but will link into the PPI Forum and the PPI groups for the PCT. (T14)

.... input from service users through our advocacy group. (T1)

National Outlook:

This basic theme revealed the participants' eagerness to raise their own awareness of developments taking place and to work in accordance with government guidelines appertaining not only to people with learning disability,

but also the national health agenda and initiatives. To achieve this they worked hard to access established networks such as the National Health Facilitation Network, the Access to Acute Network, and the electronic network administered by the Foundation of Nursing Studies.

> *So I think, you know, that I have been very aware and wanted to make use of a national perspective because of, you know, [the] health facilitator's role.* (T1)

> *Identification of trends and relating it back to government advice and government research [has been important*]. (T16)

The main local influences having a bearing on health facilitation practice were those of the Partnership Boards and Primary Care Trusts.

> *We've got a good learning disability Partnership Boards. We had good leadership on the board, and it was well represented with service users, and carers, so there was a lot of influence from them.* (T15)

> *I think you are very much led by your PCT as well, because I know if I ever talk to my colleagues they actually do the role completely different.* (T4)

Global Network 2 – Health Facilitation Activities

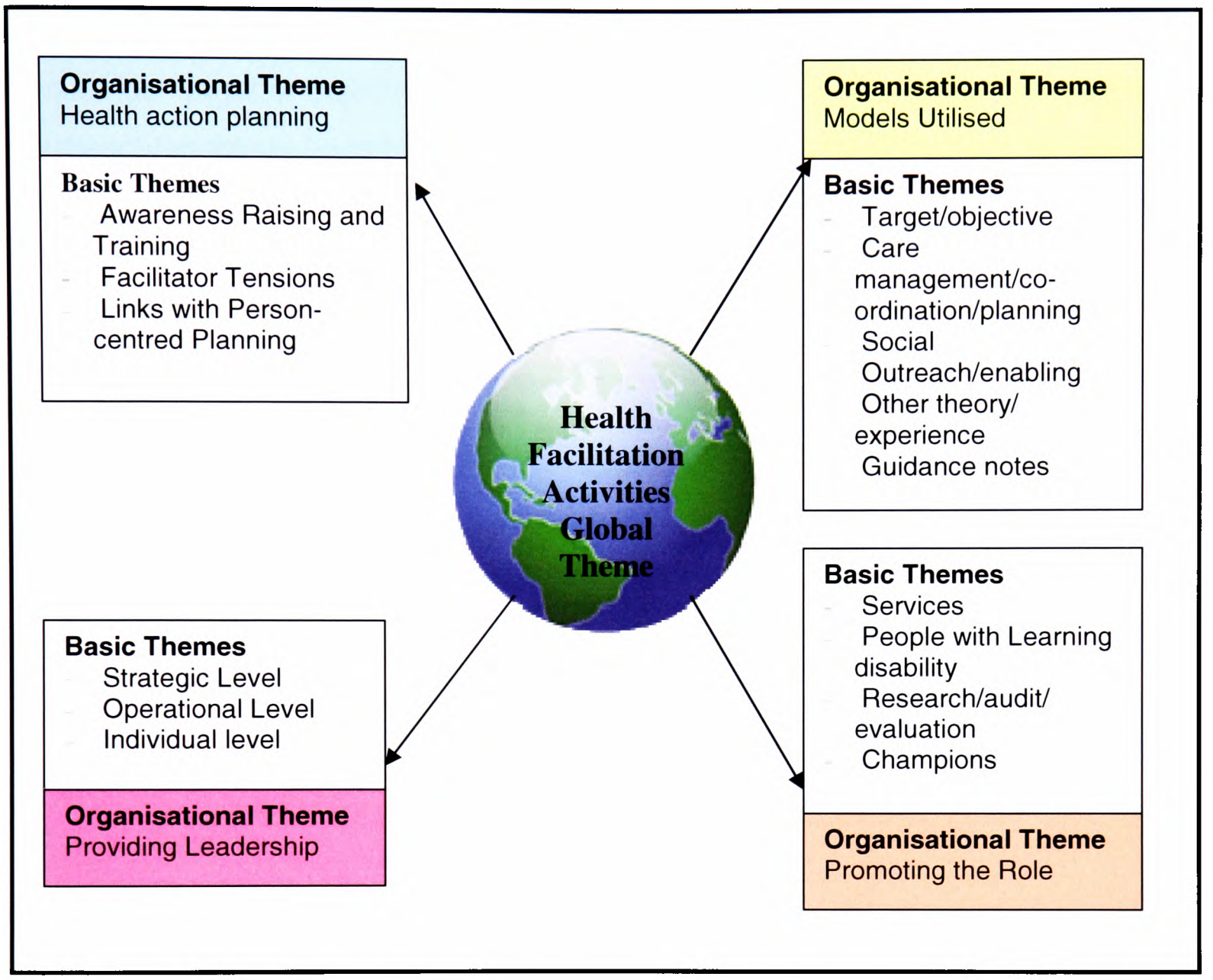

Figure 8

Global Network 2 - Health Facilitation Activities

The second global theme in the network (Figure 8) described the activities of health facilitation as practised by the study's participants. The network comprised four organisational themes: the models utilised in health facilitation; role promotion; providing leadership to others; and health action planning.

Models of Health Facilitation

The models of health facilitation employed in the field were an area with which many of the participants taking part in the Delphi study expressed an interest. Examination of the Post Interview Comments Sheets compiled immediately

after each interview recalled that health facilitators revealed anxiety and concern as to whether they were working towards a particular model or not. Some admitted to researching the topic prior to the interview to be able to fit their practice to a model rather than using a model as a starting point. The basic themes encountered within this organizational theme came under the headings: target or objective; care management/co-ordination/planning; social; outreach/enabling; based on theory or experience external to human service; and, finally, the model presented in the guidance notes accompanying *Valuing People* (2001).

Models of Health Facilitation Used

Basic Themes	Numbers of health facilitators using:
Target / objectives model	10
Care management / co-ordination model	4
Social model	3
Not using any model (Evolving)	2
Care planning model	1
Mixture of outreach and enabling	1
From other disciplines	1
Level 1 of the guidance model	1

Table 23

It was apparent that amongst practitioners taking part in the study the practice of health facilitation was based on a variety of models (Table 23); with some facilitators adhering to a single model, whilst others took a more pragmatic approach to models, taking what they saw as useful from a number of models and combining them to meet specific sets of circumstances. Others, however, did not recognise the existence of health facilitation models, whilst felt no need of a specific model to follow.

Target or Objective Model:

The predominant model used was that which the facilitators referred to as a target model, with targets emanating from a range of sources; for example, the *Valuing People* (2001) White Paper, social services departments, managers, health sub-groups, and health facilitators' self-generated targets. Targets are

freedom to take an imaginative and predictive approach to their work, and to be in control over standards, pacing and timing.

> *... a team the three of us have written all our own targets, our own objectives. (T13)*

The Care Management/Co-ordination Model/ Care Planning Model:
These three approaches have many similarities and are often used interchangeably, and so have been grouped together for ease of analysis. This model was the most widely used of all the models identified by participants working within integrated teams. Care planning is an established concept that has been a central feature of patient care for many years. Its origins related initially to nursing practice and later, following publication of *The National Health Service and Community Care Act* (1990) it was applied to social care systems too as a way of agreeing, arranging and managing the services or help needed to enable a person to live at home, or to move into a residential accommodation. Care planning and care management are similar, but care management is the term used when a person's needs are deemed to be more complex in nature and requiring significant home support from several different services, or when there is a need to move into residential accommodation.

These two approaches acknowledge that people with learning disabilities will have a range of needs, from simple to highly complex, and that this should be reflected in the nature of the system used and the degree of care management/co-ordination required (*National Treatment Agency for Substance Abuse*, 2006). Care management, introduced in the *National Health Service and Community Care Act* (1990), is the process of tailoring and targeting of resources, and planning services to meet the specific needs of individuals. Care management and assessment emphasise adapting services to needs rather than fitting people into existing services, and dealing with the needs of individuals as a whole rather than assessing needs separately for different services. Some health facilitators expressed appreciation of the fact that they were able to tailor their approach towards their individual clientele.

I've taken a bit more of an old fashioned care plan approach where you've got your goal, your rationale, and your action. Cos it's around stuff like, gastroscopy, and physio. And I thought that's probably the easiest way to translate that information so that people will use it. ..... There's only three people that we're going to do that for, all with very high health needs. (T12)

One participant stressed dissatisfaction at the lack of freedom and opportunity to choose which model to use, having been instructed to apply the care management process. Some facilitators, whilst having little choice in selecting a model to apply, could see that the care management model had much to recommend it; particularly in relation to being able to commission services for individuals, and in facilitating the building of the health action planning into the care management/co-ordination process.

We had our care co-ordination model, which is our integrated model; we do a single assessment whether it be social work or nursing, and offer people a care plan. We've actually built into the care co-ordination document, the offer of health action plans. (T15)

Nevertheless, strong feelings were expressed regarding the difficulties encountered in trying to reconcile health facilitation within the care co-ordination process.

It's really difficult to fit it in because you're doing so much care co-ordination. I recently did a sexuality and relationship group, and yet it's so hard doing it because care co-ordination was backlogging all the time, so I felt quite stressed that I was not getting that work done..... We've been told to do the health action plans, but, we haven't really, nothing's been done, nothings been formulated for that. ..... I think there's probably people on my case load that I haven't even addressed their health needs because I don't have the time to do it, I have other priorities. ..... You kind'a get stuck into the care co-ordination and it [health facilitation] goes to the back of your mind. It is frustrating because it would be really interesting to work with that sort of thing. (T5)

The Social Model of Health:

The third basic theme deliberated upon in this organizational network was the social model of health, founded upon the principle that a person's medical

condition is irrelevant, and that illness has physical, sociological and psychological origins resulting from barriers erected and enforced by society. These barriers are considered as being addressable via structural changes within society, for example, by confronting issues such as discrimination and social exclusion. This model would seem to fit comfortably with the philosophy of *Valuing People* (2001) and also with the strategic health facilitator role. It was surprising therefore to find that only three participants named this as the model to which they adhered.

> *I think I'm more social model, I think I do try and encourage that.* (T16)

> *Social model, we're following a social model, you know*, (T1)

> *We're looking at health and social models.* (T4)

Outreach and Enabling Model:

The fourth basic theme in this organisational network looked at the outreach and enabling model, as described in the literature review by Hogg et al, (2007). Only one participant cited this model.

> *I've never heard of any models of health facilitation so I did a bit of a research, and I've decided that I'm doing a mix of outreach and enabling.* (T2)

However, as participants began to elucidate on aspects of their practice, for example, systematically attempting to provide services beyond conventional limits by supplying knowledge, support and resources to primary care services and general practitioners, it was evident that this approach was embedded into the practice. This could result from the fact that the majority of health facilitators interviewed had had many years of experience of working with, and on behalf of, a group of people long disadvantaged as a result of their learning disability.

Other Models:

Given the extent of participants' past work experiences it was not surprising to find that some had drawn upon other theories and skills gained externally to that of either learning disability, or health services. One facilitator utilized the work of Konstantin Stanaslavski (1863 – 1938) from the world of drama and acting.

Stanaslavski is renowned for having developing the system of method acting involving research, looking at issues from the different perspectives and the intentions of those involved (Jones and Bishop, 2004).

Guidance Notes Model:

Following publication of *Valuing People* (2001) the Department of Health published *Action for health, health action plans and health facilitation detailed good practice guidance on implementation for learning disability partnership boards (2002).* This document recommended that the health facilitation role be developed at two levels, with level one focusing on service development work and providing information for planning and commissioning decisions. Level two facilitation concentrated on one-to-one work with individuals.

> *My model as I see it is the level one, the Strategic/Organisational level. So [I am] working quite strategically to make health services, to plan, and commission services that are accessible to people with learning disabilities.* (T6)

Although only one person specifically mentioned working to the guidance model, many more specified that they were working strategically.

> *I think it is a key role and I think it's a strategic role. Well I'm working at a strategic level as a health facilitator so I'm working at level one. I don't work at level 2, one-to-one with a person.* (T2)

> *We're working at strategic level and we're supposed to be influencing and changing the policy to enable people to facilitate health.* (T13)

A number of health facilitators were critical of the model proffered by the guidance notes believing that it did not fit with their work circumstances.

> *When you read the guidance, again I keep coming back and reading it 'cos I'm saying, 'have I missed something'? It's almost like, so simple that it's complicated, but it's not how we work.* (T15)

> *When I first started I had to actually come to grips with what it meant to be a health facilitator. So I spent a lot of time reading through the guidance and so forth, and in a way I've kind of*

tried to implement the guidance, the sort of work of the health facilitator. {But} there's not a position as such within the existing structure. (T11)

Promoting the Role

The second organizing theme pertained to the activities in which health facilitators had been involved in order to promote the role, and is supported by the basic themes of services, people with learning disabilities, research and audit and champions.

Services:

The premise and practice of awareness raising has its roots in the literature of mass communication and social change marketing and relates to communicating, or selling a concept, with the stated intention of changing attitudes, stereotypical thinking, and actions towards it (Sayers, 2006). In the first instance primary care services were seen as the fundamental environment in which to raise health facilitation's profile. Other services also targeted included hospitals, specialist community based services and residential services. Strategies employed included: presentations and education sessions; poster and leaflet campaigns; and articles in newsletters about health needs of people with a learning disability and how health facilitation can contribute to the process of meeting these needs.

I do presentations around, the needs of people with learning disabilities usually sometimes its to GP's, sometimes its practice nurses, practice nurse teams. (T1)

Obviously General practitioners are very time consumed. Some of them don't have meetings within the practice so it was just a matter of if they said 'come for five minutes and talk', and I came along and talked for five minutes. Some practices are quite good and they'll say 'Come and do a presentation. (T4)

Facilitators had actively been involved in establishing communication with individual or small groups of professionals believing that a more personal approach might be effective. They met with individuals and small groups of professionals in an attempt to increase their understanding of the health needs of people with learning disability. These comprised: podiatrists; health visitors;

community nurses; district, link, and hospital nurses; physiotherapists; breast screening staff; dentists; occupational, speech and language therapists; rehabilitation teams; HIV and AIDS teams; and mental health, residential and leisure services. Some facilitators have endeavoured to forge links using newsletter articles; poster, letter and leaflet campaigns.

> *I've put posters up and leaflets to make myself known. ..... Prior to me starting they sent letters out explaining that I would be coming into post and I would be visiting. They sent them to each practice.* (T16)

> *We did some big publicity things around putting stuff in 'Carer's Echoes'. Erm, putting things in local PCT [Primary Care Trust] newsletters, the big PR [Public Relations] around my post, what I was hoping to achieve, inviting anyone who had good experiences, and bad experiences whatever, to contact me.* (T15)

Such activities featured highly in the day to day work of participants and had, on the whole, produced only small changes to practice despite the large amount of input afforded it in terms of time, effort and resources. Awareness raising, as described by participants, consisted mainly of one-off events. No participant gave an indication that their awareness raising activities were part of a wider campaign according to a plan that included regular evaluation. Had this been common practice amongst facilitations they may have discovered more productive ways of using their limited resources.

> *She said "Well, to be quite honest the general practitioners just bin letters.* (T4)

Providing an evidence base to substantiate including people with learning disabilities within mainstream health services was a strategy picked up by a number of participants. They found being able to present research evidence to articulate and demonstrate the long term benefits of inclusion in local and national health initiatives had in some instances been successful.

> *There's been a couple of individuals who have took a really keen interest and said 'Oh, my goodness, the evidence around us, this is terrible, we must do something about that', and have gone out of their own ways to influence, and to take that information back.* (T15)

However, one facilitator expressed concern as to the efficacy of this approach, saying,

> *I'd send out any bit of information that I could glean that gave evidence about people with learning disability, I would send. But I don't think, I think our numbers were so small that it just didn't hit them hard enough really.* (T15)

Being viewed as a useful resource by mainstream services was seen as both personally rewarding and as a positive step forward by some in that they felt productive, purposeful and valued.

> *She says 'Can I have some information', so I e-mailed her the lot.* (T2)

> *I get everything through on the network and I share it out.* (T14)

Valuing People (2001) made it clear that all general practices, with support from the health facilitator, were to have identified all the people with a learning disability registered with their practice by June 2004. This statement appeared to herald an opening for facilitators to be as a seen valuable resource and subsequently welcomed into practices. The setting up of learning disability registers based on Read Codes was seen by facilitators as being pivotal to nurturing good working relationships with general practices. Read Codes are used to identify people with different health problems and conditions and are a means by which family doctors can check that they are giving everyone the service they need. These codes enable general practices to identify their learning disabled population, and to check that they are accessing the same health initiatives and opportunities as the general practice population. It was not surprising, therefore, to find that this was an area in which, with one exception, health facilitators working at strategic and operational levels were seriously absorbed.

> *What we need to do is identify the practice population.* (T16)

> *So my idea was to go round, introduce myself, tell them exactly who I was, the sort of things that I'd be doing and to say that I would help them produce a register. What I've been doing is getting names of people with learning disability from like,*

community nurses, day services, social services, so that when I visit them [surgeries] again I can say 'Well, I've got a list for you, we can Read Code these. (T4)

Many facilitators felt that to begin working with general practice on this target was an attractive proposition. However, it was not without its problems: issues around which code and terminology to use; gaining accessing accurate information; identifying the unknown population; some practices not willing to comply; and the amount of facilitator time involved in gathering data and compiling a register.

It was only then that I visited one GP practice and find out that E3 was actually mental retardation. So I was quite horrified by that. I actually wrote to the Department of Health and said 'Is this right?' and I got a response back saying that 'Yes', that was the Read Code that they wanted to use. A lot of General practitioners refused to use that Read Code, but fortunately now we've got another Read Code, it's just come out which is 918, which just says on it 'Learning Disability Register', which all the General practitioners are quite happy to use that. (T4)

My project to try and get everyone Read Coded and that had a mixed success. Some GP's actually took it on and Read Coded their patients with a learning disability but, you know, it wasn't done on a patient-by-patient basis, it was done by using social services data initially to identify people, and then passing that on to primary care for them to Read Code. ..... It was a bit bitty. Out of 20 practices, only 13 or 14 actually applied Read Codes. (T1)

Delivering training was raised by all participants in both the semi-structured interviews and focus groups as being an area that demanded much of their time. This, they felt, reflected the low levels of awareness around learning disability and health issues and high levels of inexperience within the services.

There's just such ignorance really, or lack of awareness really, there's a great lack of awareness, and that's a lot of the training I've been doing. (T16)

I mean we've got some of the homes are now managed by people who started 6 months ago as a care assistant. So they're, you know, they're not going to be able to do it, you can't expect them to, it's not fair, you know. (T12)

On occasion, participants expressed the opinion that it appeared that training was being delivered to make up for inadequacies within the mainstream health services.

> *We've also included on that training event for [level 2 facilitators] breast and testicular awareness training, because a lot of practices will not do breast and testicular screens within the practice. So I felt it was quite important that perhaps as facilitators we take on that role.* (T4)

Training had been aimed at a wide range of service personnel: medical and non-medical staff in both acute and primary care services; receptionists and administration staff in primary and secondary services; learning disability nurses working in health service residential provision; non-nursing residential services; day services; social inclusion teams; social workers; unpaid carers; and advocacy workers. Whether or not to deliver training to qualified nursing staff working within homes administered by a Primary Care Trust had raised something of a dilemma for one health facilitator, who said,

> *The other learning disability nurses that I thought were working clinically actually weren't because they had been in residential services for twenty years. They had lots of skills, but they didn't have nursing skills. They didn't have a terrific amount of knowledge about health, but people assumed they had. So they had problems getting support, even from people like me because originally we were saying 'we're not going to work with that group of people, they have got learning disability nurses looking after them'. When actually those nurses didn't know what we knew, so we were depriving them.* (T2)

Focus group member (FG2), who was working within an area that was earmarked to move to the private sector in the near future, confirmed the perception that learning disability nurses from residential backgrounds, having worked primarily as social care providers, lacked or had lost the necessary skills to function effectively in relation to health issues. It had been made clear that the private company concerned was not prepared to employ them as nurses and the Primary Care Trust was having difficulty in re-deploying them due to a lack of the skills necessary for a community nursing or health facilitation role.

The training delivered by participants had been designed to meet the expressed and perceived needs of service personnel, and the content of training packages has incorporated such issues as: defining learning disability; defining health facilitation; asking questions of someone with learning disability; ensuring user friendliness; health action planning; breast and testicular awareness; communicating with someone with a learning disability; meeting the needs of people with learning disabilities within acute care settings; learning disability specific health conditions; and issues of consent to treatment.

Although most were intensively involved with training, some facilitators expressed disappointment with the levels of uptake in some areas.

> *We developed a training sort of programme and offered it to the local wards but actually it's been very slow at taking it up.* (T11)

> *We've had discussions and we've done some training at some of the surgeries and it's gone down well as an idea, but it's still early days.* (T9)

In certain areas of the country enhanced payments were available to enable practices to offer or expand the range of services available to particular groups such as people with learning disabilities. One facilitator had successfully tied training into such a scheme.

> *I expect the practice to engage in a one hour learning disability awareness session with myself and for the first time next week I do co-training with co-trainer with learning disability. So I'm going to cover 'what is a learning disability? How do you refer them? What are actually the health needs? What is Valuing People? And then you've got sort of communication and practice tips.* (T11)

Some facilitators had developed alternative ways of delivering training, for example, providing templates for people to follow. Whilst in one instance the facilitator, rather than deliver training herself, had negotiated for an independent national learning disabilities organisation to be commissioned to provide training.

> *We're starting to see learning disability nurses teaching practice nurses clinically how to work with the annual health check. So for example, practices are now starting to call in their people with learning disability, we might actually do the first health check with a facilitator, together with a learning disability nurse who teaches quite hands on clinical skills. The practice nurses, and equally they, learn a lot about the practice nurse role as well. So all of our learning disability nurses are actually trained in using the GP computer system now, they use the EMIS computer systems and input information on to the template. And that's some really good joint working now starting to happen where people know each other and contact each other and I think it's a kind of good use of the nurse again becoming a health facilitator in the widest sense of actually working more in line with GP practices.* (T11)

Providing practical support to service providers was an area in which there was tension between health facilitators. Those working at a purely strategic level did not wish to, and some articulated feeling inadequately equipped by virtue of their backgrounds, provide operational or practical hands on support themselves, preferring instead to work through others, such as nursing teams. Conversely, some saw themselves as having a far greater role to play in the provision of practical support, for example,

> *I can foresee myself probably in the future doing some clinics myself and doing health checks.* (T4)

This was an issue which created personal conflict for some health facilitators in that, whilst they could appreciate the need to build up competencies within general practice, they believed that general practice would not have the capacity to deliver services to people with learning disabilities.

> *The plan is for the practice nurses to take more of that responsibility, so they will be that qualified nurse that will check through the ok health check, do the physical checks, and have a look through to identify any obvious physical health needs. That's to me where it starts to get a bit woolly.* (T12)

> *I've had some experience working with GP practices, and you know, it was very clear to me that there was there was a lot of people perhaps didn't have the skills to work with people with learning disabilities.* (T8)

Health facilitators had involved themselves in designing and developing a range of resources including health information files for use by people with learning disabilities, training packs, information packs, posters, web pages, and leaflets. Others have put their energies into adapting already established resources to meet their local needs.

> *Within the year I was in post I was developing quite a lot of stuff. I have developed a health diary, I was developing a poster and my own leaflets, showing them about accessibility... put together a resource book that's going to be in each practice, and we've just secured a bit of funding to have that printed up quite nicely.* (T4)

> *I see my role as being more creating the tools to be able to use, so adapting some of the stuff that's already been done. There's some very good work done, I'm not about reinventing the wheel you know. And so there's been some very good work done on patient passports and hospital books and those sorts of things.* (T13)

Not all facilitators saw the development and adaptation of resources as being within their remit, preferring to encourage public health services to take this issue on board.

> *I mean in a way the public health service should be providing for across the community.* (T14)

In some areas the Public Health and Health Promotion Departments had been found to be particularly receptive to this idea, in that they were more than willing to obtain recommended resources and to advertise their availability. Funding for resources, however, had proved to be problematic, with only a small number of facilitators having access to budgets themselves. The majority were dependent upon the goodwill of others to finance their projects. One facilitator covering a number of Trusts said that,

> *[In the host Trust it] was quite easy to do 'cos I drew on my resources, but in the other Primary Care Trusts it has taken a lot more to try and get the funding.* (T6)

Where funding was made available for the resource development this did not extend to financing translation services. Given the varied ethnic make up of some areas this was seen as a significant impediment.

Wherever possible, health facilitators involved themselves in groups, meetings and forums that they considered would provide opportunities to infiltrate national initiatives and the mainstream agenda, thus furthering the inclusion schema; for example events, connected to National Service Frameworks, equality and diversity, and disability. Facilitators perceived offering guidance and direction as being integral to the role of health facilitation. Several were disappointed at the low level of involvement they were allowed within Partnership Boards and saw this as a lost opportunity to raise health issues in terms of the wider determinants of health and to influence service developments.

> *I was invited along to Partnership Boards to just explain about who I was and what my intentions were. And I did ask the question if I could sit on the Partnership Boards and they more or less said that, obviously, they couldn't have all the professionals sitting on the board as it would be that massive.* (T4)

However, a considerable number of participants were actively involved with the Partnership Boards and with the health sub-groups in particular.

> *From the Partnership Boards obviously we've got like the sub-groups. So they have like, the Good Health Group, and I sit on the Carers' sub-group, and [colleague's name] will sit on the BME [Black and Minority Ethnic] sub-group.* (T4)

Promoting the Role with People with Learning Disabilities:

The next basic theme concerns working directly with people with learning disabilities to identify their health needs and was a considerable aspect of some facilitators' work.

> *In complex cases I would actually be the person who took on the role of health facilitator for an individual. ... ... [I] actually co-ordinate peoples' admission and discharge [from hospital].* (T13)

If somebody needs support to access mainstream then yes, at the moment we would support somebody to go through mainstream. (T4)

Diverse strategies were used by facilitators to promote their role with people with learning disabilities and their carers; including, working in partnership with other professionals to provide, or support, health education workshops around the health agenda, and also in pointing out to people with learning disabilities the benefits of health facilitation and health action planning.

A number of participants were actively involved in offering the kind of support that they felt was empowering and enabling; for example, the direct delivery of health education and health promotion sessions, some involving co-facilitation with people with learning disabilities. Some, on the other hand, saw their role as being to support generic professionals in the delivery of health education sessions around their own specialities.

We liaise with our health colleagues in dentistry or in optometry, or first aid, you know, St. John's Ambulance or dietetics or GP..... 'Can you provide a forty minute accessible workshop that people with learning disabilities on this date on this topic?' And then we would talk to the staff about, give them information around accessible information, and then we would co-facilitate the day with our partners, People First or Social Services day centres. They would take control of the day, but we would support them. The health professionals that we've brought in, they run their workshop. (T16)

We're recruiting small bands, a small group of co-trainers, people with learning difficulties, to help deliver that training, and I'll supervise them and help with their training and induction and everything. That's another thing that's come about as a result of looking at strategy and inclusion as a way forward, it's quite exciting. (T14)

Other empowering and enabling activities which participants had initiated or were involved in included consultation events and patient and public involvement programmes.

One of the things that we're trying to set up in _____ (locality) is a 'Talk About Health Group', that you know, will meet on a regular basis but will link into the Patient and Public Involvement forum and the Patient and Public Involvement groups for the Primary Care Trust, which will enable true consultation for people with learning difficulties to have a say in what is looked at nationally. (T14)

Research, Evaluation and Audit:

The third basic theme within the organizational theme of promoting the facilitation role was that of research, investigating and establishing fact; evaluation, the systematic collection of data to establish something's worth; and audit, periodically applied quality control mechanism to discover whether or not a documented system has been implemented effectively. Facilitators appeared confused as to the difference between each of these approaches and used the terms interchangeably. However, health facilitator involvement in research showed that they had used research to establish facts, help generic practitioners reach new conclusions about practice, and to promote inclusive service developments. Singled out for specific mention by participants were: locality focused research projects with which they had been involved that had helped them to endorse the worth of the health facilitator role; identifying changes in attitude since the introduction of health facilitation amongst generic health professionals; comparison of approaches to health facilitation practice; providing public health data; establishing how many people knew how to contact their health facilitator; identifying unmet health needs; establishing the training needs within general practice; identifying available resources; understanding the current experiences of people with learning disabilities when going to their doctor, and also when using Learning Disability Services.

I was able to do, I was able to do a lot of research and I compared the strategy framework, which was obviously based on 'Valuing People', 'Valuing Health for All' the 'Health action plan Guidance' and I actually followed the 'Health action planning Guidance' for how to write out a strategy. So I made sure that it fitted in with what national guidelines were saying but also I looked at all the local influences. I looked at Strategic Health Authority publications. I looked at the ... business plans, where they have one, and they didn't all have one, which is

pretty scary. I looked at the local targets for our Care Trust and made sure that I could sort of read all into what was actually happening. And the reason for that was obviously to make it as real as possible to all services. I also had to make sure that housing and leisure and employment were brought into that. So that was my first job and it was helpful as well for me because it gave me a chance to think, and reflect, on what I needed to do. (T2)

We've discovered that quite a few people have since been diagnosed with diabetes, with Alzheimer's, with high blood pressure, with athlete's foot, with impacted earwax we've had a lot of people where that has come to light. We've been able to start to identify the demand for speech and language therapy, physiotherapy and things. (T12)

Health facilitators indicated that audit was a significant feature of their facilitation activity and reported: involvement in the auditing of the number and quality of health action plans undertaken; existence and accuracy of learning disability registers within general practices; single assessment process; offering health screening to people with learning disabilities; and being used as a mechanism to trigger Local Enhanced Scheme payments to general practice.

Also described by participants was their involvement with evaluation activities; for example, they were concerned to establish the effectiveness of the training they had delivered on specific topics, such as, the expert patient programme, and health action planning. Evaluation either undertaken, or in the planning stages, was concerned with, the outcomes resulting from local enhanced schemes, and people with learning disabilities experiences of health services prior to, and following, introduction of health facilitation. Several people disclosed that attempts to evaluate health outcomes for people had proved difficult.

[Evaluation] in terms of health outcomes, I found that really difficult to do. (T15)

The majority of facilitators indicated that they foresaw research, audit and evaluation being a significant part of their role in the future.

Next year's going to be very much audits and evaluations and things like that. (T16)

> *I think it would be good to consolidate those [Read Codes], because in the future I feel that there will be more auditing, and er, you know practices will just be able to push a button and get whatever.* (T1)

Working Through Champions:

The final basic theme of this organizational network was that of working through champions. Where facilitators did not have personal access to senior Primary Care Trust personnel themselves, working through a champion was very much a feature of health facilitation. Champions are usually prominent people who use their influence within their own political sphere to advocate, stimulate, support, and once established, ensure the progress of ideas and projects (Markham and Aiman-Smith, 2001). According to participants they had worked with champions drawn from a range of sources: including, Chief Executives of Primary Care Trusts, General Practitioners with a special interest in learning disability, treatment room Sisters, Assistant General Director of Nursing, Quality Managers, Assistant Director of Public Health, Director of Modernisation, Learning Disability Team Manager, and Primary Care professionals: a long list of people who theoretically were well placed to champion the cause of health facilitation for people with learning disabilities. Although initially disappointed at their own lack of access to the locus of power and control within Primary Care Trust, the availability of a champion was valued for their potential to penetrate systems, and to gain access to meetings and forums denied to health facilitators.

> *And I think that sometimes it is the only way that learning disability gets good visibility... It's because of [the] individuals, its who they are, it's not because the PCT says 'Oh, what are we doing for learning disabilities? Unless you've got a champion I think a lot of it is lip service, which is a shame, because you can make such a difference.* (T13)

Although seen by many as valuable assets, some facilitators had encountered problems when working via a champion. Participants found that often champions changed roles and were replaced by people who did not seem to

have the same level of enthusiasm for learning disability issues, thus giving rise to facilitator frustration.

> *Every time you get a lead, first you've got to talk to them about what a learning disability is, and the background of it, and as soon as you get to that point you then start looking at what the options are. Get to that point and you think your getting somewhere and the lead changes, so you've to go back at the start.* (T6)

Several facilitators made the observation that champions usually emerged by chance as opposed to being appointed. Very often these people had a personal interest in learning disabilities arising from the experience of either having a relative or friend with learning disability, a patient with learning disability with whom they had a lot of contact, or from influences in their own professional background. One focus group member (FG1) reported her biggest champion had been married to a nurse involved in a serious mistake arising from the patient's learning disability not being taken into account prior to surgery.

Leading Others

The third organizational theme in this network was that of providing leadership to others. The basic themes supporting this organizational theme included, providing leadership at strategic, operational or organisational, and individual levels.

Strategic Level Leadership:

Strategic level facilitators felt that they utilized opportunities to provide leadership in the form of guiding and assisting senior managers within their localities via planning and development activities relating to health and learning disability issues. As strategists some spoke of themselves as being farsighted, creative thinking problem solvers.

> *I think it is a key role and I think it's a strategic role. .... We've done that across all the health action plans stuff as well as mental health, older peoples, children's. And that has gone to*

the Strategic Health Authority and to the Primary Care Trusts and that has been accepted as our framework. So we've got the overarching framework and we've got the strategy for the City. (T2)

I could make sure that all the needs of people with learning disability were identified in key documents, for example, the locality profiles and locality plans and therefore local commissioning plans. So at a very early stage I was able to influence that structurally quite well. (T11)

We put together this ... post, ... called Health Partnership Co-ordinator and basically it was based on our view of strategic health facilitation. ... I'm seen very much as one of the strategic team ... (T14)

Operational/Organizational Level Leadership:

At the operational or organizational level leadership was found to have involved directing, coaching and supporting general practice and practitioners, and accepting leadership of the Partnership Boards health sub-groups or other health related task groups. Although in some instances there had been a reluctance to take on this task, it had proved useful in influencing decision making within some Partnership Boards. At this level they have very much lead by example, offering training and 'on-the-job' coaching to service personnel with generic health and residential services. One facilitator considered this approach to have worked well, judging by the response elicited from the organisations requesting for increased training input from the facilitator.

The approach is very much that we'll facilitate for other people to be able to do the direct hands on work. (T12)

We've done some work with the _____ hospital which is the eye hospital. (T11)

We've had some real success with, you know, the GP practices ... (T9)

Individual Level Leadership:

The majority of participants within this research classed themselves as strategic health facilitators but a small number of facilitators were more heavily involved with people with learning disabilities on an individual level. They were involved in co-ordinating peoples' admission and discharge into and out of hospital,

health action planning, and undertaking health checks with people. However, working on this level had, participants believed, presented opportunities to provide leadership. Noted specifically were activities designed to enable and empower not only people with learning disabilities but also professionals and carers. In terms of a leadership role with carers many participants actively sought, mobilised, or provided direct support for unpaid carers across an assortment of settings and circumstances, including the family home and acute hospital wards. Some facilitators viewed this as a key health facilitation role,

> *I think we should be targeting those people and also perhaps people that are living with unpaid carers at home.* (T8)

> *We've got some [unpaid] carers that now act as health facilitator. I have to make sure that the health facilitator gets the right access to support in order to do the job.* (T11)

At the individual level facilitators were able, in their opinion, to be in touch with the reality of life for people with learning disabilities, thus enabling them to identify areas of concern towards which they could channel their leadership skills. Of particular concern to some participants was the vulnerability of elderly unpaid cares regarding their own poor health, which, at times impaired their ability to facilitate access to generic health services for their dependents with learning disabilities.

> *I mean, about the individual level is what I worry about, particularly for older carers.* (T8)

> *If somebody is living with an older carer then who's going to take on that role [health facilitator] and that is a big gap I think that's missing.* (T6)

Health action planning

The final organizational theme within this global network of health facilitation activities centred upon the process of health action planning. The basic themes connected to this involved awareness raising and training, facilitator tensions, and links to person-centred planning.

Awareness Raising and Training:

Differing degrees of involvement with health action planning amongst facilitators was evident. For those participants involved, the main thrust of their activity lay in raising awareness to the role of health action planning in meeting the health needs of people with learning disability via mainstream services. A significant number found it politic to take a gentle, flexible, and incremental approach in order to increase the pool from which one-to-one facilitators could be drawn, and to increase competency levels in facilitating health action plans amongst paid and unpaid carers.

> *So it's about outreach work, going into other services, building capacity, and helping develop in the way they need.* (T2)

> *I am trying to bring in social workers and care managers now into Health action planning and health facilitation very much.* (T8)

Some facilitators were involved in undertaking a 'hands on' approach as required by their job descriptions and had involved themselves in compiling and co-ordinating individual plans. Conversely, some facilitators were very reluctant to become too involved in 'hands on work' on the basis that to do so was contrary to their role as strategic facilitators and not within their resource capacity.

> *We're supposed to be strategic health facilitators but I know that my colleagues are being roped in to try and do some of the health action plans for some of the health homes. We're trying to say 'No'. That's not our role as strategic health facilitators it is about enabling the health facilitators to do their job properly.* (T13)

That there was a strong connection between health action and person-centred plans had been emphasised and energetically pursued by some facilitators who had taken up the option to combine and co-ordinated the planning training available.

> *So I worked very closely with the person-centred planning co-ordinator and we built into the person-centred planning training an element of health action planning.* (T15)

This course of action had, at times, proved to be frustrating in that some resistance had been encountered, requiring a degree of tenacity and diplomacy from the facilitators.

> *So that took a while to get up and running as well because they originally, two of the people didn't think it could be part of the same three days, but we've talked them round now, and it seems that people that are doing it jointly seem to have a flying start with health, rather than some of the people that who haven't had the training done jointly.* (T15)

Conclusion

This chapter has explored the first two global networks of health facilitators and health facilitation activities. Evident in the analysis was the fact that health facilitators were mature, educated, experienced and motivated people with a belief in the principles contained within the *Valuing People* (2001) document. What emerged from this research was that the level of ambiguity within *Valuing People* had given rise to great confusion at all levels of the health service, and amongst health facilitators themselves as to what their role should comprise and at what level it should operate. The data revealed that to practise facilitation well at a strategic level was not dependent on any specific professional qualification or background. Of greater significance was having had experience in working with, and on behalf of, people with learning disabilities.

Valuing People (2001) provided no prescription for the role of health facilitators and this research has demonstrated that no one unified model of health facilitation had been employed across the country as a whole. Although not applying an official unified approach to facilitation, health facilitators did pursue and devote a considerable amount of time and resources towards similar activities such as role promotion, liaison, and training.

Chapter 6

Results and Analysis of Semi Structured Interviews and Reference Group: Leadership, Quality, and Management.

Introduction

The next chapter presents a combination of results and analysis from the three remaining global networks. It will focus will be upon information gained via the most significant data gathering method used in the research, semi-structured interviews. This will be supported by data gained from the reference group meeting, the findings of which will be woven into the text as appropriate.

Global Network 3-Leadership

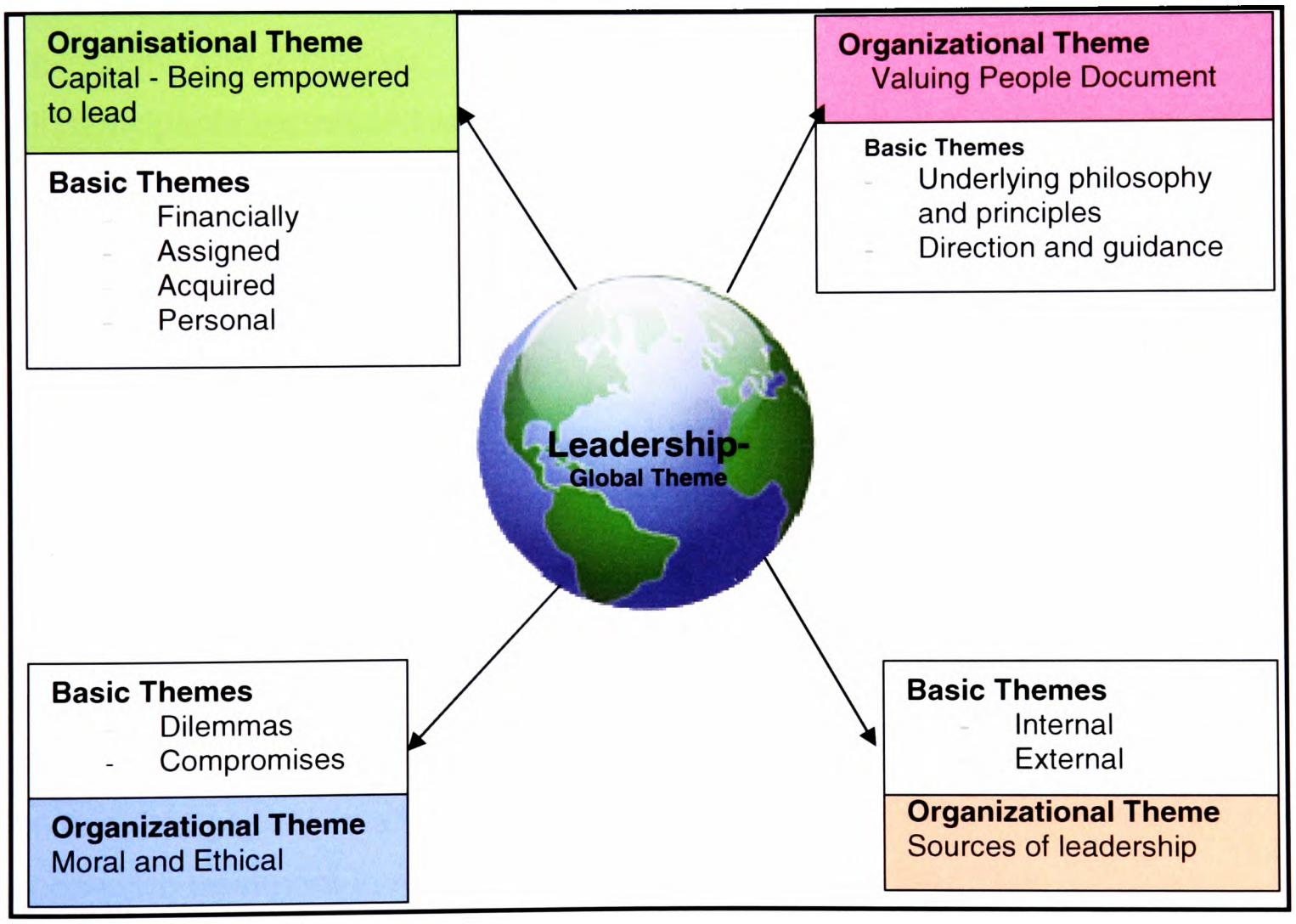

Figure 9

Global Network 3- Leadership

The third global network deliberated upon the global theme of leadership; that is, guiding and showing the way forward to others. This global theme was augmented by the four organizational themes of leadership and the *Valuing People* document, sources of leadership accessed, the moral and ethical dimensions of leadership, and being empowered to lead (Figure 9).

The Valuing People Document

The first organisational theme related to the leadership afforded to health facilitators by the *Valuing People* (2001) document itself. It was addressed within the parameters of the two basic themes of underlying philosophy and principles, and direction and guidance.

Philosophy and Principles:

All participants expressed an accord with the philosophy and principles as set out in *Valuing People* (2001). One participant expressed the commonly held view that,

> *There's some great ideas in Valuing People and I don't think anybody would argue with the main philosophy of it or anything and the underpinning, messages that are in there.* (T9)

Participants welcomed the focus placed on choice within *Valuing People* (2001) which gave people with learning disabilities a say in what happens to them generally in every day life. Facilitators had pinpointed the issue of consent as being pertinent to health related choices and saw part of their role as being to ensure that generic health professionals fully understood the implications of consent to treatment in relation to people with learning disabilities. *Valuing People's* focus on inclusion had spurred some facilitators to pursue the rights of people with learning disabilities to access health screening programmes. In this respect they believed that *Valuing People's* philosophy and values lead to a clarification of aims.

...one of my aims was to put on training to all primary care staff on ... and consent. (T4)

There are quite a lot of issues around duty of care, informed choice, that sort of thing, so, you know that's quite interesting. (T1)

...that's another thing that's come about as a result of looking at strategy and inclusion as a way forward, it's quite exciting. (T14)

...people that I used to work with, who really have no insight into their own health, what their health rights are, how they go about doing that. So I tried to focus on trying to get those people looked at first. (T8)

We made sure that we made a response to the Mencap consultation, to the Disability Rights consultation, you know, to have a voice. (T15)

We've made links with the breast screening people at ... they are happy to come and do support sessions and have done some for carers of people with learning disabilities. (T12)

Direction and Guidance:

The second basic theme in this topic area was that of the direction and guidance provided by the *Valuing People* (2001) document. Participants had looked to it as a source of direction and guidance, but many expressed feelings of disappointment and confusion that, after having waited eagerly for its publication, it failed to offer any useful pointers in terms of moving the health facilitation agenda forward. Whilst facilitators appreciated that the document's imprecision provided flexibility for meeting local needs, they also felt that a valuable opportunity to direct and guide the adoption a uniform national approach to strategic change in health care provision for people with learning disabilities had been lost. Consequently, this diversity of approach had created tensions within the health facilitator fraternity and any changes in health care provision tended to be local and small in scale.

> *It's [Valuing People] never shown, as far as we can see, 'This is how you need to be doing it'. And so it is totally open to interpretation in so many ways that you just kind of feel it would have been kind of helpful if they'd given a bit more guidance*

about the right way to do it or the expected way to do it, or the useful way to do it, so you got a bit more information about things. But there is no 'how' in it that we can see, it's just you know, 'This is a good idea'. And there are some excellent ideas, but it still left us floundering. (T9)

And I know the guidance was written with intent that it would be flexible enough so you could mould it and shape it, but I don't think it gave us anything to kind of 'bash' people over their heads with really. (T15)

...I don't know, whether 'Valuing People' should have been more prescriptive, or whether there should have been more guidance that came out alongside it. (T13)

Sources of Leadership

The second organisational theme within this global network was concerned with sources of leadership available to health facilitators and is upheld by the basic themes of sources internal and external to the employing organisations.

Internal:

In some instances health facilitators felt that they had had access to the leadership and direction they needed from line managers or from within their Primary Care Trust.

My line manager ....I felt like she had some understanding of some of the issues and was very well versed ... (T15)

... supervision comes from our clinical manager ... (T13)

... director of nursing and her deputy, who I have my clinical supervision with, she's clinical governance lead, so she has a lot to do with the practices. (T16)

External:

Some had struggled to find the leadership they felt was required for them to function effectively and had actively sought leadership from a wide variety of individuals: external clinical supervisors, Partnership Boards, service user groups, consultant nurses, peers, colleagues external to their organisations, and the Valuing People Support Team. A valuable source of leadership, viewed by facilitators as indispensable, was that provided by learning disability

networks; including the Foundation of Nursing Studies electronic network, Access to Acute network, and the National Health Facilitation network. Facilitators felt that such networks helped to keep them in touch with up to the minute developments nationally and regionally. As one facilitator said,

> *The network was a Godsend.* (T15)
>
> *... we have peer supervision but including the nurse consultant from the Health Care Trust. So she works quite closely with us so anything, sort of learning disability wise, we've been meeting with her on a regular basis. (T13)*

Ethical and Moral Dimensions

The third organisational theme in this network was concerned with the ethical and moral dimension of leadership as experienced by health facilitators and was supported by the basic themes of dilemmas faced and compromises reached.

Dilemmas Faced:

By examining the activities undertaken by facilitators it was evident that providing a positive role model for others to follow, for example, through advising, teaching, training, and providing hands on support to service providers, was seen as an important aspect of the health facilitation role. Practice, however, threw up some dilemmas that facilitators described as ethical and moral in nature. Accessing good guidance and direction in these circumstances had proved difficult, leaving facilitators feeling isolated and vulnerable.

> *It was very difficult at times. We have different people telling us what to do, so we end up doing what we feel is right.* (T12)

The majority of issues raised within this basic theme were connected to financial issues. Across the country there was a strong desire to encourage people with learning disabilities to take an active part in leading and developing services and to become involved in the training of staff and other service users. However, this gave rise to misgivings in relation to whether or not people with learning disabilities should receive payment for their services.

My other alternative is [to] ask people if they want to be involved and pay them through the voluntary payments scheme, which I will do, but I think it's a poor second to be honest. … I don't mind people doing a few hours and us paying them, but I'm not going to say to somebody work for a day a week and you can have £15 so it doesn't affect your benefits. It's exploitation. …. We talked about getting a group together to link into the Health action plan Steering Committee and at first I thought that was fine, and then after about six or seven months I thought 'I'm really uncomfortable with this' because it's patronising, you know, it's lip service. (T2)

Compromises:

Several facilitators spoke of their personal dilemma as to whether to support additional payments being made to general practitioners under the Local Enhanced Schemes.

I struggled, morally and ethically, I really struggled with that, but I kind of came round to the way of thinking, well if we get someone a health check and that picks up things then it gets the GP practices to recognise people, and then maybe ask for some help and it's a way forward, and that just seems to be the way of the world. (T15)

Why should the general practitioners be paid extra to do something they should already be doing? You know I feel quite passionately about it. That only lasted for about three months. I began to back down on that I started to think 'This is just not going to happen'. So I changed ……. My ideal is still the same but the reality is that unless you pay people extra money, you know. Someone with a learning disability will inevitably take up more time and need more preparation and it's new to primary care. I think unless you are prepared to give them some sort of an incentive they're simply not going to do it. (T8)

Empowered To Lead

Health facilitators being empowered to lead others was the fourth and final organizational theme emanating in this network. This is explored via the basic themes of financial, assigned, acquired, and personal power.

Financial Power:

Participants working in the role of care management felt financially empowered to commission social care services on an individual basis. However, they, along with the large number of other health facilitators, acknowledged that they had had little opportunity to influence financial decisions or health commissioning practices. They attributed this to their lack of direct access and consistent representation to health commissioners. The only exception to this being in those instances in which individual and expensive packages of care, requiring continuing health care funding, were being reviewed.

> *You know, they have other influences around them and start to think well, you know, 'maybe we don't need health action plans'.* (T2)

Valuing People (2001) introduced a new Learning Disability Development Fund of up to fifty million pounds from April 2002, comprising up to thirty million pounds per annum revenue and thirty million pounds capital. The document decreed that available funds would be targeted towards the government's priorities, which unfortunately did not include issues relating directly to health facilitation.

> *As there was no money that went along with 'Valuing People' in the first place, it was quite difficult.* (T13)

> *Well that was the thing wasn't it with the whole health agenda, wasn't it? It was very much on goodwill, because there was no incentive.* (T1)

> *What I also kind of quickly recognised was that I couldn't do everything, there was no extra money.* (T15)

Despite this a small number of facilitators had been able to access financial support from the Learning Disability Development Fund to purchase resources. One member of the focus group (FG1) had received financial assistance to set up a web-site aimed at general practitioners and primary care services.

Focus group member (FG4) reported being able to access monies from this source to develop a women's cancer screening project by carefully wording her proposal so that it incorporated aspects of the government's priorities; for

example, enabling local providers to develop services for people who could be challenging, and for those who may be living with older carers. Amongst the things that health facilitators wished to access funds in order to: extend or firm up existing health facilitator contracts; establish local enhanced schemes; provide additional support to people with learning disabilities during hospital stays; support the implementation of health action plan goals; undertake research activities; develop and support service user involvement in facilitation and training; ensure sustainability of projects; develop accessible information and translation services; purchase additional therapy input, for example, community nursing, physiotherapy and occupational therapy; and high quality resources for people with learning disabilities, carers and service providers.

In addition to facing ambivalence from commissioners, the complexities within which facilitators were working were sometimes constraining in themselves. There were instances in which learning disability services were commissioned by a Trust other than the facilitator's host service: some facilitators were shared amongst a number of Primary Care Trusts; some were placed within specialist Mental Health and Learning Disability Trusts with little in the way of links with Primary Care Trusts; and very often the financial demands of hospital re-provision programmes were seen as taking precedence over the development of inclusive primary and secondary care.

> *I again struggle very much because I'm sat between [locality]Partnership Trust, which is a specialist mental health and learning disability service and Adult Care Services, which are the social side, and the Primary Care Trusts, and I have a bit of a mixed identity. I'm not really sure where I should go.* (T8)

> *The Primary Care Trusts are kind of saying, 'Oh you've all this re-provision going on where we're doing so much now for people in the community, we can't possibly take any more on, and we're barely managing what we've got.* (T15)

Most health facilitators were of the opinion that learning disability and health issues were very low down on the list of Primary Care Trust priorities, and observed that their discussion was more often than not deferred or knocked off the agenda in the face of stiff competition from other services vying for access

to limited resources. Health facilitators conveyed concern that generic services were not taking on board their responsibilities towards the inclusion of people with learning disabilities within their own funding plans. One participant cited her local sexual health services as having terminated a programme established for people with learning disabilities preferring to channel the funds towards non-learning disabled people with HIV and AIDS.

Assigned Power:

The next basic theme in this organisational network was that of assigned power. Health facilitators believed that their ability to effect change was related to the level of power and authority assigned to themselves. Some participants appreciated the authority assigned to themselves as being self determining in terms of their role. Those engaged purely in strategic health facilitation welcomed the freedom from certain activities that the post afforded, for example, not having the responsibilities of managing staff. But in the main there was a sense amongst facilitators of being devoid of authority and power which resulted in some feeling ineffectual in their ability to introduce or influence change. Accordingly the prominence, position and sphere of influence experienced by health facilitators within organisations had become issues of importance to health facilitators.

> *There's huge power stuff that goes on anyway within the PCT and in the acute trust there's huge powers over what levels of people can talk to each other even.* (T13)

In most instances health facilitators articulated despair at constantly being reminded that the *Valuing People* (2001) document was aspirational and not mandatory. This, they felt, rendered them less power and authority than colleagues working within the parameters of the National Service Frameworks or within other specialist roles. Thus they considered that they were not afforded the respect their position deserved, both from generic health professionals and the learning disability teams.

> *I've got a group within [locality] General where I'm writing a collaborative document which was supposed to be a document*

which was owned by the hospital and was jointly written. I was going to facilitate its writing with me and a group of the modern matrons. I'd go to a meeting with them and they'd say 'Oh I've got to go now' and walk out with no respect at all. I don't get treated with any respect at all. It's like 'Oh I can give you five minutes'. I actually said to one of the community nurses who's joining me on that piece of work, you know, and she said 'I can't believe they did that'. It annoys me because I think 'Who do they think they are? (T13)

Titles assigned to those in health facilitation roles were felt by some as carrying considerable influence in terms of their associated power, authority, recognition and respect. Facilitators were found to be working under a variety of different titles: specialist nurse, health liaison nurse, health partnership co-ordinator, strategic health facilitator, health team co-ordinator, health access project manager, service development manager, community nurse, and community nurse/care co-ordinator.

The word 'strategic' in front of health facilitator can be a bonus because some people, particularly I found consultants receptionists in the hospital, think you're from the strategic health authority and for some reason you get treated very differently. (T13)

I don't think I had the authority and power. I think the job's name sometimes makes people believe that I am possibly from the Strategic Health Authority and I'm very glad at that. I won't do anything to say that I'm not until I'm asked. Because then people will then listen. (T8)

Of equal significance to health facilitators as a symbol of authority and assigned power was their physical location. The participants in this study were based within a range of diverse situations, including: Primary Care Trust headquarters, clinics, specialist nurses bases, learning disability teams, social service offices, within integrated team nursing and social work teams, and in care co-ordination teams. Participants felt that there were advantages and disadvantages with whichever setting they were assigned. Those based within Primary Care Trusts felt the benefit of: sharing offices with generic health professionals and other specialist nurses; having their specialism recognised; being able to share information; drawing on the support from, and being able to offer support to, generic health care professionals; gaining access to meetings appertaining to

the commissioning of services. They felt that they were better off being based in the Primary Care Trust as this gave them status and a grounding amongst the services with whom they needed to work closely. They considered that there was less likelihood of their roles being swallowed up and redirected within the Primary Care Trust than there was within a learning disability teams. Nonetheless, some facilitators found that there were some disadvantages to being located within a Primary Care Trust's headquarters and alluded to having experienced relationship difficulties with learning disability nursing teams who viewed them as being 'outsiders'. One facilitator employed by a Primary Care Trust to facilitate access to secondary health services would have preferred to have been employed by, and based within, the acute trust as she had encountered a number of barriers to progress in her practice,

> *They're supposed to all work together but they're very separate. So I think that I would have more, what's the word? More clout I suppose when setting up systems in the Trust if was employed in the Acute Trust.* (T13)

Those placed within teams made up entirely of health facilitators felt they had profited from this arrangement in that they had been able to build closer links with the consultant psychiatrist for learning disability, and believed that being based together outside the existing learning disability nursing teams had been a positive development. *Valuing People (2001)* made apparent the expectation that there would be a move towards integrated professional working (P110). For those participants practising as health facilitators from within an integrated team setting there was a commitment to an integrated team approach in that potentially all members of the multi-disciplinary team could be involved with health facilitation and health action planning. However, in some instances, whilst embracing this, some facilitators felt that it had been a difficult process. Above all some facilitators had issues as to how integration had been implemented. There was a feeling that it had been damaging to personnel who were previously under a health service umbrella, in that they have been left feeling unsupported, threatened, demoralised, taken over, unappreciated for their skills, and fearful of the erosion of the health role and perspective.

There have been a lot of issues around being undervalued, they've been handed over to somebody else who's not a health care organisation, not being listened to, they feel quite burnt out and quite fed up. I think there's been this huge fear and when they were actually taken over, that was people's biggest fear that their role would be chipped away at and they'd just end up just doing care management. (T8)

Some facilitators based within learning disability nursing teams felt this sort of arrangement afforded: a good structure within which to practice; support in relation to the health policy and agendas; and personal comfort and security arising from familiar environments, culture and practices. Alternatively, there were some facilitators, although initially preferring to be based within a learning disability nursing team, who were eventually relieved to have been placed elsewhere. Being part of a nursing team had several drawbacks, including, confusion and conflict as to how the role of health facilitator differed from that of the community nurses and feelings of resentment within the nursing teams at being overlooked for the role themselves. This was particularly evident where nurses had taken up the challenge of *Signpost for Success* (1998 p48) which urged community learning disability nursing services to review and develop towards a *facilitatory and advisory role in helping other health service staff to understand the special needs of people with learning disability'.* Indeed *Valuing People* itself (p63) had suggested that *learning disability nurses will be well placed to fulfil this role.*

"I kind of thought, as most people did, that it would be the learning disability nurses [undertaking the health facilitator role]". (T11)

One participant was a little scathing in suggesting that, far from being well placed to take on the health facilitation role, learning disability nurses were,

Jumping on the band wagon. (T3)

Most facilitators interviewed felt that in addition to there being a lack of appreciation of, and respect for, the health facilitator role, the biggest barrier that they had faced was in developing good working relationships with learning disability nursing teams.

I think some of the targets that I set the Learning Disability Teams are being, not taken very seriously... (T8)

Acquired Power:

The next basic theme under consideration is that of acquired power, encapsulating issues relating to power amassed via the acquisition of knowledge from either education or experience. Participants with higher education degrees considered this to be an asset in that it contributed towards their feeling empowered within their health facilitator role. They believed that the knowledge and skills acquired via a degree level education had equipped them to think broadly and critically and were eminently transferable to the practice situation.

I think you just draw on so many skills. I mean, I was quite a mature student when I was at university. I came to studying and education quite late. But as a mature student I think I embraced it and engulfed myself in everything whether it's teaching and learning, whether it's influencing policies, whether it's implementing policy, whether it's the political context of health and social [care]. And I actually realised that actually all of the skills that I learnt I still use now in my day to day life, and that just fascinated me. It's actually having the opportunity to influence for yourself everything that you learned theoretically, it's amazing; it's something quite fulfilling about it. (T11)

Facilitators from a health background felt that their experience of health service hierarchies, systems and cultures had helped them to relate to generic health services. Whilst one facilitator new to the National Health Services spoke of his excitement and satisfaction at penetrating what for him was new ground.

You do learn the language that's been spoken in the NHS. ..... I was doing a lot of work with other people in the beginning trying to work out what their priority was, so I think by doing that you learnt the way things had been done. I think it's just getting to grips with the culture of the local PCT. (T11)

Personal Power:

The final basic theme in this organisational network looked at the personal power in the form of qualities and characteristics that participants drew upon to lead them to feel personally empowered in the process of facilitating access to generic heath services for people with learning disabilities. Facilitators were of the opinion that strength of mind and character, self reflection, belief in what they were doing, confidence, being a team player, having a wide strategic vision, salesmanship, and persuasion had been crucial qualities to possess in enabling them to be radical in their approach to health facilitation.

> *I think I've gained in confidence, much more confidence. ... I'm a bit of a reflector.* (T2)

> *I have the confidence, I really do believe in what I'm doing ... I feel strongly. So I think I'm a good sales person, if I believe in it I can actually go out and sell it to other people and if they say 'No' I say 'I'll come back'. If you don't offer (?). 'If you're not interested in this project and working with me on it I will come back and pick on you'. I make a joke of it but I mean it. I think that's where my strength comes from.* (T8)

> *And sometimes it helps... to be a little more reflective and look at the bigger picture a bit more and put things together.* (T12)

> *I've always seen myself very much as a team player.* (T9)

> *I look at the wider strategic picture, you know I look at what's happening in general hospitals, or I'm looking at what's happening in the public health arena or whatever.* (T14)

Global Network 4- Quality Issues

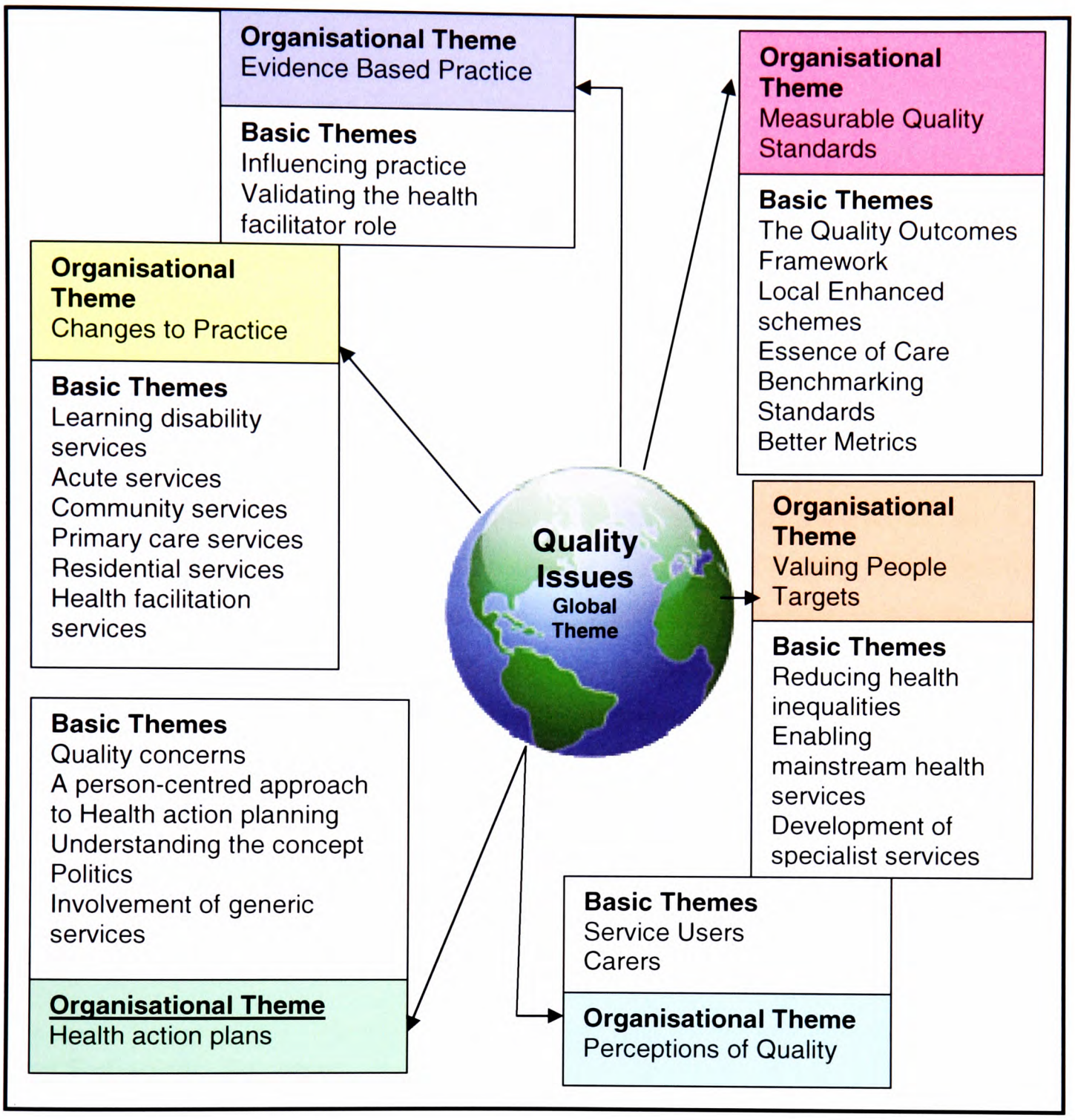

Figure 10

Global Network 4 – Quality Issues

The fourth global network (Figure 10) concerned itself with quality issues and comprised the six organizational themes of measurable quality standards, *Valuing People* targets, perceptions of quality, health action plans, changes to practice, and evidenced based practice.

Quality Standards

The first organizational theme to be addressed within this global theme is that of measurable quality standards. The basic themes upholding this topic area were the Quality Outcomes Framework, Local Enhanced schemes, Essence of Care Benchmarking Standards, and Better Metrics.

The Quality and Outcomes Framework:

This framework was introduced in 2004 as part of the general practitioner's contract. Participation is on a voluntary basis and achievements are rewarded by conferring points that are convertible into financial payment (The NHS Information Centre, 2007). The framework aimed to deliver substantial financial rewards for high-quality care through setting out a range of national standards based on the best available research evidence. The revision to the general medical services contract in 2006/2007 asked that practices produce a register of their patients with learning disabilities for which they would be awarded four points. This research revealed that, in the main, health facilitators welcomed the introduction of a learning disability standard within the Quality Outcomes Framework as they felt it gave general practitioners the impetus to begin addressing learning disability and health issues. However, one participant pointed out that the introduction of learning disability to the Quality Outcomes Framework had prevented the development of a local enhanced scheme in her area. Planners declared their preference as being to wait and see if other learning disability outcomes would be added in subsequent years which would consequently negate the need for a Local Enhanced Service.

Local Enhanced Services:

The second basic theme within the organizational theme of quality standards focused specifically upon Local Enhanced Services. One participant spoke of how he devised such a scheme within his locality based upon on a set of published standards and an outline of its proposed implementation.

> *It's also obviously quality standards within the local enhanced scheme. ..... [It is based on] the National Patients' Safety Agency Report. ..... All of the standards applied to the LES [Local Enhanced Service]. I don't have a lot of money to offer but I do want it to bite at some at some stage so you can actually now say, 'Well, I'm not paying you because'* .... (T11)

This example was the exception rather than the rule in the experience of participants.

> *.... we looked at sort of an enhanced service perhaps to enable health checks to take place, which has what's happened in a lot of other parts in the country but there aren't you know, the funds, and there won't be.* (T1)

> *...we're still going to hang fire on the enhanced service because of reconfiguration issues within the Trust.* (T16)

Essence of Care Benchmarking:

Basic theme three involved the Essence of Care Benchmarking standards. Benchmarking has long been recognised in industry as an effective means of improving business performance, and involves finding and implementing best practice (Royal College of Nursing, 2009). Despite the government's commitment to the Essence of Care benchmarking programme, only two participants mentioned any involvement in the process. One had been asked to become involved in the Primary Care Trust's clinical benchmarking steering group, whilst another described having utilised a health action planning benchmarking standard acquired through the electronic network.

Better Metrics:

The final basic theme of this organizational theme is that of Better Metrics. The Better Metrics project, which began in 2004, aimed to improve the way the performance of health services were measured and monitored. The term 'metrics' referred to measures of performance, such as indicators, targets, or benchmarks, used to assess and monitor the quality of care that patients received in health services. Better Metrics was one of a range of measures used by the Healthcare Commission and was wide ranging in its requirements. It included specific objectives relating to services for people with learning disabilities; including, the need for all general practitioner practices to have a system in place for identifying patients with a learning disability that would enable them to have a health action plan initiated or checked by a primary care professional based on a comprehensive health check, and those not having attended the surgery for three years to be invited for health screening. Of the

Primary Care Trusts it required systems to be in place to: identify one-to-one facilitators for people with learning disabilities and their families to help them navigate health services; review National Health Service funded hospital beds (in and out of district) where the duration of stay exceeded twelve months; enable people with learning disability and mental health needs to swiftly access local mental health services; result in reductions in the number of people described as severely challenging or who have a mental health or forensic in need of out of area treatment provision; and ensure that patients with learning disabilities benefited from the local implementation of the National Service Frameworks, and Cancer Plan (Health Care Commission, 2006).

In general, the direction of the activities undertaken by health facilitators was in accordance with the Better Metrics learning disability objectives. However, only two participants stated specifically that they were involved in working formally and directly with the Better Metrics project in a way that would allow for the measurement of achievement. One of these participants had designed her own working targets and objectives specifically upon the Better Metrics standards, whilst the second had joined her trust's Better Metrics Project Team, which she had found helpful in that the group had the backing of the Trust and she no longer felt isolated.

Valuing People Targets

The *Valuing People* (2001) targets made up the second organizational theme, together with three basic themes founded upon the three sub-objectives, 5.1, 5.2, and 5.3, and the key actions associated *with Valuing People* Objective 5. The Department of Health pledged to develop *Valuing People* performance indicators at a later date in order to compare the health status of people with learning disabilities within the general population. The objective aimed specifically at health within the *Valuing People* document (pp125,126), aimed to enable people with learning disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary (Good Heath Objective Five). This objective was further broken down into three sub-objectives and associated key actions reducing health inequalities:

sub-objective 5.1 was concerned with reducing the health inequalities experienced by people with learning disabilities. The key action associated with this was to explore the feasibility of establishing a confidential inquiry into mortality among people with learning disabilities. None of the health facilitators involved in the study made any direct reference to this key action but did express an awareness of the importance of their role in addressing the health inequalities experienced by people with learning disabilities.

> *I became much more aware of how the inequalities were for people with learning disabilities. How it seemed short sighted not to be more proactive with people, you know, when we are looking at the long-term effects of perhaps not diagnosing diabetes or things like that. The implications financially are, if you look at it purely from that aspect for primary care, are, you know, greater, and we're not necessarily talking about huge numbers of people really.* (T1)

Enabling Mainstream Health services:

Sub-objective 5.2 required mainstream National Health Services, with support from specialist learning disability staff, to meet the general and specialist health needs of people with learning disabilities. The key action associated with this was that health facilitators would be identified by spring 2003. Five of the health facilitators interviewed and four members of the focus group were all working in areas that had not achieved this target. This resulted in members of the community nursing teams taking on this role in addition to their routine duties. This was problematic in that no allowances had been made in relation to their usual workload levels, and clinical work with people with learning disabilities always took precedence over matters of a strategic and operational nature. Members of integrated teams in areas where there was no strategic health facilitator in post found it increasingly difficult to include any health facilitation into their role because they were working to the standards of the social work team, and any health facilitation tended to result in their getting behind with care co-ordination work,

> *I recently did a sexuality and relationship group, and yet it's so hard doing it because care co-ordination was backlogging all*

the time, so I felt quite stressed that I was not getting that work done. (T5)

Action to challenge discrimination against people with learning disabilities from minority ethnic communities was a requirement of *Valuing People* (2001). Participants reported working with various minority ethnic groups including people from India, Pakistan, Bangladesh, China, Eastern Europe, Romany Gypsies and Irish Travellers. Four facilitators made specific reference to the work they had been involved with in relation to this target; for example, negotiating for a seconded health facilitator post to work specifically with this client group, or targeting surgeries with high numbers of people with learning disabilities from specific minority ethnic groups (T10). A number of challenges emerged in attempting to confront discrimination issues; such as, authorities being reluctant to acknowledge the true scale and effects of the discrimination in existence and the lack of funding available for translation services.

I've tried to do some work around ethnic minorities, we have a very big Chinese community in [locality] and we're making some inroads into that as we speak. I blame us as an authority for that because we tend to go, 'We don't have many people', which is true, but it doesn't make it that the people we have don't have needs, you know. But you know, we don't have the same problems as [name of city] but it's been our 'get out' as well. (T15)

All people with a learning disability were expected to be registered with a GP by June 2004. The majority of participants saw supporting general practice to achieve this as being a major component of their role and had either compiled registers for their districts, which could be used to inform general practitioners about the population of learning disabled people within their practices, or supported practice staff to compile their own registers. A number of difficulties had been encountered in relation to setting up registers, including access to comprehensive data and the inconsistent use of Read Codes. Existing databases were not always complete; due in some cases to the fact that entry was optional in some areas, and in other areas registers had not particularly well managed. Facilitators found that the use of Read Codes was inconsistent in that a number of different codes were being used making meaningful data extraction difficult. Some facilitators had encountered problems within the

surgeries in relation to what was considered to be inappropriate terminology. The code in common use, E3, was singled out as being unsuitable and resulted in raised emotions as this code brought the term 'mental retardation' up on computer screens in full view of patients.

> *It was only then that I visited one GP practice and find out that E3 was actually mental retardation. So I was quite horrified by that. I actually wrote to the department of health and said 'Is this right?' And I got a response back saying that 'Yes', that was the Read Code that they wanted to use. A lot of general practitioners refused to use that Read Code, but fortunately now we've got another Read Code, it's just come out which is 918, which just says on it 'Learning Disability Register', which all the general practitioners are quite happy to use that.* (T4)

There was an expectation upon the National Health Service that it would ensure that all hospital services would be accessible to people with learning disabilities. Penetrating the acute sector had proved difficult for health facilitators participating in this study. Some areas had chosen to appoint health facilitators to work specifically within the acute hospital environment. Whilst in others, facilitators had incorporated working in acute settings with the work undertaken in primary care services. The opinion expressed by some facilitators was that to cover both the acute and primary care sectors was too much to expect.

> *Originally they wanted me to take on the acute side as well!* (T8)

The National Service Framework for mental health was anticipated as bringing new benefits to people with learning disabilities and reducing the discrimination people with learning disabilities faced in trying to access mental health services. Working proactively with mental health services was an area in which health facilitators were eager to make progress. In a minority of cases regular liaison with mental health services was a feature of the facilitator's role. However, for the majority, accessing mental health services in general had emerged as an area fraught with difficulty. The reason for this, facilitators felt, was the removal of links that some of them had with their local Mental Health Trusts.

We're in the process of trying to build the links with the mental health service and the learning disability service. Oh. It's been at loggerheads! There's always been that 'It's yours, it's mine', situation. (T7)

Health action plans were a major feature of *Valuing People's* (2001) measures to improve the health status of people with learning disabilities and it was predicted that everyone would have one by June 2005. That this was an action that the majority of health facilitator s had taken very seriously, investing time and commitment into setting up planning systems and developing and delivering health action planning training programmes was evident during interviews and the reference group meeting. Nevertheless, some facilitators expressed negative thoughts and feelings about the fact that this key action was unrealistic and virtually impossible to achieve,

And at the end of two years I am expected to have offered all, all those 3000 people on the case register in _____ the opportunity to have a Health action plan. I don't think we'll meet that target, although I'm not supposed to say that. (T2)

Some participants clearly conveyed that in their opinion this key action was about ensuring that service providers were equipped to undertake health action planning with their own service users rather than facilitators being responsible for undertaking whole scale health action planning. The challenges faced in attempting to carry out this key action have included ambivalence from commissioners as to the efficacy of health action planning as a concept and a high staff turnover within residential services.

It was clear that a new role for specialist learning disability services, which made the most effective use of their expertise, was expected. One facilitator spoke with great pride of how she had been able to involve all members of the multi-disciplinary team in health action planning. In describing the challenges she had had to overcome to achieve this, she spoke for many of the other facilitators who faced the same opposition.

I would say my greatest achievement would be in changing the way that that team in [locality] worked. ... ... And actually being the change agent in the process of getting everybody

within the team, from social services community support workers, up to the consultant psychiatrist, in having to carry out a health action plan and assessing somebody's health needs.. (T13)

Another spoke of the resistance encountered within her locality,

I went in and talked about health action plans with them [the specialist multi-disciplinary team] and it was, it was unbelievable! ... ... They couldn't see what their role was, ... the biggest challenge has been getting my own learning disability service to take on board what health facilitation and what health action plans are all about. (T2)

One facilitator highlighted that in some cases it was the learning disability nurses who were reluctant to get involved in health action planning because they felt that such plans were closely aligned to the care management role, a role they desperately wanted to avoid. Those working within integrated teams felt that the health section of the single assessment process and resulting care plan was sufficient to serve as a health action plan.

Development of Specialist Services:

Sub-objective 5.3 promoted the development of National Health Service specialised learning disability services that were evidence based and delivered services focused upon the whole person. The key action attached to this called for the development of local specialist services for people with severe challenging behaviour to be a priority for the capital element of the learning disability development fund. At no point in this research was this issue raised by participants.

Perceptions of Quality

The third organizational network of this global theme concerned perceptions of quality and was made up of two basic themes; that is, the perceptions of service users and unpaid carer as construed by participants.

Service User Perceptions:

Health facilitators had concerned themselves with activities which they believed to be empowering and enabling to people with learning disabilities and their

carers. As a result they felt that some people with learning disabilities perceived that their health needs had been identified, that they were now more familiar with the terms health facilitation and health action planning. Also some were participating in research looking at their current experiences of health care.

Unpaid Carer Perceptions:

The perceptions of unpaid carers to the quality issues associated with health facilitation were reported positively. Some participants (T8, T10, T11, T12) testified that unpaid carers were better informed and better equipped to facilitate the health care of the person in their care and were satisfied with the increased flexibility experienced within surgeries. However, some health facilitators recognized that not all unpaid carers felt so quite satisfied. Some recounted feeling that their relatives were patronised by generic health service personnel, and that they, as carers, continued to feel intimidated in generic health care settings, in some instances being expected to provide much of the care for their relatives themselves when hospitalised.

Health action plans

The next organizational theme deliberated upon is the quality of health action planning; and comprised the basic themes of quality concerns, a person-centred approach to health action planning, comprehension of the concept, politics, and training issues.

Quality Concerns:

A small number of participants expressed the belief that the health action plans of which they were aware constituted a positive aspect in people's lives in that people with learning disabilities had found them to be: conducted in a relaxed and informal manner; an opportunity for one-to-one input even if it was somewhat limited; and a means of generating referrals to generic health services. Nevertheless, the majority of participants gave voice to the fact that they were disappointed with the level of quality in the health action plans encountered. In some instances they felt that the planning format used was uninspiring, and that poor quality plans were not conducive towards

encouraging generic health professionals to become involved with the health action-planning concept.

It was felt that the quality of health action plans was dependent upon the calibre of provider services and in the investment they made in terms of staff recruitment, training and supporting their staff to take on the role of health action plan facilitators. Health facilitators invested heavily in terms of their time to deliver health action planning training to ground floor staff within services. However, there was a feeling that perhaps they had targeted the wrong level of staff to train, given the transient nature of staff within residential services. Despite the time, effort and resources devoted to health action plan training, the numbers of staff trained and available within establishments became depleted very quickly. On reflection some facilitators expressed the opinion that perhaps taking a 'cascade' approach, training managers first and empowering them to train their own staff in turn could have been more effective. Certain facilitators were striving to gather data relating to health action plans, which they anticipated would help them to begin to address quality issues at some point in the future, for example, building a data base of the health action plans in place. There was a belief among some facilitators that health action planning, unlike person-centred planning, lacked co-ordination, thrust and drive.

> *I think for the key workers within services how person-centred their approach is very, very, dependent on the quality of that service, the numbers of staff they have and the amount of training they have generally and that support they have. And in my experience that all tends to be fairly poor so everybody is scratching around really trying to do the best they can. And you know, the differences with that all depends on individual's personality and if someone's personality is really do a good job and really understand their job well they will give the person-centred approach. But if someone is trying to, you know, be a mother to everybody, or they can do this or stack shelves, then they're not going to be person-centred. There doesn't seem to be that drive from above to make sure everybody does.* (T12)

Health facilitators reported a mixed response from residential care staff asked to take on the role of facilitating health action plans. Some staff thought that the

role needed to be undertaken by medically qualified staff, whereas others were keen to get involved, seeing it as being a vital part of their role.

Person Centred Approach to Health Action Planning:

Some health facilitators reported a level of satisfaction with the person-centredness of the health action plans they had encountered. This was based on the fact that plans involved: facilitators using an individual's preferred mode of communication; providing a choice as to who would take on the health facilitator role; spending time going through and identifying, with the person with a learning disability, their health needs; and promoting ownership of the plan by having the person write out the health action plan and signing their name to acknowledge that the process had happened. Nonetheless, some health facilitators expressed concerns about the lack of a person-centred approach in some of the health action plans with which they had come into contact. Their concerns were based on the opinions that in some instances the involvements of the person with learning disabilities were tokenistic, and there was a tendency for health action planning to be 'done to' people rather than 'with' them.

> *I think there are probably very few people with a learning disability who know they have a health action plan.* (T12)

> *We could tick the box and say that they've been done but I question their efficacy really or their normal, person-centred, person owned approach.* (T14)

Facilitators believed that the choice of who should take on the role of health facilitator was viewed as fundamental to the person-centred health action planning process. However, experience had shown that sometimes both paid and unpaid carers would make the assumption that it was they who should make this decision, often putting themselves forward for the role.

> *A lot of paid carers and unpaid carers will make the decision themselves when they know about Health action plans that they will be the person's health facilitator and that isn't necessarily what that person wants.* (T14)

One health facilitator supported the idea that it was permissible sometimes to be manipulative where health action plans were concerned.

> *I'm not naïve enough to say that you've got to be very, very 'right on' about health action plans. There are times when you are manipulating the whole thing.* (T2)

There was a plea from participants for health action planning to be seen as an integral part of, rather than being separate from, the person-centred planning process and some were currently actively involved in delivering training in conjunction with person-centred planning co-ordinators.

Understanding the Health Action Planning Concept:

This basic theme highlighted the anxieties of health facilitators in relation to the level of understanding about the whole notion of health action planning within families and service provision. In particular, there were issues around the driving force behind health action plans. Concerns were expressed that in practice this proved to be carers, organisations, and external bodies rather than service users or general practice. Also proving to be difficult was the ability to differentiate between care planning, assessment and health action planning.

> *And the training's been done. People have enjoyed it, and they really do want to do it but there's a problem with getting people to understand the difference between enabling somebody to do health action plans and doing it to somebody. And the number of times supported living staff have said to me, 'I can't wait to get back and do a health action plan for so and so', and I have to go 'stop, do you hear what you've just said?' That's not what we've talked about. And we have to like, wind back and start again. ..... But it's also that 'enabling' and I think that in health action planning the message of enabling is lost a lot of the time. I was trying to explain to him that that health part of their care plan is lead by, CSCI [Commission for Social Care Inspection] standards, it's lead by the housing association standards, and it's lead by the Care Trust standards. It's not lead by the person.* (T2)

Politics:

Two facilitators alluded as to how politics, nationally and locally, had impacted on the process of health action planning. One expressed pleasure at contributing to the guidance document accompanying *Valuing People* (2001)

but was nevertheless disappointed in the end product. Editing meant that on publication contributions had been changed.

> ... *because it's so politica*l. (T14).
>
> *The actual, the hands on with the people with a learning disability should be a simple process of training. You know, we'll offer the support and training to the key workers in the services, they complete the ok health checks. And then either us or the practice nurses, depending on where we are, do complete the ok health check with them, and do the physical checks and help with the health action plan. That should be fairly simple for the service user. It's just all the politics behind it and how its evolved and where it's going, it's all a bit bonkers really.* (T12)

The population targeted to receive health action plans proved to be source of worry for some who felt the politics behind health and social service departments working together was sometimes a barrier to good health action planning. There was a feeling that perhaps some organisations had aimed at easy options in that they had given priority for health action planning to those people with learning disabilities who were in receipt of formal services, and who, theoretically, should already have been well served. Some health facilitators voiced anxieties regarding the lack of health action planning being directed towards those people with learning disabilities living at home with elderly carers, or those who were living independently or with limited support. Considerable difficulty had been experienced in accessing support to enable people with milder learning disabilities to acquire health promoting behaviours and activities. This has been particularly problematical where parents and carers were elderly with health problems of their own, or were no longer physically and mentally resilient enough able to manage the behaviour of their relative in generic health care settings.

Another area of disquiet among health facilitators was centred upon those people with learning disabilities living independently or semi-independently with contracted support. Facilitators cited this group as being particularly vulnerable due to their high level of health need, their lack of insight into their own health, and a poor level of knowledge of their rights or how to access services. In their experience participants found that those people living semi-independently were

in receipt of support contracted in by social services from private care agencies and whose time with their clients was limited to the point that they were unable to support health action plan goals.

> *[We have] people living independently within the area who need support and have got really complex health care needs although they're living independently. ..... They still require support, because of their health care needs, and they don't know where to go, who to access, how to access it.* (T7)

Involvement of Generic Health services in Health Action Planning:
The guidance notes *Action for Health, Health Action Plans and Health Facilitation* (2002) published to accompanying *Valuing People* suggested that if a health action plan was not initiated by a generic health professional, then it should be checked by them in order to ensure they do not include actions that are inappropriate for that person's general health status, for example, a sudden vigorous exercise programme for someone who has a heart condition, and that no health improvement opportunities have been missed. This issue was never alluded to by any of the health facilitators involved in the study. What this research did reveal, however, was a good degree of success in involving generic services in the health action planning process in those areas that had introduced local enhanced schemes. Some areas without enhanced schemes were also making inroads towards involving primary care staff in a leading role with health action plans but at a slower rate. However, not all areas had made such progress and facilitators expressed the belief that to expect general practice to accept this responsibility was a step too far.

> *To actually sit and get a health action plan completed for the client to take away and to keep, you know, wherever, it's just impossible, the primary care aren't going to do it".* (T16)

> *The plan is for the practice nurses to take more of that responsibility, so they will be that qualified nurse that will check through the ok health check, do the physical checks, and have a look through to identify any obvious physical health needs. That's to me where it starts to get a bit woolly, because practice nurses don't have the time to look through it in the same way as we do.* (T12)

Change to Practice

Change to practice was the penultimate organizational theme within the global theme of quality issues and was made up of the six basic themes of learning disability services, acute services, community services, primary care services, residential services, and health facilitation services.

Learning Disability Services:

Some health facilitators cited a number of changes that they felt were evident amongst the learning disability teams with whom they worked; for example, some community learning disability nursing teams had taken the responsibility of being a named nurse for individual general practices and these 'link' nurses attended practice meetings. Within some integrated teams everyone in the team, from social services community support workers up to the consultant psychiatrist, had been involved in health action plans and assessing the health needs of people with learning disabilities. Some learning disability teams had incorporated the role of health facilitation within their existing work loads, and had been heavily involved in delivered training to mainstream services.

> *The link nurses who I coordinate, we meet monthly, and their job is to do the more hands on stuff, to talk to the practices, to raise awareness, to work with people who want a health action plan within a practice.* (T2)

Several barriers to bringing about changes to practice within learning disability teams had been encountered by participants, such as the demoralisation experienced learning disability nurses following integration with social services. It had been difficult to gain access to these nurses once managed by social services who gave the impression that for them the health agenda was not a priority. Even in learning disability nursing teams gaining access was difficult, with facilitators being viewed as outsiders, and the pressures the nurses were under due to issues associated with the Agenda for Change programme and the amount and rate of change being experienced by the health service.

> *I don't think the change that I would like to have seen happen in the teams has happened. ... ... The nurses were seconded over to go and work for Social Services Adult Care Services, and I personally feel that the health agenda is just a 'bolt on'*

and nothing else. The managers really aren't recognising the importance. (T8)

Acute Service:

Changes to practice within the acute sector were also evident in some parts of the country, with some areas having appointed health facilitators to work specifically in hospitals. Participants testified to several modifications to practice having occurred, such as: participation in training based on learning disability issues; specific groups and committees established to consider issues of health and learning disability; changes to signage; accessible information being made available; and people with learning disabilities taking part in the audit of hospital facilities to assess accessibility,

I think the acute trust actually is starting to see a difference. I have had feedback saying that a piece of work I've been involved in has helped. (T13)

Conversely, a few facilitators were disappointed with the amount of change evident in the areas they covered.

I'm not sure that if you ask them [acute sector staff] if we've had impact, because you know, it takes a lot of time and that but I think they're further advanced than four or five years ago when they said well 'Who are they? Who are the nurses?' (T10)

There's nothing that I'm aware of where there's been a real change in practice. (T15)

Community Services:

The rate of change within community services has not been as great or as rapid as in other services, but changes were reported; for example, using health action planning to support annual eye screening, and involvement in sexual health services. Facilitators' attempts to effect change to established practices within primary care services had resulted in both positive and negative responses. On the positive side: good working relationships had been established with general practices resulting in a number of pilot projects being embarked upon; changes in attitude towards people with learning disabilities were evident; generic professionals had appraised the accessibility of the

information they provided and made adjustments where necessary; the development of learning disability registers, health screening templates, and recall systems; and community staff taking part in learning disability awareness training.

Primary Care Services:

Also observed was an increased degree of flexibility within partnership working with primary care services leading to improvement in service delivery.

> *I managed to get learning disabilities on the delivery plan and consequently got some money, some Primary Care Investment Plan monies. I don't understand all these different projects, but I know that they gave us money enough for the practices to get a practice nurse four times a year to work together with the learning disability nurse. To have a specialist L.D. [Learning Disability] nurse and the practice nurse together, you get both essential elements there, the expertise from the practice nurse and the expertise of the LD nurse together to give a good health outcome.* (T8)

General practitioners were singled out for particular mention in that some of them were beginning to modify their practice and acknowledge the vulnerability of people with learning disabilities by: providing longer and more flexible consultation times; taking on board local enhanced services, thus providing health checks on an annual basis and contributing to the Health action plan process. Regrettably, not all facilitators had had such a good response. Some reported that whilst they did feel that some individuals within primary care services had taken an interest in what health facilitation was aiming to achieve, changes to practices had been limited. The reasons for this, they felt, were due to: lack of an ongoing commitment to people with learning disabilities; lack of funding to provide additional practice nurse time; the amount of change being experienced within health services; and the expectations and pressures upon general practice. One facilitator spoke of practices refusing to engage with her at all.

Residential Services:

Health facilitators testified in general to the willingness of residential service providers to participate in training, to take on the role of health facilitator for health action planning, and provide the one-to-one support a person with learning disability might need to acquire and maintain good health. However, there had been a number of obstacles to overcome on the way, including the care staffs' reservations about their ability to carry out these duties adequately.

> *There's the, a lot of people say 'We can't do it' you know. ..... At first they were saying 'Oh, we're not medically qualified. We try to explain that they've all always, if they are in a residential home they've always taken the clients to the doctors, they've always advocated for them. We just help them reflect on situations where this has happened.* (T10)

Health Facilitators:

The final basic theme of this organizational topic of changes to practice suggested that some health facilitators felt that they too had experienced changes as to how they viewed their role from the time of appointment to their post to the point of the research interview. They judged themselves to have become more flexible and open minded and to have a greater appreciation of the pressures upon general practitioners and primary care services.

> *I think we don't fully understand the GP [General Practitioner] and what constraints they're under, and what they work under because we're not in that practice, but we're beginning to understand really.* (T10)

Evidence Based Practice

Working to, and providing, an evidence base was the next organizational theme to be addressed and was supported by the basic themes of influencing practice and validating the role of health facilitator.

Influencing Practice:

Facilitators, when attempting to bring about changes to practice within mainstream services, had supported their proposals by evidencing them against government documents.

> *I wrote the report for it and tried to evidence that as much as I could with the White Paper and you know, Signposts other things, and actually got that document together to take that to the PCT, to Social Services, to demonstrate how we would achieve what we needed to achieve.* (T12)

Facilitators acknowledged the need to gain credibility amongst generic health professionals and strove to provide community services and general practice with evidence for the need for changes in practice.

> *The opticians are a bit, (short pause) at the moment they are not quite convinced that that's what they need to do. But we do, we've got all the evidence to show it. So, we're meeting with them, and that's something else we're taking forward.* (T2)

Evidence from localities had been extracted by health facilitators and utilized to support their strategies and proposals for changes to service delivery.

> *I've teamed up with a psychologist and I'm in the process now of developing a questionnaire and we're going to just send that out to one PCT. It's just to get a, I think I already know but I could be saying that I think everybody needs a basic learning disability awareness training for their staff, all receptionists, you know everybody needs it, all the nurses, , but I need some evidence of that to actually, you know, be able to support doing something about it.* (T8)

Health facilitators urged service providers to use evidenced based health assessments, citing the OK Health Check and the Cardiff Assessment Tool as examples. Additionally, facilitators had found it profitable to draw upon local evidence in order to demonstrate the efficacy of any proposed modifications to practice. However, those health facilitators in a care co-ordination role expressed disappointment at the fact that they did not have the time to devote to seeking out evidence based data required to inform adaptations to practice.

I feel care co-ordination has a massive effect on that because you've even less time to think, never mind do evidence based practice. (T5)

Validate the Role:

Participants reported the need to produce evidence to support the future need for their role. At times this had been difficult for them.

I feel like I've had a, I really questioned my post after three years, it was difficult to kind of keep putting bids in for funding because I kept thinking 'What evidence have I got to say I'm making a difference? (T15)

So we've got some, you know, some evidence and background to that now, which is good. (T9)

... we've got evidence then to support our roles. (T12)

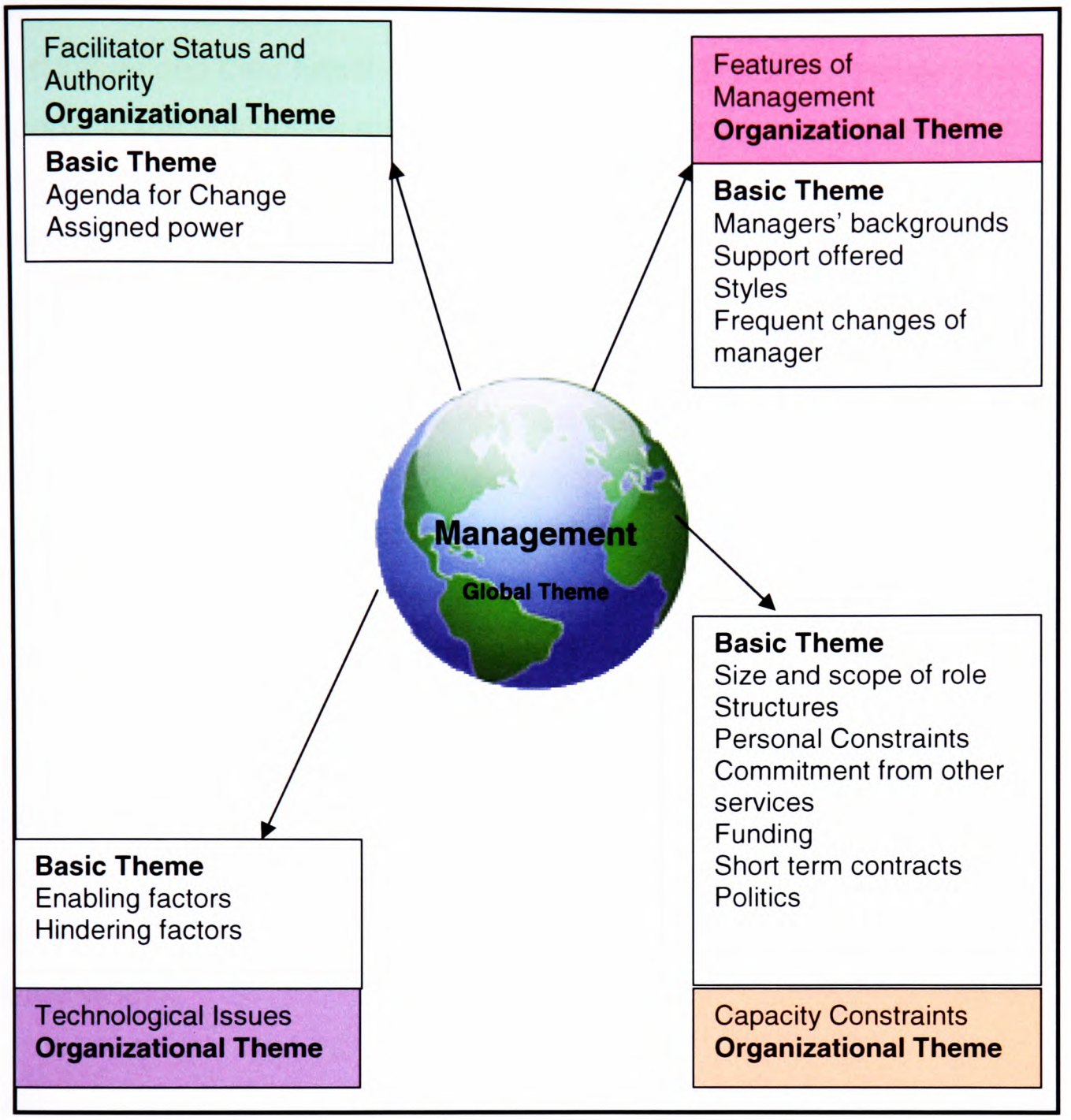

Figure 11

Global Network 5 – Management

The final global network (Figure 11) centred around the influence of management on the experiences of health facilitators. The network was divided into four organizational themes under the headings of features of health facilitator management, capacity constraints, technological issues, and authority.

Features of Management

The first organizational network, features of management, consisted of four basic themes, namely; managers' backgrounds; support offered; management style and position; and frequent change of managers.

Manager's Background:

Health facilitators believed that the background of the person managing them had influenced their health facilitation practice. The data revealed that those people in the position of managing health facilitators were drawn from a variety of professional circumstances. There were participants who expressed their satisfaction at being managed by someone from outside their own professional background, but on the whole most facilitators found that being managed by someone with little, or no, learning disability or health background was problematic. The managers concerned were found to lack a comprehensive understanding of learning disability, health and health facilitation issues. Consequently facilitators felt that the health needs of people with learning disability often featured low on their managers' lists of priorities. Facilitators recounted having to spend time helping their managers to understand the health section of the *Valuing People* (2001) document. Some facilitators found themselves being managed by people with an already huge management remit. In one instance a manager was responsible for managing the district and school nursing services, health visiting services, the chronic disease team, and health facilitation teams. Participants reported feeling like very small cogs in a very large wheel.

Although a manager from a learning disability background was seen as being helpful, the preferred option amongst facilitators was to be managed by someone who was from both a learning disability and health background.

> *I struggle to try and get them to recognise the importance really of the health role. Obviously I'm a health facilitator and it's my whole job and it's extremely important you know, a small component in somebody's life but it's not really a small component, it's a huge part. And I struggle sometimes with this, I know managers have a huge agenda, you know lots of different priorities and I struggle to try and get them to recognise the importance really of the health role.* (T8)

> *Our manager within the team is Social Services. She's very good with support but I don't feel that she truly, truly understands how to do it as a nurse [would]. (T12)*

Support:

Positive support from the manager, whatever their background, was appreciated by facilitators and was described as: providing an advisory and supportive structure within which to work and receive feedback; working in partnership; being coached, affirmed and appreciated; and being given the freedom to envisage possibilities.

Style:

Management style, and position in the organisational hierarchy, irrespective of the professional background of the manager, was a subject that had resulted in a number of health facilitators feeling ill at ease. Some conveyed feelings of: being unsupported, disregarded and confused due to a lack of good management; distressed at having views and opinions dismissed; and frustration with managers' insistence on a target approach towards health facilitation. They also felt that managers were either too busy, too far removed from what happened in practice, or lacking in influence within Primary Care Trusts themselves to influence a change of approach towards the delivery of generic health services to people with learning disabilities.

> *[My manager] he's listened to but he's not always accommodated.* (T14)

Some facilitators found it difficult to adapt to working within new and less structured systems. Whilst employed within learning disability services they felt that they had benefited from robust management structures affording plenty of opportunities for one-to-one meetings with their managers. Others, however, complained of autocratic managers often fuelled by the need to meet targets.

> *So she'll sort of say 'This is what I want done', and we'll say 'Well this is where we are and this is how things are happening and that's going to be difficult to do'. She'll say 'Well I'm not interested in that these are the targets that we need to meet. ... To me it felt it more important to meet the targets and the objectives than it was to actually to put a quality thing into place.* (T12)

Managers' individual idiosyncrasies were cited as being problematic, for example, indecisive managers proved a challenge for some facilitators in that in their indecisiveness they gave mixed messages to facilitators as to how they saw the health facilitation role developing. Further to this some managers were found, having reached a decision, to go on to change their minds frequently. A source of increasing annoyance was a management via e-mail approach favoured by some managers, which facilitators found to be overwhelming and impersonal and resulted in feelings of anger and frustration.

> *The time that it all takes ... it really is a big problem. And if you don't address it you miss out on so much and you pay for it don't you? Because many of my orders from on high are e-mailed, I [have to] check them and the attachments.* (T9)

Frequent Change of Manager:

The frequency of managerial change was a significant feature for many health facilitators, resulting in their feeling unsettled and insecure due to intermittent, limited and inconsistent managerial support. Temporary or acting managers were characteristics of many health facilitators' experience, with some facilitators reported having had up to five changes of managers whilst in post.

> *I've had five managers in three and a half years so we get somebody for maybe six months. The manager that we've got now has upset a lot of people I have to say. He's come in and really railroaded ... because we haven't had that leadership every time somebody's come in they've changed something, or they've brought a new idea but it's never got to fruition because somebody else has come in and changed it again. So there's been a lot of throughput of managers over the last three years, which has been very unsettling and people are fed up with change you can't blame them.* (T7)

Capacity Constraints

The second organizational theme is capacity constraints and is concerned with issues that participants felt should have been addressed by their managers. These issues are categorized under the basic themes of: size and scope of role; the structures within which facilitators operate; personal constraints of facilitators themselves; lack of commitment from other health service providers; funding; short term contracts; and politics.

Size and Scope of Role:

Health facilitators expressed the opinion that the size and scope of the health facilitation role was, in many instances, beyond their capacity to achieve. They based their opinions on the fact that they were dealing with a population the size of which was unknown and could only be estimated. Facilitators perceived there to be unrealistic expectations of what they were able to accomplish. Particularly demanding and difficult to manage was the requirement to facilitate at different levels simultaneously, and to encompass facilitation into the day to day business of an existing role. As a result participants felt overwhelmed and under resourced.

> *I literally did it all from being involved in pulling the framework together to consultation with service users. My role was also interpreted as doing all of the health action plans for every single person we had, which was just impossible. Education and training, anything at all, that had anything to do with health at all, even when it came down to continuing health care funding for the PCT, somebody from the PCT would say 'Oh is that [name's] job to do? If learning disabilities and health was mentioned, you know, in the same sentence, it kind of came to me so it was difficult. I had to keep thinking 'hang on get this focus back'.* (T15)

Structures:

The second basic theme within this organisational theme covered the very different structures within which facilitators functioned. No one structure was common to health facilitators. Participants found this to be quite stressful in that it made drawing upon the support of others difficult. Some facilitators found themselves working with both Primary Care Trusts and Unitary Trusts; several were working with just one Primary Care Trust; whilst others could be found working with permutations of between two and eight. A number found that being contracted to provide a service to a number of trusts, whilst being hosted by just one of the trusts, had proved to be very challenging. Similarly, those facilitators working within specialist learning disability or mental health trusts had found it difficult to identify with health facilitation as practised by facilitators working within generic health environments. One facilitator spoke of her mixed feelings when one of the six trusts with whom she worked decided that they

would prefer to address health facilitation in their own way and to dispense with her services. She gave details of feeling a mixture of rejection whilst at the same time feeling, to some extent, relieved by the decision as it served to reduce her workload. As a result of trying to function within such complex structures, health facilitators described feeling overwhelmed, confused, apprehensive, vulnerable and stressed.

Personal Constraints to Self Management:

This basic theme considered the facilitator's own personal constraints to self-management. Some facilitators acknowledged that aspects of themselves sometimes had an impact on their capacity to carry out their role effectively. Amongst the constraints identified were issues relating to being from a learning disability nursing background. They found this taxing, as some facilitators with this background believed that, despite being well educated, their experience in learning disability nursing was lacking in something. A number of participants disclosed that they were trying to redress this by pursuing generic health care knowledge, skills and qualifications.

That they lacked the assertiveness skills required by the role was a complaint made by several participants, who wished they could be more assertive in their dealings with both primary and secondary health care colleagues. None of the interviewees or focus group members indicated that as health facilitators they had received any specific training related to facilitating changes to practice within generic services. A few facilitators highlighted that it would have been beneficial to have had training in assertiveness, negotiation, and presentation skills, prior to taking up their health facilitation role.

Lack of Commitment from Others:

Health facilitators were of the conviction that support from higher management within their organisations would have helped them to overcome the constraints of this basic theme. Facilitators articulated that they were aware of feeling that they were very much on their own in introducing the concept of health facilitation to generic health services and were faced with: a general lack of interest in the provision of health services for people with learning disabilities;

scepticism that this would mean more work for general practice; a disinclination to accept that existing services could possibly be improved upon; an unwillingness to take ownership of, or responsibility for, the health of people with learning disabilities amongst service providers; and a reluctance within primary care services to take up learning disability orientated training opportunities when offered.

> *...the biggest problem with it was the numbers of people that we would have to access and the lack of commitment we had from other health services to support us. We were very much there on our own. (T12)*

> *... very slow start to training. 'Cos obviously GPs are very time consumed, some of them don't have meetings within the practice so it was just a matter of if they said come on five minutes and talk and I came along and talked for five minutes.* (T4)

Most residential services were happy to accept the fact that they had responsibilities towards the health of their residents. However, management issues arising within residential services did place constraints on health facilitation work and its outcomes. In response to the question as to what had constituted the biggest challenge in their experience as health facilitators, some participants cited the futility of investing a lot of time in training residential staff in issues of health facilitation and health action planning. They were perturbed to find that difficulties with staff retention were a trait within residential services. Such frequent change of personnel often meant that progress towards achieving desirable health outcomes based on the needs and preferences of people with learning disabilities was restricted. Participants in both the interviews and reference group had found themselves revisiting establishments to deliver the same training to new members of staff. Consequently, facilitators had had to reflect on their approach to training and arrive at what they thought would be a more effective method of dissemination.

> *[I've] had varying levels of success because the people you are actually working with in services are generally speaking, untrained, quite poorly paid for the responsibilities they have got, plus they'd got ten thousand other jobs to do as well, so that's been very, very difficult, they move on to other things.* (T12)

We've also organised some training and this training was Train the Trainers, so we will train people to be key trainers in their area to go back and do health facilitation training. (T2)

Funding Constraints:

Having limited access to funding to support health facilitation activities was alluded to as being another constraining factor facing facilitators. Participants felt that their managers had not fully understood, or thought through, the financial implications of health facilitation prior to their appointment. Consequently, they felt their capacity to publicise and endorse health action planning was impeded due to their inability to purchase well produced, good quality supporting resources, to extend their own posts, or to sustain health related activities and projects.

One PCT managed to look at its funding and agree to a payment mechanism, but [although] the others were very keen on it, they just couldn't get the funding. ..... I did feel a little bit at the time that my post was kind of 'tick in the box' and the PCTs [Primary Care Trusts] were like, 'We've got a health facilitator' and it's like 'You're just not getting it', you know. (T15)

Short-term Contracts:

Short-term contracts were a feature of health facilitation for many. Participants thought this was constraining in terms of what could reasonably be achieved within relatively short spaces of time. Participants with short-term contracts spoke of their anxieties about their own futures, and about not being able to achieve what they had hoped to achieve on behalf of people with learning disabilities.

It's been a huge thing for me this short term project because I feel very pressured. I feel very strongly it needs to be permanent, you know if they are really going to take this seriously they need to stop giving people short term contracts and start doing some planning. Again it's, you feel you're not valued. (T8)

The wisdom of offering short-term contracts, given the long term nature of the changes in mainstream heath service provision envisaged by *Valuing People*

(2001), was questioned by facilitators. Temporary posts were viewed as being a management mistake, and an inhibiting factor in relation to their capacity to achieve their perceived goals. Some facilitators, conscious that they were time limited, had adopted a narrow focus to their work. No accommodation had been made within management expectations for setbacks and hindrances. Consequently, facilitators with time-limited contracts experienced a degree of anxiety.

> *I am always very conscious that I've got two years. I've got this roll out plan that I devised at the beginning, I'm already four months behind with that plan.* (T10)

> *We knew my post wasn't going to be everlasting if you like, but it felt like it was cut short, it felt like there was still so much to do.* (T15)

Political Constraints:

Health facilitators were confronted by political constraints on both a national and local level, and this constituted the final basic theme in this organisational network. Politics is the process by which individuals or groups of people attempt to exert influence over the actions of an organisation. At a local level, whilst endeavouring to forge links between the mental health and the learning disability services, health facilitators described encountering situations in which the politics of including people with learning disabilities in generic mental health services had seriously compromised the well being of the patient. A similar state of affairs had also been evident in some public, and primary health care services.

> *Oh it's been at loggerheads! There's always been that 'It's an, it's yours, it's mine', situation.* (T 7)

> *It's just all the politics behind it and how it's evolved and where it's going.* (T12)

Also constraining was the local political melee surrounding who could and who should and who should not be served by the National Service Frameworks. These are long term strategies for improving specific areas of care such as

coronary heart disease, older people, long term conditions, mental health, diabetes, renal disease, and chronic obstructive pulmonary disease. The government intended that they would be accessible and inclusive of all sections of society, including people with learning disabilities. Some facilitators faced resistance to their efforts to gain access to the National Service Implementation Groups. The reason given was that these groups were disease rather than group specific. This was surprising to some, who challenged, firstly the view that being an older person did not necessarily mean that they had a disease, and that in not paying attention to the needs and rights of people with learning disabilities within the frameworks they were in fact guilty of discrimination and in danger of not meeting their vulnerable people's targets. Some health facilitators were in the process of gathering data to establish how accessible and inclusive frameworks had been. They were using general practice learning disability registers to establish how many people with learning disabilities fell into the national service framework categories and how many had been linked to the national plans and frameworks.

> *We can do that because we've got, for the first time, public health data. We can actually go now to the NSF [National Service Framework] for long term conditions, diabetes, etcetera, because we really have all the information at our finger tips now.* (T11)

One member of the focus group (FG4) spoke of her tenacity and persistence when repeatedly denied access to her local National Service Framework group looking at coronary heart disease and diabetes in advocating that the group address the special needs of the population with learning disabilities. Eventually she was invited to give a presentation to the group to support her future involvement. This resulted in a public apology from the leader of the group, who held a high ranking position in public health, based on the fact that he had not been aware that coronary heart disease was the second highest cause of death amongst people with learning disabilities. She was invited to be a full member of this group and also to be a full and active member of the chronic obstructive pulmonary National Service Framework group by its leader who was present at the time and was also unaware of the impact this condition had on people with learning disabilities.

> *... you're not meeting your vulnerable people's targets because we know there are 10 people who are not getting cervical screening, breast screening or whatever it is within those local indicators that they have to meet.* (T2)

Health facilitators expressed strong feelings about helping people with learning disabilities to become more politically aware, and believed that their involvement in government initiatives such as the Expert Patient and Patient and Public Involvement programmes would serve to raise the profile of people with learning disabilities, their health needs and ultimately that of health facilitation.

> *Are you aware of the expert patient's programme? You know we run it for (locality), for people with learning disabilities?* (T14)

Technological Concerns:

The penultimate organizational theme in the management global network covered health facilitators' encounters with information technology systems. These are contained within the basic themes of enabling and hindering factors.

Enabling factors:

Some participants embraced, and found advantageous, the technology available to them. That it was enabling to their practice of health facilitation was evident in that they had been involved in compiling computerised data bases; and some were in the process of, or planning to, use electronic records to extract statistical information and to facilitate access to health checks and screening programmes for people with learning disabilities.

> *Once the OK health checks have been completed relevant information will be transferred, or some of it, or relevant information will be transferred for, which will be inputted onto the computer, how many people have got diabetes, how many people have got epilepsy. And then we can go to those services and say well actually we've got you know, 300 people who have severe epilepsy on medication and yet they are not all supported by neurology, that sort of information.* (T12)

I mean in terms of the health action plans we're keeping a data base of people that you know, who actually have a health action plan ... (T1)

Hindering Factors:

Despite the positive aspects of technology, some facilitators had found it a hindrance and a constraint to their work; citing in particular, not having access to a joint health and social care database and having to contend with inconsistencies in coding, outdated and poorly managed data bases, and incompatible software systems. Also difficult to deal with were: issues relating to the labelling of people as having a learning disability; confidentiality issues regarding the transfer of information related to Data Protection Act; and Caldicott Guardian issues. Also of concern was the fact that not all people with learning disabilities received services. In some instances entry on to learning disability databases was optional, and incomplete data consequently meant that some people remained unknown.

It's confidentiality because they won't, the GP surgery won't be responsible for, you know they don't have paper copy, they can't print you out a copy of it and off you go, because they will be responsible for it under data protection. So that's a bit of a stumbling block really. (T12)

The data bases that I have managed to get hold of are so out of date. ..... Health use something called 'Caremed', the social side are now using something called 'Isis', and the two don't appear to speak to each other. ... ... A joint team, but they don't have joint databases. So the actual task of trying to pick up all the people that are in that team and see it through to take out names that have been duplicated, whatever, is just huge. (T8)

Facilitators' Status and Authority

In the last organizational theme of this global network facilitator status and authority are explored via the basic themes of Agenda for Change and lack of assigned power.

Agenda for Change:

Agenda for Change, launched in 2004, was a single payment system introduced into the National Health Service. For the first time staff were to be paid on the basis of the jobs they were doing and the skills and knowledge they applied to these jobs. It was apparent from interviewing the study's participants that there was disparity between the health facilitators' perspective of their role and that of their managers, which had been reflected in the low level bandings that had been awarded. Facilitators believed that they had suffered in the banding process due to the fact that the role was new and that there was not yet a standard job description against which they could be matched nationally. Given the findings of this research regarding the diversity of interpretation of the health facilitator role across the country as a whole, it was perhaps not surprising to find that the bandings awarded were varied and ranged from band five to band seven. On the whole, the agenda for change experience appeared to have impacted negatively on participants, leaving them feeling demoralised, unsupported, undervalued and unappreciated by their managers.

> *It's just the difficulty of the clarity of the role, it's been difficult in going through Agenda for Change 'cos there's no job matched, we've had to do it ourselves.* (T13)

> *I think going through the agenda for change is a nightmare in itself.* (T4)

> *Staff are feeling very demoralised. ... They've banded me as a six, yeah, I know! In fact I got a lower grade than my community nurse colleagues they were on the scale, and I think it's a really good example of people don't appreciate how strategic the jobs are that I am doing.* (T14)

> *The Agenda for Change stuff and looking at the job descriptions has been quite entertaining for that because obviously we've got our idea about what we do and yet the managers don't necessarily share that idea, so it ends up very general in terms of what your job description is.* (T12)

Assigned Authority:

Participants felt powerless to facilitate change in those services that declined to engage and work with them. Not having been assigned to a position of power and authority meant that they could not offer incentives or impose sanctions as a means of harnessing support to develop relationships with generic health services. A large number of facilitators had experienced feeling discouraged and powerless at being unable to access the support of learning disability nursing teams. The difficulty here appeared to lie in the facilitators' inability to penetrate sufficiently the teams themselves, or their management systems, to foster a climate of support for their role.

> *I do get really frustrated. I think that has to have been one of my biggest frustrations, how teams function they can't provide me with the things, the tools I need, to help me do the jobs you know.* (T8)

Conclusion

The chapter presented a combination of results and analysis from the three remaining global networks of leadership, quality and management. The issue of leadership, or lack of, arose throughout the participant interviews and reference group meeting. Participants were disappointed with the level of guidance and direction available from sources such as *Valuing People* (2001) itself, Primary Care Trusts, and Partnership Boards. Whilst some were able to access leadership from within their employing organisations, others felt the need to seek it externally. The quality of the health facilitation they were able to deliver was thought to be restricted as a result of some managers and organisations adhering to values that were not health orientated. The rate of change, both locally and nationally, had been slow and patchy and was a source of real disappointment to health facilitators. Changes to practice had been supported where possible with evidence based material gathered from research, good practice guidelines or self-generated data, and had been easier for those working under a health service umbrella to achieve than it had for those based within integrated learning disability teams.

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A considerable source of frustration amongst facilitators was their lack of power and authority to influence change. A common thread throughout interviews and the reference group meeting was dissatisfaction with the role's lack of position, respect, and esteem within both employing organisations and generic health care services. Additionally, a lack of time and resources proved to compound these feelings.

Many expressed the belief that *Valuing People* (2001) had not been taken seriously locally, and that health facilitation had not been thought through thoroughly enough at a national level prior to publication. This was based on the belief that not enough attention had been paid to how and where facilitators would fit into the existing services and systems, and as a result their employers were unprepared and did not really know how best to place and utilize them.

Chapter 7

Discussion

Introduction

This chapter offers reflection on the problems encountered by health facilitators in the process of facilitating access to mainstream health services for people with learning disabilities in line with the expectations of the *Valuing People* (2001) policy. It will present the principles, relationships and generalisations emerging from the results and the point by point analysis of the findings. It will look at how this research extends that previously undertaken; make recommendations for the future of health facilitation practice; and outline plans for the dissemination of the knowledge gained.

Given the evidence contained within Mencap's *Death by Indifference* (2007) report of institutional discrimination within the National Health Service towards people with learning disabilities, and the conclusions drawn within *The Michaels' Report* (2008) that they face risks in the care system due to reasonable adjustments not being made to services resulting in health problems being untreated and in some instances the occurrence of avoidable deaths, it would appear that health facilitation has made little headway in improving access to good quality health care for people with learning disability. This research has identified several issues that practising health facilitators considered to have been detrimental to the progression of health facilitation for people with learning disabilities. These concerns comprise: the prevalence of ambiguity within the *Valuing People* (2001) document; a lack of adequate leadership at all levels; and a general lack of power and influence (capital) surrounding the health facilitator role. This discussion chapter will examine these prevailing issues in relation to the emergent experiences of health facilitators in this research, drawing upon material from the literature review and relevant theory where appropriate.

Ambiguity

The first issue to be considered is the degree of ambiguity health facilitators faced in the execution of their duties. Ambiguity is an intriguing concept because of the essential relationship between language, meaning, and usage. Ambiguity around the role of health facilitators was widespread within *Valuing People* (2001). Firstly, the policy stated that health facilitators were to be identified and appointed from each local learning disability team but the document omitted to clarify which organisation or body was to undertake this. Hence, as this thesis shows, facilitators had been recruited from several sources and, in some areas, no action whatsoever had been taken to identify or appoint facilitators, leaving it to practitioners to take on the role in addition to their day to day responsibilities. In terms of the health facilitator role the implication within *Valuing People* was that facilitators would intervene at general practitioner and primary care level to facilitate, advocate and ensure access to health care services. Unfortunately, it also indicated that the role be orientated towards intervention at an individual level in its claim that health facilitators were also to be responsible for the completion of health action plans. It is possible that the policy envisaged health facilitation being aimed at two different levels, and involving different kinds of health facilitators. This was not clear and led to much confusion in the field of health facilitation practice.

Valuing People (2001) called for *all people with a learning disability to be registered with a GP* and for *All people with a learning disability to have a health action plan'* (p61). Such statements appear to disregard individual choice, despite its high profile as one of the key underpinning principles of the policy. The use of the word 'all' was unfortunate in that it set out an expectation that was impossible to meet, at least in relation to health action plans. The target was also difficult to measure as it could not be possible to know if all people with learning disabilities had benefited from these moves given that the exact number of people with learning disability was unknown. Also anticipated within *Valuing People* was a review of the role of Learning Disability Teams to allow them to enable access to mainstream services as much as possible, but no recognition was given as to how they were to overcome the existing boundary

disputes between learning disability services and some mainstream services, and the subsequent financial implications.

Facilitators were quick to acknowledge and appreciate that some level of vagueness could be positive in that it provided the flexibility that local authorities and Primary Care Trusts might require in meeting local needs. Indeed, some facilitators welcomed the ambiguity of the health facilitation definition and its associated tasks, together with inconsistent direction from mangers, as it allowed them the freedom to shape their own role and allow for some degree of risk taking in how they interpreted the *Valuing People* (2001) vision. It could be argued that maintaining a degree of ambiguity within organisations can lead to greater efficiency in that it ensures options and adaptability to change are available. In such circumstances the chaos created by ambiguity is viewed as being necessary to sustain the kind of flexible reactions necessary for environmental change (Menz, 1999). However, whilst there may have been benefits for organisations, the majority of facilitators interviewed for this research regretted the amount of ambiguity present within *Valuing People*. They saw it as a valuable opportunity lost to adopt a uniform, national approach to strategic change in health care provision for people with learning disabilities. Difficulties with ambiguous policies begin immediately the policy starts to be implemented because collaborators and implementers, unable to find common definitions and opinion, are brought to a point of confusion and disagreement which could lead to either immobilisation or withdrawal of support for the changes envisioned within the policy leaving those involved feeling disillusioned and betrayed (Mckevitt and Lawton 1994).

Several health facilitators disclosed that they had experienced a measure of strain and anxiety which they associated with the *Valuing People's* (2001) ambiguity in general and in its presentation of health facilitation in particular. It has been well documented that ambiguity can give rise to tensions and those working with long term ambiguity have found it to be more taxing and labour-intensive than simply working through prescriptive standardized procedures and actions (Meyerson and Scully, 1995, Alvesson M., 2001, Hertting et al, 2004). The presence of ambiguity can impact negatively on a person's behaviour as it can have a stultifying affect due to the need to avoid doing anything that might

get them into troubling and stressful situations, which ultimately has the propensity to result in less efficiency and effective performance of their role (Kahn et al, 1964). Without doubt, in the presence of ambiguity some health facilitators tended to behave cautiously, relying on old, familiar, and comfortable, pre-facilitator roles and working practices, whilst at the same time worrying about the possibility of not achieving the *Valuing People* outcomes. Not surprisingly this resulted in a degree of pessimism about their role (Orton and Ratcliffe, 2005, Menz, 1999, Kelsey and Spanjers, 2004).

This research revealed a marked amount of role ambiguity and role conflict amongst health facilitators due to unclear expectations, not only within *Valuing People* (2001), but also from their employing organisations. Role ambiguity is thought to be associated with negatively valued states such as tension and low job satisfaction (Jackson and Schuler, 1985). Interestingly, although experiencing a great deal of pressure and dissatisfaction as a result of ambiguity in the work environment, none of the health facilitators who were interviewed mentioned wanting to leave their employment as a result. Indeed, the level of passion amongst health facilitators to make a difference was high and a consistently strong feature amongst the study sample as a whole. That role conflict has been an issue for health facilitators was evident. Facing confusion within individual working environments, the configuration of health facilitation and its tasks was a strongly contested issue amongst health facilitators themselves, giving rise to powerful emotions. Given such inconsistencies, it was not surprising to hear facilitators describe themselves as feeling stressed, dissatisfied, and concerned as to whether they were performing less effectively than other facilitators elsewhere in the country.

An ambiguous approach to policymaking is not limited to *Valuing People* (2001). New Labour policies have often been characterised in terms of ambiguity, tension and contradiction (Lister, 2001, Clarke, 2004). Ambiguity may well be attractive to policymakers as it allows them to find some middle ground between political ideology and the political power game whereas concrete proposals carry the risk of implying promises that may be too specific to carry through to fruition. Vague statutes and mandates, therefore, are born out of the need for

compromise among competing interests and can create major problems in governance and policy making (Shepsle, 1972, Alesina and Cukierman, 1990, Pandey and Rainey, 2006). The legislative processes in this country are complex, and manoeuvring through them can be complicated. It has been suggested that a degree of ambiguity surrounding a policy can increase its chances of being accepted (McKevitt and Lawton, 1994). But this comes at a cost, and the cost is to be found in attempts to implement and administer indistinct policy. Ambiguity is thought to be a sign that policymakers lack conviction and passion for the policy's content. Policy makers with weak and fragile opinions, or whose objectives are somewhat unstable, have a tendency to be more ambiguous and less credible (Cukierman and Meltzer, 1986, Huckfeldt et al, 1998). The lack of space and clarity allotted to health facilitation within *Valuing People* could be an indication of the degree of certainty and belief in the need to address the health issues of people with learning disabilities, preferring to focus upon other aspects of life, such as employment and housing which fitted well into the New Labour social inclusion drive. Given the intensity of feeling against the medical model of care for people with learning disabilities prominent prior to, and for several years after the publication of *Better Services for the Mentally Handicapped* (1971), perhaps this is not so surprising.

Ambiguity has positive aspects in that it can lead to an open arena for action and innovation. A degree of ambiguity in policies provides policymakers with a degree of manoeuvrability, thus enabling them to disassociate themselves from aspects of policy should the need arise. An example of this is evident in the 2009 Ombudsman's Report, *Six lives: the provision of public services to people with learning disabilities published in March 2009.* The ombudsman investigated complaints brought by the charity Mencap on behalf of the families of six people with learning disabilities who died whilst in National Health Service or local authority care between 2003 and 2005, some two and four years following the publication of *Valuing People* (2001). The report pointed the finger of blame mainly at statutory services, saying that there was ample policy and guidance available but that implementation was inconsistent, and in some cases non-existent. However, policy makers were not able to manoeuvre

themselves totally from criticism in this instance as the Ombudsmen called for greater clarification of exactly what actions should be taken and by whom and recommended that these issues should be followed up and monitored by the Department of Health. This was an indication that greater clarity within *Valuing People* would have been useful.

All participants in this research expressed feeling some level of satisfaction and achievement in relation to the work they had undertaken either on behalf of individuals with learning disabilities or through individual primary care practices. However, with only one exception, they all articulated feeling overwhelmingly powerless to implement changes on a larger scale. Eight years after *Valuing People* (2001) was introduced, the refreshed document *Valuing People Now: The Delivery* Plan '*Making it happen for everyone'* (2009) was published. It, too, included better health for people with learning disabilities amongst its key objectives but it still failed to provide any definition of health facilitation or the health facilitation role; in fact the only reference to health facilitation was to make the point that guidance would be issued at a later date. Working with ambiguity of such intensity, it is no surprise to learn that participants reported the presence of negative emotions in relation to their work. Prolonged association to role ambiguity has been found to be linked to conflict, low job related esteem, negative outcomes, and feelings of being out of control and incompetent due to the inability to accurately assess and understand the role expectation (Jackson and Schuler, 1985).

Despite the government's push to ensure good practice based on sound evidence, it failed to explore and learn from previous examples of health facilitation within mainstream health services. Such evidence was available and is explored within the literature review of this thesis. Successful schemes had the benefits of specific tasks within a specific and small area. Health facilitation in learning disabilities was undefined and covered whole authorities. Consequently, health facilitators felt that, unlike those facilitators cited in the literature review, they were unprepared for their role as health facilitators, and this contributed towards their feelings of uncertainty about their role and the roles of others. As a result they were confused about the structures and

mechanisms of Primary Care Trusts with whom they were expected to work. Those facilitators who were able to embrace ambiguity due to their personal attributes found it empowering. However, others, less self assured, found it restricting and required a more didactic approach.

Leadership

Valuing People (2001) emphasised the importance of effective leadership in order to achieve the changes it required at both national and local levels, but failed to enlighten the reader about the concept of leadership per se, and to distinguish between types of leadership such as, professional and managerial leadership. For change to occur, political leaders need to work with others as co-producers of change (Davies, 2004). Whether this is possible under a New Labour government is open to debate, given that New Labour policy reflects both deep ambivalence and a reluctance to provide direct leadership (Lister, 2001, and Juniper, 2008), and a Third Way management stance of opting to encourage local level government of policy changes through entrusting local leaders with the task of implementation in attempts to give greater credence to local governance. This is not altogether a bad option, but for it to work well it requires powerful and creative figures to provide that local direction (John and Cole, 1999), which, in the case of most of the facilitators taking part in this study, was virtually non-existent.

In leadership positions it should not be assumed that the individual possesses the personal qualities of leadership; and data gathered during interviews indicated that many health facilitators were dissatisfied with the quality of managerial support available. The most common complaints involved managers being uninformed of, and disinterested in, learning disability and health issues and, more often than not, heavily involved in health care issues with higher profiles and demands. Some facilitators had hoped for leadership and guidance from their managers and were disappointed when this did not materialise. Management and leadership, although often complementary, are different entities (Kotter, 1999). Leadership can be said to be concerned with motivating, inspiring, overcoming resistance and installing best practices, and helping people to cope with change (Kotter, 1999, Plsek and Wilson, 2001).

Management has the task of coping with the complexity of fulfilling the vision via planning, setting goals and objectives, and allocating resources accordingly. Some facilitators were fortunate in being managed by people equipped to both inspire and manage simultaneously. However, given the different priorities of managers to control, and leaders to guide and enthuse, it was unrealistic to expect this to be available to all.

There is a contradistinction between leadership and management, which could result in complications at a local level where managers have been relied upon to provide leadership, as evident within the research findings. The reliance on local leadership has allowed the New Labour government to avoid taking the lead in a direct assault on deep seated structural inequalities. Good leadership is about values and ideals and requires a sound vision. *Valuing People* (2001) set out the government's vision for people with learning disabilities across a range of services based on the four key principles of rights, independence, choice and inclusion. However, it omitted to clarify how the proposed changes aligned with the present and future direction of organisations as a whole, and the expectations placed upon staff.

The term 'vision' is encountered many times within *Valuing People* (2001); seventy three times in fact and it even has a whole chapter (chapter two) devoted to it. What then is understood by the term 'vision', which in itself is a somewhat ambiguous term? In this instance it is perhaps safe to assume, given the nature of *Valuing People,* that it is concerned with long term objectives rather than a religious or mystical experience. Given, therefore, the long term aspect to the *Valuing People* vision, many health facilitators felt hindered by the short term nature of their contracts of employment. This however, fits with the New Labour government's short term thinking and approach in general and as such cannot be dismissed out of hand. Indeed Ezer at al (2007) speak highly of such an approach believing it to be both acceptable and valuable and urges for it not to be mistaken for mere whimsy, but appreciated for its ability to generate innovation and experimentation in response to circumstances and environments. Tension exists between concentration on short-termism and its immediate pay offs. Lack of investment

in longer term measures can prevent the development of sustainable strategies (Laverty, 1996). Indeed, Booth (1999, p 4) defined short-termism as approaching ... ... *issues within the time frame of the next election, not the next generation*. Changing attitudes, values and service systems to enable people with learning disabilities to access mainstream health services within a complex organisation such as the National Health Service was always going to be difficult and require longer term thinking and time.

Governments may well suffer from short term thinking as they focus upon election results and may set political goals in keeping with their desire to please their voters, and their length of time in office (Issing, 2006). New Labour has become obsessed with short term dividends and has shown a lack of concern over long term investment (Anderson and Mann, 2003). But what of the risks involved in taking such a short term approach? What happens should the promised goals not be met? Unintended tensions can arise, and faith in politicians can be lost amongst both implementers and the electorate. Evidence from participants of this research demonstrated a preference for longer term strategies in relation to facilitating and sustaining access to generic health services for people with learning disabilities. Health facilitators recognised that the resources needed to meet short term aspirations are fundamentally different from those required to achieve longer term objectives, necessitating greater and longer term investment in the form of finance and personnel. The literature review revealed that short term thinking, even with very clear expectations and goals, was seen to sometimes equate with short lived results and that the successful introduction of health facilitation into mainstream National Health Services required long lasting cultural changes.

The Third Way comprises a set of ideas that inform the government's approach to the delivery of public services that fits with an image of the state as an enabler and partner; withdrawing the role of government to one of policy making whilst leaving the guiding of policy implementation to others (Crawford, 2001). Throughout times of major change, successful outcomes have been attributed to effective leadership (Kan and Parry, 2004). In the case of *Valuing People* (2001) the leadership task fell to the National Support Framework whose brief

was to share good practice, provide ideas, nurture leadership, forge partnerships, push the boundaries, remove obstacles, and call to account. Unfortunately, whilst the National Support Framework was appreciated by health facilitators, it failed to supply the leadership for which they hoped. Within an organisation leadership starts at the top and is crucial if attitudes, behaviours and performance are to improve: facilitators called for a stronger and more directive top down approach to leadership. *Valuing People* made clear its expectation that Partnership Boards and Primary Care Trusts were to demonstrate leadership by ensuring the development of clearly articulated and integrated plans for supporting the primary and general health care services to work with people with learning disabilities. However, evident from the findings was that attitudes towards health issues varied between Partnership Boards, whilst some were supportive, many functioned with little or no input from Primary Care Trusts. This is not to suggest that they have been deliberately excluded from the Boards, but rather that learning disability had not been seen as a big enough priority within Health Trusts to ensure a commitment in the form of a dynamic presence within Partnership Boards meetings in order to provide leadership. Primary Care Trusts have a major leadership role in improving health and health services to their locality's entire population of disadvantaged people: leadership is essential if policy is to be delivered effectively for vulnerable groups in society. In not being more prescriptive towards Health Trusts as to their responsibilities towards establishing health facilitation it failed to ensure the provision of robust, quality leadership and as such *Valuing People* policy failed both people with learning disabilities and health facilitators. Undoubtedly, there were some examples of co-operation and close partnership working within Partnership Boards. This has been achieved through local initiatives and unconnected to any directive from the Department of Health; a fact supported by the findings of the Disability Rights Commission (2006) *Equal Treatment-Closing the Gap* (p13). Stronger leadership is required if a more positive culture of respect for human rights in England's mainstream health services are to be achieved (Institute for Applied Health & Social Policy 2003).

It was reassuring to find that on considering future leadership *Valuing People-Now* (2009) proposed to continue to support the role of leads within the regions, as some, not all, facilitators referred positively to the leadership and support available from individual *Valuing People* Regional Officers. The plan outlined involved locating regional leads within a revamped support framework, still with a National Director overseeing progress in improving the quality of healthcare for people with learning disabilities. The somewhat distanced style of leadership encountered within *Valuing People* (2001) fits with what Lewin, Lippitt, and White (1939) first described as being laissez faire. Such leadership provides little or no direction, and enables those with responsibility for introducing change to have considerable freedom in their approach. As an approach it has much to recommend it if applied under favourable conditions, such as, when those directly affected by the change have the knowledge, skills, capacity and desire to work differently, and can be supported skilfully. However, it could be said that such a style of leadership indicates a sense of *indifference* and *abdication of responsibility* Sudha (2008 p 603). Avolio (1999) believed that any form of leadership is better than a laissez-faire approach, and Bass (2000) stressed the point that for organisational learning and change to take place proactive leadership is required. Leaders who are proactive,

> *... effect environmental change; they identify opportunities and act on them, show initiative, and persevere until they bring about meaningful change. They transform their organization's mission, find and solve problems, and take it upon themselves to have an impact on the world around them.* (Crant, and Bateman 2000, p65)

The need for leadership at both a national and local level was mentioned several times within *Valuing People,* and the Learning Disability Development Fund was identified as the vehicle to support it. Unfortunately for health facilitation, health completely failed to feature amongst the list of priority areas identified by policy makers.

The evidence within this research has been made available to the national Valuing People Support Team and has thus contributed to the content of the new guidance document *Health action planning and Health Facilitation for*

people with learning disabilities: good practice guidance (2009). This guidance document acknowledged that, despite the best efforts of many, the achievement of the health-related targets in *Valuing People* (2001) *was* one of the areas where least progress had been made in the preceding eight years. This guidance is to be commended for: its provision of a clear description of what constitutes good practice in health facilitation; for placing the emphasis on the strategic rather than the one-to-one aspects of the role; the expectation of Strategic Health Authorities, Primary Health Care Trusts and Partnership Boards; and in its emphasis throughput on the importance of leadership in achieving the required outcomes. This research has demonstrated that health facilitators were keen to have good quality leadership made available to them. Leadership was recognised by *Valuing People – Now (2009)* as crucial if the vision outlined in *Valuing People* was to become reality. Health facilitators believed leadership to be essential if the *Valuing People* policy was to be delivered effectively. The evidence gathered throughout this research would suggest that *Valuing People,* as a policy, has failed both health facilitators, and ultimately people with learning disabilities.

Capital

The majority of health facilitators who participated in this study believed themselves to have little or no capital or standing within primary health care circles, hence the expressions of their perceived powerlessness. Successful individuals and groups need to be able to draw upon a variety of different types of capital if they are to uphold and improve their positions in the social order (Swartz, 1997). Within organizations capital on the whole is multi-faceted comprising four aspects: finance; having access to money and relevant resources; culture, such as educational credentials; social, having access to people and networks; and finally, symbolic, having legitimacy within a given organisation or community.

Financial Capital

In relation to financial capital *Valuing People* (2001) decreed that available funds would be targeted towards the Government's priorities. Unfortunately, this did not include issues relating directly to health facilitation. As a result, all

participants felt that *Valuing People* had been remiss in not allocating specific funding to support the inclusion agenda into mainstream health services. Of particular concern to health facilitators was their inability to access resources to support healthy living initiatives for people with learning disabilities. Personal Health Budgets recently announced by the Department of Health (2009), based on social care's direct payment scheme and part of the government's empowerment and personalisation agenda, offers them hope that this issue will be addressed. It is anticipated that Personal Health Budgets will enable greater choice and control over the services needed to achieve health outcomes. Personal Health Budgets have been criticised by the National Health Service Confederation, the independent membership body for the full range of organisations that make up the National Health Service, for carrying risks that could outweigh any benefits they could bring. The feeling about these budgets was that enthusiastic advocates were in danger of promoting them *beyond that which there is evidence to support* (National Health Service Confederation, 2009, p2), and that they would incur double running costs as patients were anticipated as moving over to them gradually leaving the National Health Service to cover the fixed costs of an unpopular services as well as the personal budgets of the patients. A personal health budget pilot programme began in 2009, but is not due to be evaluated until the years 2012/13, some twelve years after the publishing of *Valuing People.*

Some health facilitators working in the role of care management felt empowered to commission on a small scale social care services for individuals. On a larger scale however, facilitators, with just one or two exceptions, felt that they had experienced little opportunity to influence commissioning policies and practices, which many saw as being the key to whole sale change. *Valuing People* (2001) envisaged Local Partnership and Integrated Commissioning Boards developing and implementing joint investment plans and overseeing the inter-agency planning and commissioning of integrated services. To enable this to take place Section 31 of the *Health Act* (Department of Health 1999) facilitated the pooling of the learning disability finances of health and social services, thus paving the way for the joint commissioning of existing or new services. The *World Class Commissioning* (2007) document revealed that for some time there

had been concerns over the difficulties experienced in developing commissioning strategies for specialist adult learning disability health services that reflected current policy and best practice (p6). Guidance in the form of *Signposts for Success,* available since 1998, provided a comprehensive developmental framework for commissioners and services providers by encouraging mainstream health services to become more responsive to the special circumstances and needs of people with learning disabilities. Although widely acknowledged within learning disability circles, this document failed to make any lasting impression on the commissioning process; leading to a situation in which there existed a lack of expertise and capacity within Primary Care Trusts to commission evidence based learning disability services (World Class Commissioning, Department of Health 2007, p 9).This research has revealed strained relationships between facilitators and commissioners, with commissioners described as being inaccessible and ambivalent towards the health needs of people with learning disabilities. The inability of Primary Care Trusts to commission evidence based learning disability services was recognised by the Chief Executive of the National Health Service who, in November 2006, wrote to all Strategic Health Authorities and Primary Care Trust Chief Executives to emphasise the importance of ensuring capacity and expertise around commissioning learning disability services (*World Class Commissioning,* Department of Health 2007, p 9). To this end, the Department of Health, in partnership with the Health Care Commission, produced advice as part of the *Better Metrics Programme* (2007) to assist Primary Care Trusts in developing local performance measures for both specialist learning disability health services and the inclusion of people with learning disabilities into the mainstream commissioning.

This research discovered that in those areas where Local Enhanced Schemes had been commissioned health facilitators expressed feeling highly satisfied with the outcomes achieved despite having encountered a number of stumbling blocks. One significant stumbling block to introducing health facilitation into mainstream services had been a 'what's in it for me' mentality. Research has shown that mercenary cultures have a strong positive attitude towards change providing the rewards are attractive enough (Zabid et al, 2004). Enhanced

payment schemes proved very popular and provided facilitators with some financial negotiating power. In recent years it has been mooted that Primary Care Trusts should be directed to commission enhanced primary care services (Giraud-Saunders et al, 2003). This notion was supported in the 2008/09 *Clinical Directed Enhanced Services Guidance for General Medical Services Contracts* in which The National Health Service employers and the General Practitioners Committee of the British Medical Association agreed five new clinically directed enhanced services, one of which was learning disabilities. It was envisaged that any enhanced service would include: the integration of health checks, personal health records or health action plans subject to patient's consent; the full involvement of carers and support workers; liaison between practices, learning disability health professionals, social and educational services; and a suggested payment of one hundred pounds per patient checked.

Commissioners of services for people with learning disability have an important part to play if the goal of inclusion into mainstream health services is to be attained, and although funding and commissioning responsibility for people with learning disabilities is anticipated as involving the transfer of funds from the National Health Service to local government, this should not include general mainstream health services, Commissioners will be expected to support the interests of individuals and populations by producing strategic needs assessments and making purchasing decisions within current resources (*Valuing People Now: From progress to transformation* 2007 p98). *The Valuing People - Now Delivery Plan* (2009) recognised the pivotal role of commissioning in enabling Primary Care Trusts to identify gaps in service and develop new models of provision, supporting work to identify how person-centred information can inform commissioning at strategic levels. However, this document failed to keep pace with demographic, social and economic trends. Commenting on the *Valuing People Now Delivery Plan*, Dame Jo Williams, co-chair of the Learning Disability Coalition, said it was,

> *... unrealistic to expect that improved service provision for an increasing number of people can be delivered within the current*

> *financial envelope. At the moment resources for people with learning disability are allocated on inadequate and outdated information'..... We now need a careful evaluation of how much it will cost to deliver Government promises.* (The Profound and Multiple Learning Disability Network 2009)

Health facilitators' frustration at their inability to access financial resources to further their work was palpable, and the *Valuing People - Now Delivery Plan* (2009) with its disregard for the role of health facilitator offers little hope of this being eased.

Cultural Capital

Culture, in its broadest sense, can become a power resource (Swartz, 1997). The term 'cultural capital' refers to such resources as knowledge and educational credentials and a general cultural awareness of an organisation or community through its systems and processes. It has been described as being institutionalised in that institutions give recognition to the cultural capital held by individuals (Bourdieu, 1986). This research revealed that the inability of health facilitators to access financial resources in order to further their work confirmed their low status within the culture of their organisations. Consequently, they did not have the impact both personally desired and professionally expected. For educationally based capital to have a value it needs to have value in an area of activity that recognises and shares that value. There was a belief amongst some health facilitators from learning disability backgrounds that their basic nursing qualification was lacking when compared to those of their generically trained colleagues. Facilitators originating from outside of mainstream service provision also admitted feeling inadequate in their own knowledge of the employing organisation's processes.

The task of health facilitation is concerned primarily with changing attitudes, values, beliefs and practice. However, because of the nature of the *Valuing People* (2001) document many facilitators clearly felt ill equipped to achieve and sustain a meaningful degree of change. Communication and negotiation are crucial features in the facilitation of change (Dexter and Prince, 2007), and

evident within the literature review studies was a degree of negotiation regarding incentives and clear terms and conditions with all those involved prior to the commencement of what amounted to even small-scale facilitation projects. These projects were carried through invariably as a result of participating practices and practitioners being willing volunteers. Such co-operative circumstances created empowering and enabling environments in which to work: a feature on the whole absent in the experience of health facilitators for people with learning disabilities. At no point in the data gathering process did facilitators indicate having knowledge of change models and processes, and as such could be considered ill equipped to undertake a role involving changes of the magnitude required. For example, if facilitators' attempts to initiate changes to generic health service provision for people with learning disabilities are observed within Prochaska and DiClemente's (1982) five stage model of change it is apparent that the majority of health facilitators were unable to complete the cycle of change. Whilst some facilitators were successful in getting to stage four in which desired changes are initiated, it was not uncommon for facilitators to find that they could not progress further than stages one or two which at best reflected a state of ambivalence.

Making inroads into changing practice in what many facilitators believed to be an alien culture, in which they felt unacknowledged and unappreciated, was very difficult. That much practice today in health care lacks a systematic approach has been acknowledged (McCormack, Manley, Kitson, Titchen, Harvey G, 1999), together with the fact that practice development is often undertaken by individual practitioners who are poorly prepared for their roles and often inadequately trained or supported; which has been the experience of many of the health facilitators interviewed. The task of bringing about changes to the delivery of mainstream health services to people with learning disability was of such magnitude and complexity that to be successful health facilitators needed to feel secure in their knowledge and skills and supported in their role. The fact that many believed their basic qualification for the role was of lesser value than their mainstream colleagues was compounded by the fact that not one participant referred to having received any form of induction into the role,

training that was facilitation specific, or anything more than nominal training in change management processes and their evaluation.

Social Capital

Facilitators were further frustrated by the perception that they possessed little in the way of social capital. The theory of social capital attempts to describe the influences that form the quality and quantity of social actions and social institutions and has been depicted as the entity that holds societies together (McKenzie, Whitley and Weich, 2002), and as *the intensity of networks among people and the shared values that arise from those networks* (Office of National Statistics, 2003). A lack of social capital proved to be a significant hindrance to health facilitators. The literature review demonstrated that for successful development of health facilitation access to significant personnel was imperative. Working with, and through, existing staff teams was viewed as one of the main mechanisms of facilitating and developing changes of approach and practice. Several facilitators were proud of how they had been able to overcome resistance and engage with existing teams in some circumstances. By far the greater, however, were those who felt that they had made little headway, despite prolific efforts to engage with generic services by offering liaison and training events. The reasons for this can be considered within the different teams encountered; that is, learning disability nursing, integrated, and generic health teams.

Working together was a strong theme throughout the *Valuing People* (2001) document and the New Labour policy as a whole, which called for *effective partnership working across communities, local government, the National Health Service, business, administration, retailers, voluntary sector, media, and faith organisations* (Department of Health 2004, *Choosing Health – Making Life Choices Easier,* p3). Learning disability nursing teams had proved particularly difficult to connect with. *Valuing People* described health facilitation as a complementary task involving team work with the expectation being that specialist staff teams were to add it to their existing clinical and therapeutic roles. The study participants acknowledged their need for good working relationships with local learning disability nursing teams in particular; but

expressed surprise, powerlessness, and discouragement at the level of difficulty encountered when attempting to connect with them. That such teams have a duty to facilitate and support mainstream health professionals in providing better quality services to people with learning disability was iterated by Giraud-Saunders (2003) and supported by the Department of Health in its *Good Practice for Learning Disability Nurses* (2007).

Facilitators working purely strategically with a number of Trusts, or who had originated from outside a health service background, felt especially fraught in respect to their efforts to forge links with nursing teams. Even facilitators with nursing backgrounds expressed their concerns, and believed the resistance stemmed from health facilitators being viewed as interlopers whose presence could impact negatively on the nursing role. Some learning disability nursing teams conveyed a sense of resentment at what they appeared to perceive as being snubbed and overlooked, given that *Valuing People intimated* that they were well placed to take on this role. Whether *Valuing People* was right in making this assumption was debatable in light of Mir et al's study (2007), which identified as problematic in the fact that learning disability nursing teams had been found to lack the capacity and facilitation skills for the role. This research found that where facilitators encountered learning disability nursing teams who admitted lacking the confidence and skills required of health facilitation there was a reluctance to accept or become involved in it. Resistance to change is perhaps to be expected and is often cited as a common component of unsuccessful change. Facilitators felt such resistance had been able to establish itself as a result of the ambiguity surrounding *Valuing People's* concept of health facilitation (Giroux, 2006).

Those areas with a Local Enhanced Scheme reported positive experiences of working in partnership with primary care colleagues. Some areas without enhanced schemes were also making inroads towards involving primary care staff in a leading role with health action plans, but at a slower rate. Nonetheless, the majority of facilitators articulated that they were aware of feeling that they were very much 'on their own' in introducing the concept of health facilitation to generic health services; and were faced with a lack of

interest, knowledge, awareness of *Valuing People* (2001), the health needs of people with learning disabilities, and the existence and scope of health facilitation and the specialist services. Moreover, there appeared to be a reluctance to accept that current practice might need to be improved upon; that capacity and competence could be an issue; or that primary care had any responsibility for the health of people with learning disabilities. Changing practice and established ways of working requires the relinquishing of deeply held beliefs of individual and collective identity. Those whose established existence is jeopardised by new ideas and practices will inevitably feel anxious and frustrated, and will naturally rush to defend the status quo if they feel their security or status is threatened. (Folger & Skarlicki 1999, Piderit, 2000). Change provokes old dilemmas between offering fresh hope and destroying venerated practice (Comfort, 1994). Whilst resistance to change is too big an issue to be dismissed out of hand, it is important to remember that resistance in itself is not always a bad thing. Over-enthusiasm or too trusting an acceptance of the latest trend without a careful examination of the facts may be equally disadvantageous. Those being asked to change their practice needed to be able to discuss doubts about any proposed changes and this could have been a good starting point for reform.

One way of overcoming resistance is to get to know individuals by infiltrating their established networks. Networking involves developing and maintaining contacts and personal connections and it provides valuable opportunities for communication, collaboration, problem solving, and the building of trust. Studies on social capital have found that the trust built up in this way is significantly and positively connected to the successful introduction of innovative practice (Dirks and Ferrin, 2001). Researchers have shown that the chances of making a positive connection in any given networking encounter is high (Watts and Strogatz, 1998) and that the transformation that occurs through connectedness contributes towards social capital as the hidden factor which makes for greater efficiency and effectiveness (Dastmalchian et al, 2005). Strong associations with agencies, groups, and practitioners likely to feel the impact of health facilitation for people with learning disabilities were therefore fundamental to successful health facilitation.

It is evident from this research that facilitators had not received as much help and support in this direction from their employing organisations as they would have liked. Had employing organisations recognised their responsibility to address the social capital needs of health facilitators there were several options open to them. Firstly, they could have pursued a recruitment and selection process that would have sought to appoint facilitators not just for their knowledge and skills, but for their potential for making contacts and building networks (Hitt et al, 2002). Secondly, how an individual is received and accepted within networks has been found to be influenced by their position within an organisations structure (Erickson, 1988) and had health facilitators been graded at a suitably prestigious position it is possible that their social capital could have been enhanced. Thirdly, the provision of appropriate working environments conducive to promoting positive interaction could have improved their status and sphere of influence. Finally, in recognition that networks and the development of productive relationships are considered as hallmarks of good strategic leadership in the twenty first century, the drawing up of comprehensive induction programmes to support this would have been helpful.

Social capital is an aspect of social structure that creates value and facilitates the actions of the individuals within that social structure (Coleman, 1990). In the workplace social capital has been found to be connected to both a sense of well-being and improved efficiency (Statistics Finland, 2006). That the majority of health facilitators reported feelings of stress and anxiety could indicate the absence of social capital in their working lives. Unless due consideration is paid to power differentials and the need to develop a degree of respect and trust between key personnel, efforts to be of assistance to the socially excluded would be ineffective. Even having access to the best equipment, ideas, and personnel, will, *amount to nothing unless that person has access to others to inform, correct, improve and disseminate his or her work* (Szreter and Woolcock, 2004 p69). The understanding of the efficacy of social capital in its institutional context is dependent on the quality of individual institutions. Where the need for social capital of health facilitators is ignored the implication is that there will be little to show for the most well intentioned efforts.

Symbolic Capital:

Symbolic capital may described as a representation that communicates to others that a person has authority within their particular environment or set of circumstances, and therefore has a degree of power available to them (Webb et al, 2002). It refers to the ways in which value may be conferred, and can be said to be embodied in prestige, renown, reputation and personal authority (Bourdieu, 1998). The amount pf power a person has within an organisation depends on their position and the amount of capital they possess. Successful leaders of change inherit a mantle of legitimate power with a formidable set of institutions and the ability to manipulate symbols to further their ends (John and Cole, 1999). Symbols instil beliefs and shape the attitudes that underpin social structures. Examples of symbolic capital include: job titles, name badges, involvement in organisational rituals, status symbols such as office location and furnishings, personal administrative support, and so forth. Symbols take on important meanings in organisations; meanings that are defined by culture, social conventions and interactions and serve to legitimise and give credibility to their holders. Throughout this research it was evident that health facilitators sought such legitimisation but in reality often found themselves marginalised and struggling to facilitate change. Many facilitators had been issued with temporary or time limited contracts of employment. As contracts of employment are regarded as being a symbol of one's capital within an organisation it is not surprising they reported feeling insecure to the degree that, rather than concentrating on improving access to mainstream health care provision for people with learning disabilities, they sought funding to protect or advance health facilitator posts. Marginalized people are in a continual *search for respect* (Sandberg, 2008 p3), which was evident by the considerable amount of time being invested by facilitators into activities designed to prove their worth. For facilitation to have been successful, employing organizations would have done well to reflect on the importance of symbolic capital and its management in the early stages of projects (Zott and Huy, 2007).

Studies into brain activity and subjective happiness in recent years have revealed that a key component regarding the quest for status comes from the fact that humans make social comparisons when assessing their own value

(Fleissbach et al, 2007 and Layard, 2005). The main areas of dissatisfaction amongst facilitators in relation to their perceived lack of symbolic power were: variations in job titles across the country, manifesting in confusion amongst both health facilitators and generic health care professionals; dissatisfaction with the National Health Service re-grading exercise; and the working environment and location of bases. Many facilitators felt that the titles assigned to their posts failed to reflect their occupational prestige, professional credentials, specialized training, the job's authority, and significance in the path of decision making (Baker et al, 1990). Distinctions among job titles are relevant to social stratification within organisations. Rank and status dynamics have been identified as a potentially significant source of workplace stress, as was evident amongst the majority of facilitators interviewed. Workplace stress has been estimated as being the biggest occupational health problem in the United Kingdom at the present time. A greater understanding and awareness of its importance is required given that the health of human beings is likely to be affected if rank dynamics are operating in the background of potentially stressful relationships and interactions within organisations (Collins, 2006). Job titles are important in that they provide insight into the organization of work and associated values and beliefs. Unfortunately many organisations, such as Primary Care Trusts, regard the specification of job titles and job boundaries as purely technical matters (Strang and Baron, 1990 p 480), and failed to take into account the fact that titles help the post holders to be validated within the organisation. Health facilitators were desirous of job titles that would define their role, reflect the levels at which they wished to function, provide a means of advancement, increase their confidence, encourage co-operation, confirm their importance in the organization, and give them a sense of pride in their role.

Symbolic capital is not always recognised. Whilst its accoutrements may not mean much in themselves, for example, where and how someone is accommodated within an organisation, it can mean a lot to observers in that they are more likely to perceive such things as symbols of power and authority (Webb, et al, 2002). This was another of the issues that contributed towards facilitators feeling undervalued and lacking in capital. The majority expressed a desire to be based within Primary Care Trust Headquarters, or at least with

senior staff from the generic services possessing a similar brief to their own. In reality, facilitators were based within a variety of different settings that failed to meet their expectations. This, they felt, rendered them less power and authority than colleagues working within the parameters of the National Service Frameworks, or within other specialist roles. They considered that they had not been afforded the respect their position deserved, both from generic health professionals and the learning disability teams. The study undertaken by McGuire and McLaren, (2009) identified a relationship between the working environment and employee commitment and wellbeing, which suggested that more thought needs to be paid to such issues by Primary Care Trusts when establishing new roles and positions. Under the circumstances it is perhaps not surprising that many facilitators felt that their role had had a negative impact upon their emotional wellbeing.

In the experience of some facilitators the *Valuing People* (2001) document itself, by the virtue of its status as a White Paper, lacked the symbolic power of an act of parliament or a National Service Framework. This led to facilitator despair at constantly being reminded that *Valuing People* was aspirational, not mandatory, and as such was not enforceable. As facilitators considered themselves lacking a degree of capital in all its forms it is easy to understand the level of anxiety expressed. Employees unsure of their authority, what is expected of them, or how they will be judged, may find themselves immobilised, reverting to comfortable but inappropriate working practices, or relying on a trial and error approach (Rizzo et al, 1970): all three actions being evident within the research data gathered. Such a lack of attention to capital in all its forms had played a part in putting facilitators in weak and ineffectual positions from the outset. In the words of Bourdieu, (1998, p3) it could be claimed that facilitators were sent out *to compensate for the most flagrant inadequacies ..... without being given the means to really do their job.* How then could they not have a sense of being, constantly powerless, undermined and let down by the way *Valuing People* (2001) was being interpreted and implemented?

Conclusion

This discussion has set the primary research presented in this thesis within the context of health care for people with learning disabilities and the theoretical frameworks of ambiguity, leadership and capital. The former has ensured that the research can be understood within recent investigations that have confirmed the depth of the problem faced by people with learning disabilities who try to access good health care. The latter allows the research to be interpreted and understood in terms of the confusion reported by so many of the research participants. As a concept, health facilitation is challenging to describe because essentially it is concerned with the process of making something happen rather than being simply outcome based. The literature reviewed in chapter two upholds the notion that the measuring of outcomes is vital (Cook 1994) in calculating the efficacy of the change process (Astrop, 1988, Cook, 1994, Garbowski and Farquhar, 1987, Lemelin et al, 2001, Stetler, 2006, and Shinn, 2002). This study's participants were yet to make an impression in this area, due in part to *Valuing People* (2001), whilst having identified that the key elements of health facilitation failed to provide any health related performance indicators. As a result facilitators faced a lack of direction, monitoring, an agreed framework for evaluation, and a sense of accountability.

Ambiguity about the facilitation role and what it was expected to achieve is thought to be characteristic of New Public Management reforms (Cumella, 2008), whereby they were seen as a pragmatic strategy to be encouraged and embraced by policy makers as a sensible exit strategy in circumstances in which numerous perspectives on any given issue are inevitable. Ambiguity places policy makers in an advantageous position in that they can use it to their advantage as they are in control of the degree of vagueness to be conveyed (Chen, 1992), thus offering them significant flexibility should they need to protect themselves should things not work out as envisaged (Giroux 2006, Chen, 1992). This approach has attractions for policy makers but is not without risk to health facilitators. The interpretation of a vague term such as health facilitation has resulted in some localities making no official arrangements for health facilitation, and where provision has been made there have been numerous variants of models and practices. Participants agreed that in their

experience ambiguity was a significant barrier to widespread policy adherence and an impediment to implementation and were eager that the health facilitator role should be formalised in order to clarify its scope and parameters. They were unanimous in the opinion that the *Valuing People* (2001) targets were too ambitious to be achieved within the stipulated time and financial constraints. The absence of clear objectives and outcomes within the *Valuing People* text left health facilitators feeling vulnerable in the face of their own or others' interpretation of their role. Not surprisingly very few facilitators had been able to effectively evaluate their level of achievement.

Recent government documents have stressed the need for mainstream health services to step up and accept their responsibility to provide equitable and high calibre services for people with learning disabilities. However, *Valuing People-Now* (2009) chose not to actively promote the role of the health facilitator despite the evidence contained within *Valuing Health for All* (2003), which found that Primary Care Trusts needed a nominated lead person, with dedicated time to take forward the learning disability agenda. Similarly, *Commissioning Specialist Adult Learning Disability Health Services* (2007) postulated that it was critical to ensure there was an effective and identifiable strategic presence within the Primary Care Trust to inform and support the commissioning and delivery of accessible, high quality health care for people with a learning disability. It is all very well issuing additional guidelines for health facilitators, but who will read this document?

This study found that lack of prominence within *Valuing People* (2001) resulted in health facilitation being disregarded to a great extent, a situation which could be repeated because the guidance document published to accompany *Valuing People –Now* (2009) was aimed specifically at health facilitators rather than the health services as a whole. It would have been preferable to have given health facilitation a higher profile in a wider arena. In some Primary Care Trusts strategic health facilitators' have been appointed to undertake the facilitation role and have been instrumental in meeting the need to provide strong leadership in order to change generic health practices and promote health facilitation and health action planning at the individual level. However, the failure

of other Trusts to invest in specialist learning disability health professionals with the capital required enabling them to facilitate change and support primary care staff and general hospitals to meet the needs of people with learning disabilities had been a causal factor in the low level of reform achieved. Therefore, in conclusion, one may suggest that for health facilitation *Valuing People* (2001) was a missed opportunity.

Chapter 8

Conclusion

Introduction

The general purpose of this research was to investigate the phenomenon of health facilitation within learning disability services in England. It looked primarily at identifying, describing, and understanding the health facilitator's subjective experience of health facilitation whilst also exploring the perceived effect of *Valuing People* (2001). The second function was to undertake a close examination of *Valuing People,* the vehicle of social policy behind the development of health facilitation as a means of improving the health of people with learning disabilities. This research is of particular importance as investigation into health facilitation in learning disabilities has been at best limited, and from the perspective and experience of health facilitators in the field, absent.

A qualitative research design was employed using an eclectic phenomenological approach. This allowed a degree of flexibility in order to adequately explore the phenomenon of health facilitation as proposed in *Valuing People* (2001) and practiced at a specific point in its development. Four data gathering methods were utilised. Firstly, a policy analysis involving a pragmatic and detailed investigation of the text of *Valuing People* (2001) was undertaken with the assistance of a policy analysis tool emanating from the Queensland Government of Australia, which afforded a measure of objectivity into what was an intricate and complex document. Secondly, a modified Delphi study designed to elicit the opinions of a group of experts from the world of learning disability as to their perception of the major issues relating to health facilitation in England was carried out. This was subsequently analysed via a process of systematic refinement and consensus development. A series of semi-structured interviews set around the findings from the modified Delphi study and participant generated issues were undertaken and scrutinised using a thematic network approach to analysis. And finally, a reference group was used to provide a forum for a broad discussion and debate of the issues emerging from interviews. Information gathered from this source was subject to a tape,

notes, and memory based analysis. The study sample was selected to encompass all the Valuing People Support Team Regions throughout England.

The research has met its aim of identifying, describing, and understanding the subjective experience of health facilitation by health facilitators within the field of learning disability, whilst at the same exploring the perceived effect of *Valuing People* (2001) on the provision of accessible mainstream services to people with learning disabilities. Several difficulties arose during the course of conducting the research. Recruiting enough participants to each of the Valuing People Support Team regions proved to be difficult and resulted in the need to target facilitators in those specific areas proving to be less forthcoming. Saturation point in the interview process was reached after thirteen interviews when no new evidence emerged from those participants consulted in the latter part of the process. Also difficult was the recording of the reference group meeting due to the context in which it was held. On reflection, if this research were to be repeated, it would be wise to consider using fewer participants in the semi-structured interview process; employing the services of a scribe during the reference group meeting leaving the researcher free to facilitate; or, indeed, to have included all the Valuing People Support Team areas in the interview process thus reducing the need for a reference group.

The research findings, whilst supporting the findings of previous studies (Caan et al 2005, Thomson et al 2007, and Mir et al 2007), expand the knowledge base around health facilitation in that it focussed on the process of health facilitation as experienced by health facilitators as opposed to concentrating on the outcomes of health facilitation; and took a nationwide approach as opposed to one that was simply locality based. In this way it has been able to identify some of the more subtle barriers to successful policy making. The significance of this research lies in its multifaceted exploration of health facilitation. The analysis of the *Valuing People* (2001) document allowed health facilitation to be integrated within the wider world of learning disability service provision and politics. The semi-structured interviews were arranged around those issues identified by experts in the field of learning disability as being pertinent to the promotion of good health and equality of access to mainstream health services

for people with learning disabilities. The reference group enabled interactive exploration leading to further insight into the experience of health facilitation. Consequently it has been possible to identify some of the more subtle barriers to policy implementation. This research is of particular importance in the light of the *Valuing People – Now* document (2008) which, like *Valuing People* (2001), regrettably remains a 'guidance' document mentioning health facilitation only briefly. Its findings will be of value to policy makers, Partnership Boards, Primary Care Trusts, primary care and learning disability professionals, training providers, and those charged with implementer and leadership roles.

Initially health facilitators welcomed the publication of *Valuing People* (2001) believing it to be a creative and innovative policy, and fully endorsed its vision, underpinning values and principles. Particularly welcomed was the involvement of people with learning disabilities and their families in its construction and the fact that it was linked to a range of other government policies and legislation. However, the research results discovered that health facilitators in practice found *Valuing People* lacking in power and robustness as a policy due its vague and discretionary nature. In their experience, health facilitation, as presented within *Valuing People,* was a concept that was: ambiguous leading to a lack of comprehension and understanding as to its nature; lacking in foresight thus leaving practitioners ill prepared and ill equipped to function effectively; and lacking in meaningful leadership and support at all levels.

An assumption declared prior to commencing these investigations was that health facilitators would interpret health facilitation in their own way. In some instances this was in fact the case but in others health facilitators felt constrained in their practice as a result of the interpretation placed upon health facilitation by managers and Primary Care Trusts, for example. Given the lack of clarity surrounding the role and deficit of leadership, it was perhaps inevitable that this would be the case. That *Valuing People* (2001) lacked a full understanding of what would be involved in introducing this concept into mainstream services was substantiated by the policy analysis which revealed that it was introduced without the benefit of an obvious, vigorous and explicit underpinning evidence base. Such an omission ran the risk, in a climate of

evidence based medicine, practice and policy, of alienating mainstream services and severely compromising the possibility of introducing health facilitation for people with learning disabilities into generic health care services. Facilitators believed this demonstrated a lack of understanding and foresight into the complexity of health facilitation and the differing levels of implementation. Each of the data gathering methods employed revealed *Valuing People's* vagueness, particularly in relation to the level at which health facilitators should function and the marked absence of health facilitation focused outcomes and the means by which they could be achieved and measured. As a result, health facilitators felt both powerless and let down by *Valuing People's* ambiguity; believing it to have rendered them vulnerable to a sense of aimlessness, an inability to prove the value of their role, and susceptibility to blame should the rate of progress prove to be limited.

Valuing People (2001) emphasised the importance of effective leadership in realizing the changes it required at both national and local levels. However, whilst some facilitators were satisfied with the leadership and support mechanisms established by the government via *Valuing People* (2001), the majority deemed them inadequate to meet their needs. Lack of direction was a recurring theme amongst participants who believed that establishing the need for change within *Valuing People* was clearly not enough in itself, but rather that health facilitation needed to have been actively and rigorously supported throughout the change process. General practice and some Primary Care Trusts evidently viewed *Valuing People* as a guidance only document that they had the option of pursuing or not. This manifested itself in learning disability issues being afforded low priority on their agendas and in some instances Primary Care Trusts' input and support to Partnership Boards, the body charged with implementing *Valuing People,* was minimal or non existent. McNally (2004) expressed concern about the danger of bureaucratic structures interfering with supportive health facilitation interventions. This was a factor experienced by most participants, who discovered the systems and structures within general practice and primary care services difficult to penetrate effectively without leadership and support. The negative impact of bureaucracy was also palpable within integrated teams where facilitators found their role to be

subdued by the competing elements care management and care co-ordination to the point where they felt their involvement in health facilitation activities was restricted.

The point was made by Gates (2001), that in order to value people it was also necessary to value those who cared for them. That facilitators felt that they had not been valued was a persistent theme throughout this research. A major contributory factor to this was the sense of powerlessness to affect the changes demanded by *Valuing People* (2001) due in general to the lack of capital afforded them and their role. The amount of power and influence a practitioner has within an organisation depends on their position and the amount of capital they possess. Facilitators felt that Valuing *People's* emphasis on the role being a complementary component to existing roles had deterred some organisations from taking it seriously. Consequently, the tendency towards short termism adopted by some organisations that chose to issue temporary time limited contracts or offer short periods of secondment was a source of facilitator anxiety. This demonstrated a lack of understanding of the health facilitator role, investment, and a commitment to long term sustainable improvements in health care delivery to people with learning disabilities. Very little attention had been paid to empowering facilitators via their status within organisations, or investing in equipping them with the necessary skills for the task. Health facilitators participating in this research were well educated, held professional qualifications and believed themselves to have the qualities and abilities required of a health facilitator. However, many were poorly prepared and supported in their roles, and lacking the essential skills of facilitation.

To date, emerging themes from this research have been presented at learning disability conferences throughout England, and a Royal College of Nursing International Nursing Research Conference. In addition they have been made available to the Department of Health via the Valuing Support Team based in Leeds, West Yorkshire. It is the intention to take this research forward into the learning disability and health world by circulating a summary to each of the learning disability networks and to each participant as agreed prior to commencement of the study. Further to this, the publication of a series of

articles in health and learning disability publications is anticipated, together with the submission of abstracts to health, learning disability and research orientated conferences to be considered for presentation. In this way it is expected that a wide range of service user and professional groups will be accessed.

The recommendations resulting from this research are that the provision of health facilitation be made a mandatory and accountable requirement of Primary Care Trusts and Partnership Boards. The scope and parameters of all levels of health facilitation should be formalised and clarified across England to enable meaningful conclusions to be drawn as to its effectiveness. There should be specific training made available to health facilitators prior to taking up post, and on appointment a period of induction into appropriate health care networks. Also advised is that Primary Care Trusts and Partnership Boards give consideration to the capital needs of health facilitators in their role as change agents. A final endorsement arising from this research would be that adequate support and leadership be assured for all facilitators at whatever level of practice.

In that this research has built on the work of previous studies, there is, likewise scope to develop and broaden understanding of health facilitation in learning disability services. Of value as future research would be an investigation into the difference the publication of *Valuing People – Now* (2009) makes to the experience and achievements of health facilitators; and a comparison between health outcomes and access to mainstream health services between England and the devolved countries of the United Kingdom, given that England is the only country in which health facilitation and health facilitators have been a feature.

Final Thoughts and Reflections

It is disappointing to end this thesis in the knowledge that the health of learning disabled people in England remains poor. Some of the literature discussed in this thesis has been published recently and still notes problems similar to those that the health facilitators were trying to deal with when interviewed. Put starkly, learning disabled people still have poorer health outcomes and die earlier than the general population. This thesis has helped to explain that this complex

problem needs more than good intentions to be overcome. Health policies for learning disabled people will be judged successful when the health outcomes for this group of people improve.

Ultimately a PhD is judged by the new knowledge gained. This thesis has revealed new information relating to the impact upon health facilitators of: ambiguity within the *Valuing People* (2001) document; a lack of adequate leadership at all levels; and a general lack of power and influence (capital) surrounding the health facilitator role. However, for me, this PhD means much more than this. This thesis stemmed from thirty years of working with people with learning disabilities, of which twenty three also involved managing community learning disability nurses. Following publication of the Labour government's *'Valuing People'* (2001) document, aimed at improving the life chances of people with learning disabilities in England, I became aware that the nurses I managed were struggling to implement the requirements of the document's '*Good Health'* chapter. Attempts by the nursing team to initiate discussion and partnership working with general practitioners and acute hospital services were disappointing and frustrating. In order to make sense of health facilitation and to support the nursing team in their practice I decided to seek new knowledge about health facilitation via the PhD process. It is still rare for nurses in the United Kingdom to undertake doctoral research; particularly so for nurses from my own speciality, learning disability nursing, to work at this level. This may account for the level of suspicion, negativity, and lack of understanding and support that I experienced from my managers. It is my belief that they felt that I was moving into areas that they did not fully comprehend and that my involvement with the academic world had the potential to overtake and undermine them.

It is perhaps understandable, therefore, that, whilst excited at the prospect of studying at this level, I experienced doubts about my ability to become a serious researcher. However, my passion and commitment to people with learning disabilities and the nurses striving to break down the barriers to good quality mainstream health spurred me on. I found the whole research experience both stimulating and liberating in that it enabled me to enter into free and open

debate about issues with other PhD students and to pursue an approach to research unfettered by a requirement to adhere to the rigid institutional rules, policies and procedures encountered throughout my nursing career.

Undertaking this thesis proved to be a both a developmental and affirming process that has stretched my abilities, both professionally and personally, on a number of levels. For example: the basic skills of research to enable me to complete a distinctive long-term piece of research; writing research reports and updates has improved my presentation and communication skills, both written and oral; and the self management skills needed to work in non-structured situations and to be able to balance the needs of the thesis alongside the needs arising within other areas of life; and the ability to be flexible and willing to make changes where necessary, and to take advantage of opportunities that arise. As a result I have become an independent, original and critical thinker prepared to adopt a sceptical approach and to question carefully in order to obtain a broader, more comprehensive perspective on presenting issues.

Although at times arduous, I have thoroughly enjoyed completing this doctoral journey. I owe a debt of gratitude to my immediate colleagues for their supportive, to all those who have shared their knowledge and skills with me along this journey, and also to the doubters who told me I was 'too old', 'too ill', or 'out of my league'. Such negativity was truly motivational.

REFERENCES

Abraham A., White J., (2009), Ombudsman's Report, *Six lives: the provision of public services to people with learning disabilities,* Office of Public Sector Information, London.

Achiaga N.P., (2006), Does health promotion decrease or exacerbate health inequalities? A case for people with learning disabilities, *Learning Disability Psychiatry,* Volume 8 (1), p3.

Adler M., Ziglio E., (1996), *Going into the Oracle. The Delphi Method and its Application to Social Policy and Public Health*, London., Jessica Kingsley Publishers.

Alesina A., Cukierman A., 1990, The Politics of Ambiguity, *The Quarterly Journal of Economics,* Vol. CV (4,) pp 829-850.

Alvesson M., 2001, Knowledge Work: Ambiguity, Image and Identity, *Human Relations,* Vol. 54; p863.

Anderson P., Mann N, (2003), Safety First: The Making of New Labour, Chadwick A., Heffernan R. (Eds), in *The New Labour Reader*, Polity Press, p92-97.

Anderson J.,Worth V., (1995), *Society and Social Science Foundation Course Glossary Index,* Milton Keynes, Open University Press.

Anson R., Bostrom R., Wynne B., (1995), An Experiment Assessing Group Support System sand Facilitator Effects on Meeting Outcomes, *Management Science*, Vol. 41, pp 189-208.

Asthana S. (2003) Intermediate care: Its place in a Whole-Systems Approach, *Journal of Integrated Care*, Vol.11 (6), p15-24.

Astrop P, (1988), Facilitator – The Birth of a New Profession, *Health Visitor*, Vol.61, pp 311-312.

Attride-Stirling, J. (2001), Thematic Networks: an analytic tool for qualitative research, *Qualitative Research,* Vol.1 (3) pp 385-405.

Avolio J.B.(1999), *Full Leadership Development Building the Vital Forces in Organizations,* Sage, National College for School Leadership 2003, p2.

Baggott R., Allsop J., Jones K., (2005), *Speaking for Patients and Carers, Health Consumer Groups and the Policy Process,* Basingstoke, Palgrave Macmillan.

Baker G., Gibbs M., Holmstrom B., (1994), The Internal Economics of the Firm: Evidence from Personnel Data, *The Quarterly Journal of Economics*, Vol. 109, (4) pp. 881-919.

Bashir K., Blizard B., Bosanquet A., Bosanquet N., Mann A., Jenkins R., (2000) The evaluation of a mental health facilitator in general practice: effects on recognition, management, and outcome of mental illness, *British journal of General Practice*, Vol.50, pp626-629.

Bass B.M., (2000) The Future of Leadership in Learning Organizations, *The Journal of Leadership and Organisational Studies*, Vol.7, (3) p18 – 40.

Bell J, (1999), *Doing Your Research Project*, Maidenhead, Open University Press.

Bertrand J.J., Brown J.E., Ward V.M., (1992), Techniques for Analyzing Focus Group Data, *Evaluation Review,* Vol.16; p198-209.

Benchmarking: Raising standards through sharing excellence (2007), www.nhsbenchmarking.nhs.uk: Accessed 23.7.07.

Bentley T., (1994). *Facilitation: Providing opportunities for learning*, London, McGraw Hill.

Berger P. Luckmann T., (1966), *The Social Construction of Reality,* London Penguin.

Booth, K. (1999), 'Nuclearism, Human Rights and Construction of Security', *The International Journal of Human Rights,* Vol. (3) (2), pp. 1–24.

Bourdieu, P., (1986), The Forms of Capital, in G. John (Editor), *Handbook of theory and research for the sociology of education*, edited by John G., New York, Greenwood Press.

Bourdieu, P. (1998), *Practical Reason. On the Theory of Action*, Stanford., Stanford University Press.

Bourdieu P., (1998) *Acts of Resistance, Against the New Myths of Our Time*, Cambridge, Polity Press, p3.

Bowles N. (1999), The Delphi Technique, *Nursing Standard,* Vol. (13) pp32-36.

British Broadcasting Corporation (2005) available at www.bbc.co.uk/dna/actionnetwork/A1184672: Accessed 3.02.08.

Burton M., Kagan C., (2006), Decoding Valuing People, *Disability and Society*, Vol.21, No. 4, pp299-313

Caan W., Lutchmiah J., Toocaram J., Thomson K., (2005), Health Facilitation in Primary Care, Primary *Health Care Research and Development*, Vol.6, pp348-355.

Carroll L., Thirlwall M., Wilson A., (1993), Medical Audit and the Role of the Facilitator, *International Journal of Health Care Quality Assurance*, Vol.7, (3), pp 8-10.

Centre for Economic and Social Inclusion (2002), www.cesi.org.uk/kbdocs/socinc.doc: Accessed 4.9.06, p1.

Chen R., (1992) Ambiguity can be Pragmatic, and a Good Thing Too, The Sixth *Annual International Conference on Pragmatics and Language Learning, University of Illinois* (Transcript).

Clarke, J., (2004), Dissolving the public realm? The logics and limits of neo-liberalism, *Journal of Social Policy*, Vol. 33, (1), pp27–48.

Cole M., Avison D., (2007), The potential of hermeneutics in information systems research, *European Journal of Information Systems*, Vol. (16), pp 820-833.

Coleman J.S., (1990) *Foundations of Social Theory*, Cambridge, Harvard University Press.

Collins M., (2006) Taking a lead on stress: rank and relationship awareness in the NHS, *Journal of Nursing Management*, Vol.14, (4) pp310–317.

Comfort LK, (1994) Initiating Change: A Dialogue between Theory and Practice, *Journal of Public Administration Research and Theory,* Vol. 4 (3) pp323-325.

Conger J.A., (1989), The Charismatic Leader. Behind the Mystique of Exceptional Leadership, San Francisco, Jossey-Bass.

Cook R., (1994) Facilitators: looking forward, *Health Visitor*, Vol.67, (12), pp 434-435.

Council of Europe, (1950), *The European Convention on Human Rights*, Rome, 4.11.1950.

Crant J.M., Bateman T.S., (2000). Charismatic Leadership Viewed From Above: The Impact of Proactive Personality, *Journal of Organizational Behaviour*, Vol. 21(1) pp. 63-75.

Crawford A., (2001) Joined up but fragmented. Contradiction, ambiguity and ambivalence at the heart of New Labour's Third Way, in Mathews R., Pitts J.(Eds), *Crime, Disorder and Community Safety: A new Agenda*, London, Routledge, (p63).

Cukierman A., Meltzer A., (1986), Theory of Ambiguity, Credibility, and Inflation under Discretion and Asymmetric Information, *Econometrica,* Vol. 54, No. 5 pp. 1099-1128, The Econometric Society.

Cumella S., (2008) New Public Management and Public Services for People with an Intellectual Disability: A review of the Implementation of *Valuing People* in England, *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 5, No. 3, pp 178-186.

Curtis EA, Redmond R, (2007), Focus Groups in Nursing Research, *Nurse Researcher*, Vol. 14, No.2, p25.

Dastmalchian A., Rezac D., Javidan M., (2005) Leadership + Positive Networking = Social Capital, *Business Class,* Spring Edition, p12-13.

Davies C., (2004), Political leadership and the politics of nursing, *Journal of Nursing Management* Vol.12, pp235–241.

Davis J.H., Schoorman D., Donaldson L., (1997), Toward a Stewardship Theory of Management, *The Academy of Management Review,* Vol. 22, (1) pp. 20-47.

Davis P., Howden-Chapman P., (1996) Translating research findings into health policy, *Social Science and Medicine,* Vol.43, pp865-872.

Denscombe M., (1998), *The Good Research Guide for Small-scale Social Research,* Buckingham, Open University Press.

Denzin, N.K. and Lincoln, Y.S. (eds.), (2005), *The Sage Handbook of Qualitative Research*, Third Edition, Thousand Oaks, Sage.

Department of Health and Social Security, (1971), *Better Services for the Mentally Handicapped,* London, Her Majesty's Stationery Office.

Department of Health, (1990), *National Health Service and Community Care Act*, London, Her Majesty's Stationery Office.

Department of Health (1998), *The New NHS: Modern, Dependable*, London, Her Majesty's Stationery Office.

Department of Health (1998) *Information for Health: An Information Strategy for the Modern NHS 1998 – 2005,* London, National Health Service Executive.

Department of Health, (1998), *Signposts for Success*, London, National Health Service Executive.

Department of Health (1999), *Doubly Disabled: Equality for disabled people in the new NHS, Access to services,* London, National Health Service Executive.

Department of Health, (1999), *Saving Lives: Our Healthier Nation*, London, Her Majesty's Stationery Office.

Department of Health, (1999), *Facing the Facts, Services for People with Learning Disabilities: A Policy Impact Study of Social Care and Health Services,* London, Her Majesty's Stationery Office.

Department of Health, (1999), *Modernising Government,* London, Her Majesty's Stationery Office,.

Department of Health, (1999), *Once a Day*, London, Her Majesty's Stationery Office.

Department of Health, (2000), *The NHS Plan,* ,London, Department of Health Publications.

Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*, London, Department of Health Publications.

Department of Health (2001), *Nothing About Us Without Us,* London, Department of Health Publications.

Department of Health (2001), *Family Matters,* London, Department of Health Publications.

Department of Health, (2002) *Improvement, expansion and reform - the next 3 years: priorities and planning framework 2003-2006*, London, Department of Health.

Department of Health, (2002), *Action for health, health action plans and health facilitation detailed good practice guidance on implementation for learning disability partnership boards,* London, Department of Health Publications.

Department of the Deputy Prime Minister, (2004), *Mental Health and Social Exclusion: Social Exclusion Unit Report*, London, Department of the Deputy Prime Minister.

Department of Health, (2004), *Choosing Health – Making Life Choices Easier,* London, Department of Health Publications.

Department of Health, (2004), *Agenda for Change: What will it mean for you? A Guide for Staff*, Department of Health Publications, London.

Department of Health and Home Office, (2006*), National Treatment Agency for Substance Misuse: Care Planning Practice Guide*, London, National Treatment Agency for Substance Misuse.

Department of Health, (2009), *Good Practice in Learning Disability Nursing*, London, Department of Health publications.

Department of Health, (2007), *Commissioning specialist adult learning disability health services*, London, Department of Health Publishing.

Department of Health, *(2007), World class commissioning: vision*, London, Department of Health Publications.

Department of Health, (2009), *Valuing People Now: The Delivery Plan, 'Making it happen for everyone',* London, Department of Health Publishing.

Department of Health, (2009), *Health action planning and Health Facilitation for people with learning disabilities: good practice guidance,* London, Department of Health Publishing.

Department of Health, (2009*), Personal Health Budgets Update, December*, London, Department of Health Publishing.

Dexter B., Prince C., (2007), Facilitating change: the role of educators as change agents, *Strategic. Change,* Vol.16, pp341–349.

Dickson N., (1999), *What is the Third Way?* British Broadcasting Company News Report 27.09.1999.

Dietrich A.J., O'Connor G.T., Keller A., Carney P.A., Levy D., Whaley F.S., (1992) Cancer: improving early detection and prevention. A community practice randomised trial*, British Medical Journal*, Vol. 304, March, pp687-91.

Dirks, K.T., Ferrin D.L.,(2001), The role of trust in organizational settings. *Organization Science* 12: 450–467.

Disability Rights Commission (2006) *Equal Treatment - Closing the Gap*, London, Disability Rights Commission.

Dismukes R.K., McDonnell LK., Jobe K.K., Smith G.M., (2000), What is Facilitation and Why Use It? In Dismukes R.K. and Smith G.M. (Eds), *Facilitation and Debriefing in Aviation Training and Operations* (Pages 1-12) http://human-factors.arc.nasa.gov: Accessed 3.02. 07

Dobrow M.J., Goel V., Upshur R.E.G., (2004), Evidence-based health policy: context and utilisation, *Social Science & Medicine*, Vol.58 (1) p207-217.

Elias, J. L., & Merriam, S. (1980). *Philosophical foundations of adult education*, Melbourne, Krieger Publishing Co.

Eliasson G., Berg L., Carlsson P., Lindstrom K., Bengtson C, (1998) Facilitating Quality Improvement in Primary Health Care, *Quality in Health Care*, Vol.7 pp48-54.

Elwyn G., Hocking P., (2000), Organisational Development in general practice: lessons from practice and professional development plans (PPDPs), *Family Practice*, December, Vol.1, (2), pp1471-1479.

Encarta Dictionary, (2007), World English Dictionary [North American Edition] http://encarta.msn.com/dictionary: Accessed 4.04.05.

Erickson, B.H. (19880, The relational basis of attitudes, in B. Wellman and S.D. Berkowitz (Editors) *Social structures: A network approach*, New York, Cambridge University Press, pp91-212.

Ezer J., Demetis D.S., (2007), Down with strategy: in defence of short-term thinking *Journal of Business Strategy*, Vol. 28, (1) pp57-62.

Fairclough N., (1989,) *Language and Power,* London, Longman.

Fleissbach, K., Weber B., Trautner T., Dohmen T., Sunde U., Elgar C.E., Falk A., (2007), Social Comparisons Affects Reward-Related Brain activity in the Human Ventral Stratum, Science, Vol. 318,(5854), pp 1305-1308.

Folger, R., Skarlicki, D., (1999), Unfairness and resistance to change: hardship as mistreatment, *Journal of Organizational Change Management*, Vol.12 (1) pp35-50.

Foucault M., (1982), The Subject and Power, *Critical Inquiry*, Vol. 8 (4), pp. 777-795.

Foundation of Nursing Studies, (2007) www.fons.org; Accessed 3.04.07 and 21.01.10.

Fullard E., Fowler G., Gray M., (1984), Facilitating Prevention in Primary Care, *British Medical Journal*, Vol.289, December Issue, pp 1585-1588.

Gates B, (2001), Valuing People: Long Awaited Strategy for people with Learning Disabilities for the Twenty-First Century in England, *Journal of Intellectual Disabilities*), Vol. 5; (3) pp203-207.

Gee J.P., Michaels S., O'Connor C., (1992) Discourse Analysis. *In* LeCompte M. D., Millroy W. L., Preissle J., (eds) *The Handbook of Qualitative Research in Education,* San Diego, Academic Press Inc., pp. 227-291.

General Assembly of the United Nations, (1948), *The Universal Declaration of Human Rights*, Adopted and proclaimed by General Assembly resolution 217 A (III) of 10 December 1948.

General Practitioners Committee, (2004), *Focus on Enhanced Services*, British Medical Association. www.bma.org: Accessed 2.9.07.

Giorgi A., (1997) The Theory, Practice, And Evaluation of the Phenomenological Method As A Qualitative Research procedure, *Journal of Phenomenological Psychology,* Vol.(28), (2), pp235-260.

Giraud-Saunders A.M., Gregory, G., Poxton, R.J., Smith, C. and Towell, D.,(2003), *Valuing health for all: PCTs and the health of people with learning disabilities,* Institute for Applied Health & Social Policy, King's College London.

Gilbert T., (2003), Exploring the dynamics of power: a Foucauldian analysis of care planning in learning disabilities services, Nursing Inquiry, Vol. 10 (1), pp37-46.

Giroux H., (2006) It Was Such A Handy Term: Management Fashion and Pragmatic Ambiguity, *Journal of Management Studies*, Vol.43, 6th September pp1227-1260.

Goh M., (2000) Quality circles: journey of an Asian public enterprise, *International Journal of Quality & Reliability Management,* Vol.17, (7), pp 784-799.

Gow P. B. S. Smith D. Ross D., (1999), Care co-ordination improves quality-of-care at South Auckland Health, *Journal of Quality in Clinical Practice,* Vol. 19 (2) pp107-110.

Grabowsky T.A., Farquar J.W., Sunnarborg K.R., Bales S.V., (1997), *Worldwide Efforts to improve Heart Health: A Follow-up to the Catalonia Declaration – Selected Programme Descriptions*, U.S. Department of Health and Human Services, p 49.

Gray DE, (2004), *Doing Research in the Real World*, London, Sage.

Greenhalgh L., (1994), *Well Aware. Improving Access to Health Information for People with Learning Difficulties,* Milton Keynes, Milton Keynes General National Health Service Trust.

Greig R., (2002), *Response to the Improvement, Expansion and Reform*, London, Valuing People Support Team.

Greig, R., (2003) Valuing People, Changing the Culture, *British Journal of Learning Disabilities*, Vol. 31, pp150-152.

Handy C., (1993) Understanding Organisations (Fourth Edition), London, Penguin.

Hanlon, G., (1998), Professionalism as enterprise: service class politics and the redefinition of professionalism. *Sociology,* Vol. 32, (1), pp43-63.

Harvey G., Loftus-Hills A., Ryecroft-Malone J., Titchen A., Kitson A., McCormack B., Seers K., (2002), Getting evidence into practice: the role and function of facilitation, *Journal of Advanced Nursing*, Vol. 37(6) pp 577-588.

Heidegger M., (1962), *Being and Time*, Oxford, Blackwell Publishers.

Helliwell J.F., Putnam R.D., (2004), The Social Context of Well-being, Philosophical Transactions, London, The Royal Society, p1435 -1446.

Hertting A., Nilsson K., Theorell T, Larsson U.S., (2004), Downsizing and reorganization: demands, challenges and ambiguity for registered nurses, *Journal of Advanced Nursing,* Vo. 45 (20) pp145-154.

Hitt M., Ireland R., (2002) The Essence of Strategic Leadership: Managing Human and Social capital, *Journal of Leadership and Organisational Studies,* Vol, 9 (1) pp3-14.

Hogg W., Baskerville N., Peterson C., Soto E., Martin C.M., Lemelin J., (2005), Improving the Delivery of Preventative Services in Primary care: A rationale for Outreach Facilitation, Priory Lodge Education, http://www.priory.com/fam/outreach.htm: Accessed 13.1.2008.

Hogg W., Lemelin J.,Graham I.D.,Martin C., Moore L., Soto E., O'Rourke K., (2007), Improving prevention in primary care: evaluating the effectiveness of outreach facilitation, *Family Practice*, Vol. 25 (1) pp40-48.

Holman A (2001), The Foundation for People with Learning Disabilities, Vol. 2004 www.learningdisabilities.org.uk: Accessed 9.09.06.

Housing Options (2008), Fact sheet 5, www.housingoptions.org.uk: Accessed 1.3.08.

Huckfeldt R., Beck P.A., Dalton R.J., Levine J., Morgan W., (1998), Ambiguity, Distorted messages, and Nested Environmental Effects on Political Communication, *The Journal of Politics*, Vol.60, No. 4. pp 996-1030.

Husserl E., (1917) Pure Phenomenology, its Method and its Field of Investigation (Jordan R.W. transl.), Inaugural Lecture at University of Freiburg, http://www.baylor,edu/_scott.

Husserl E., (1931) *Ideas: General Introduction to Pure Phenomenology.* Translated by W. R. Boyce Gibson. London, George Allen & Unwin Ltd.

Husserl E., (1965) Philosophy as a Rigorous Science. In *Phenomenology and the Crisis of Philosophy* (Lauer Q. Trans), Harper and Row, New York, pp71-147, Originally Published as *Philosophie als strenge Wissenschaft*

Hutchins D. (1982), Ringing the Bell with Quality Circles, *Management Review and Digest,* Reprinted on **www.hutchins.co.uk**: Accessed 15.07.05.

Ibarra H., (1993) Network Centrality, Power, and Innovation Involvement: Determinants of Technical and Administrative Roles: *The Academy of Management Journal*, Vol. 36, (3). pp. 471-501.

Illback R., Neil TK., (1995), Service Co-ordination in Mental Health Systems for Children, Youth, and Families: Progress, Problem, Prospects. *Journal of Mental Health Administration,* Vol. (22) (1), pp17-28.

Improvement and Development Agency, (2007) www.idea: Accessed 14.01.10.

Information Centre, National Health Service, Quality Outcomes Framework 2006/7, www.ic.nhs.uk/services/qof: Accessed 23.7.07.

Institute for Applied Health & Social Policy, (2003), *Valuing Health for All*, London, King's College, p54.

International Humanist and Ethical Union (2007), available at www.iheu.org: Accessed 17.12.07.

Into the Mainstream, (2007), www.intothemainstream.cswebsites.org: Accessed 4.04. 07.

Irwin L.G., Johnson J., (2005), Interviewing Young Children: Explicating Our Practices and Dilemmas, *Qualitative Health Research,* Vol.15 (82) p821-831.

Issing O., (2006), Central Bank Independence – Economic and Political Dimensions, *National Institute Economic Review*, Vol.196, (1) pp66-76.

Jackson SE, Schuler RS., (1985) A Meta-analysis and Conceptual Critique on Research on Role Ambiguity and Role Conflict in Work Settings, *Organizational Behaviour and Human Decision Processes,* Vol:36, pp16-78.

John P., Cole A., (1999), Political leadership in the new urban governance: Britain and France compared, *Local Government Studies*, Vol. 25 (4), pp98 - 115.

Jones J., Hunter D., (1995) Qualitative Research: Consensus methods for medical and health services research, *British Medical Journal,* Vol. 311. p376 - 380.

Jones T., Bishop B.W., (2004), *Stanislavski,* Dramateatro revista digital - número 11 /tercer año - febrero/abril 2004, available at http://dramateatro.fundacite.arg.gov.ve/sistema_stanislavski/sistema_stanislavski: Accessed 12.01.06.

Jones N., and Waddington E., (2000), Joint Investment Plans: Welfare to Work for Disabled People - A Workbook, Nuffield Institute for Health.

Juniper T., (2008), Acts of populism cannot conceal a lack of leadership, *The Independent,* March 13th 2008, http://www.independent.co.uk/.

Kahn, R. L., Wolfe, D. M., Quinn, R. P., Snoek, J. D. and Rosenthal, R. A. (1964). *Organizational Stress: Studies in Role Conflict and Ambiguity*, New York, Wiley.

Kan M.M., Parry K.W., (2004) Identifying Paradox: A grounded theory of leadership in overcoming resistance to change, *The Leadership Quarterly,* Vol.15, pp467-491.

Katrak P., Bialocerkowski A.E., Massy-Westropp N., Kumar S., Grimmer K.A., (2004), A systematic review of the content of critical appraisal tools, *BMC Medical Research Methodology,* Vol. 4 (22) Available from http://www.biomedcentral.com/1471-2288/4/22, (Accessed 23.08.2010).

Kelsey D., Spanjers W., (2004), Ambiguity in Partnerships, *Economic Journal,* Vol. 114 (497), pp 528-546.

Kilcher A., (2005), *The art of network facilitation*, Nottingham, National College of School Leadership.

King J., (2002), Effective facilitation, *British Medical Journal Career Focus*, p324:36-40.

Kleinman S, (2004), Phenomenology: to wonder and search for meanings, *Nurse Researcher,* Vol.11, (4), p16.

Kotter J.P., (1999), *What Leaders Really Do,* Boston, Harvard Business School Press.

Kruger D., (1979), *An Introduction to Phenomenological Psychology*, Cape Town, Juta.

Lammers J. Galinsky A.D., Gordijn E.H., Otten S., (2008), Illegitimacy Moderates the Effects of Power on Approach, *Psychological Science* Vol. 19, (6), pp 558–564.

Laverty, K. J. 1996. Economic "short-termism": The debate, unresolved issues, and the implications for management practice and research. *Academy of Management Review,* Vol. (21) pp825-860.

Laverty, S., (2008) Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations, *International Journal of Qualitative Methods,* Vol. 2, pp 21-35.

Layard R., (2005), *Happiness; Lessons from a New Science*, London, Penguin.

Lemelin J., Hogg W., Baskerville N., (2001) Evidence to action: a tailored multifaceted approach to changing family physician practice patterns and improving preventive care, *Canadian Medical Association Journal*, March 20, 164 (6), pp757-763.

Lewin, K., Lippit, R. and White, R.K., (1939). Patterns of aggressive behaviour in experimentally created social climates, *Journal of Social Psychology*, Vol.10, (1939), pp 271-301.

Lister R., (2001), New Labour: a study in ambiguity from a position of ambivalence, *Critical Social Policy,* Vol. 21, (4) pp 425 - 427.

Lopez KA, Willis DG, (2004*), Descriptive versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge,* Qualitative Health Research, Vol. 14 (5), p726-735.

Lukes S., (2005), Power: A Radical Review, (Second Edition), New York, Palgrave.

Lupia A., (2001), Delegation of Power: Agency Theory, *In* Smelser N.J. and Baltes P.B.,(eds.) *International Encyclopaedia of the Social and Behavioural Sciences,* pp 3375 – 3377.

Maggs-Rapport F., (2001), Best research practice: in pursuit of methodological rigour, *Journal of Advanced Nursing,* Vol. (35) (3), pp 373-383.

Markham S.K., Aiman-Smith L. (2001), Product Champions: Truths, Myths and Management, *Research-Technology Management*, Vol.44 (3) p 44-50.

Masterson A., Maslin-Prothero S., (eds), (1999) *Nursing and Politics; Power through practice,* Edinburgh, Churchill Livingstone.

Mays N., Pope C., (2000), Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal* 320: 50-52.

McGowan C., Neville R.G., Crombie I.K. Clark R.A, Warner F.C., (1997), The facilitator effect: results from a four-year follow up of children with asthma. *British Journal of General Practice*, Vol. 47, (March,) pp156-160

McGuire D., McLaren L., (2009), The impact of physical environment on employee commitment in call centres: The mediating role of employee well-being, *Team Performance Management,* Vol.15 (1) pp35-48

McIntyre R., Smith D.W., (1989), Theory of Intentionality.*In:* Mohanty J.N., and McKenna W.R., (eds), *Husserl's Phenomenolgy: A Textbook*, Washington DC,

Centre for Advanced Research in Phenomenology and University Press of America, 1989, pp 147 – 179.

McKenzie K., Whiteley R., Weich S., (2002), Social Capital and Mental Health, *British Journal of Psychiatry*, Vol.181 pp 280-283.

McKevitt D., Lawton A., (1994), *Public Sector Management Theory, Critique and Practice*, London, Sage, p167.

McNally S., (2004), Plus ça change: Progress achieved in services for people with an intellectual disability in England since the publication of Valuing People, *Journal of Learning Disabilities* Vol.8 (4) pp 323-329.

Meehan S., Moore G., Barr O., (1995) Specialist services for people with learning disabilities, *Nursing Times*, Vol. 91(13) pp32-5.

Mencap (2003), *Out of Sight Out of Mind,* London, Mencap.

Mencap, (2004), *Treat me right! Better healthcare for people with a learning disability,* London, Mencap.

Menacp, (2004) *'Valuing People' Review Submission,* London, Mencap.

Mencap, (2008*), Death by Indifference*, London, Mencap.

Menz F., (1999), 'Who Am I Gonna do this with?': Self-organization, Ambiguity and Decision-making in a Business Enterprise, *Discourse and Society*, Vol.10, 1, pp101-128.

Merleau-Ponty M., (1964), *The Primacy of Perception*, Evanston, North-western University Press

Meyerson DE, Scully M, (1995), Tempered Radicalism and the Politics of Ambivalence and Change, *Organizational Science*, Vol. 6 (5), pp585 – 600.

Michael Sir J., (2008), *Healthcare for All, Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*, London, Department of Health Publishing.

Miles M.B., Huberman A.M. (1984), *Qualitative Data Analysis: A Source Book of New Methods,* Newbury Park, Sage Publications.

Miles M.B., Saxl E.R., Lieberman A., (1988) What Skills Do Educational Change Agents Need? An Empirical View, Curriculum *Inquiry,* Vol.18 No. 2, pp157-193.

Mir G., Allgar V., Cottrell D., Heywood P., Evans J., Marshal J., (2007), *Health Facilitation and Learning Disability,* Leeds Institute of Health Sciences, University of Leeds.

Moss S. Turner S. (1995) *The Health of People with Learning Disabilities,* Hester Adrian Research Centre, and University of Manchester.

Moustakas C., (1994*), Phenomenological Research Methods,* Thousand Oaks California, Sage Publications.

Muir Gray J.A., (2004), Evidence Based Policy Making, *British Medical Journal,* 329(7473): 988-989.

Nagykaldi Z., Mold JW., and Aspey C.B.; (2005) Practice Facilitators: A Review of the Literature, *Family Medicine* Vol.36, (8) pp581-588.

NHS Confederation (2009), *Shaping Personal Budgets, A View from the Top,* London, NHS Confederation Publications.

NHS Employers, (2009), *Clinical Directed Enhanced Services Guidance for General Medical Services Contracts,* London, NHS Employer.

Office of the Deputy Prime Minister, (2004), *What is Supporting People?* London, Office of the Deputy Prime Minister.

Office of National Statistics, (2003), *Social Capital, Measuring Networks and Shared Values.* www.statistics.gov.uk: Accessed 17.022005.

Organization for Security and Co-operation in Europe, (1996), *The Lisbon Summit Declaration*, European Commission, Brussels.

Orton M., Ratcliffe P, (2005), New Labour Ambiguity, or Neo-liberal Consistency? The Debate About Racial Inequality in Employment and the Use of Contract Compliance, *Journal of Social Policy*, Vol.34, (02), pp 255-272.

Osborne J., Erduran S., Simon S., (20040, Enhancing the Quality of Argumentation in School Science, *Journal of Science Writing,* Vol. 41, (10), p994 -1020.

Pandey S.K., Rainey H.G., (2006), Public Managers' Perceptions of Organizational Goal Ambiguity: Analyzing Alternative Models, *International Public Management Journal*, 1559-3169, Volume 9, Issue 2, 2006, Pages 85 – 112.

Parliamentary Joint Committee, (2004), Joint Committee on the Draft Disability Discrimination Bill: First Report, www.parliament.uk/parliamentary_committees/dddb.cfm: Accessed 15.05.06.

Piderit, S.K. (2000, Oct). Rethinking resistance and recognizing ambivalence: a multidimensional view of attitudes toward an organizational change. *Academy of Management*, Vol.25 (4) pp 738-794.

Plsek P.E. Wilson T., (2001), Complexity, leadership, and management in healthcare organisations, *British Medical Journal,* Vol. 323, 29 September, pp 746-749.

Prasad R., (2003), *Where There's a Will*, Guardian 26.11.2003.

Prochaska, J.O. & DiClemente, C.C. (1982) Transtheoretical therapy: Toward a more integrative model of change, *Pscychotherapy: theory, research and practice,* Vol.19, pp. 276-288.

Prunty J.,(1985), Signposts for a critical educational policy analysis, *Australian Journal of Education,* Vol. 29 (2), pp133-140.

Puligandla R., (1970), Phenomenological Reduction and Yogic Meditation *Philosophy East and West*, Vol. 20, (1), 1970), pp. 19-33.

Raven B.H., French J.R.P., (1958), Legitimate Power, Coercive Power, and Observability in Social Influence, *Sociometry*, Vol. 21 (2), pp. 83-97.

Rizzo J.R., House R.J., Lirtzman S.I., (1970) Role Conflict and Ambiguity in Complex Organizations, *Administrative Science Quarterly*, Vol. 15, No. 2 (Jun., 1970), pp. 150-163.

Robbins, B. (2001), Association of Directors of Social Services, Vol. 2004.

Robinson N, (1999), The use of focus group methodology – with selected samples from sexual health research, *Journal of Advanced Nursing*, Vol. 29, pp905-913.

Robson C., (2002), *Real World Research*, Oxford, Blackwell.

Rogers CR, (1969), *Freedom to Learn*, Columbus, Charles E. Merrill.

Rogers C (1980), *A Way of Being*, Boston, Houghton Mifflin.

Royal College of General Practitioners, (1981) *Prevention of Arterial Disease in General Practice,* Report from General Practice, No19.

Royal College of Nursing, (2009), *Understanding Benchmarking*, London, Royal College of Nursing.

Russell B., (1938) Power, A new social analysis, London, George Allen and Unwin Ltd.

Saaty T.L., (1996), *The Analytic Hierarchy Process*, New York, N.Y., McGraw Hill, 1980, reprinted by RWS Publications, Pittsburgh, 1996.

Sandberg S., (2008), *Symbolic capital and linguistic practice in street culture* University of Bergen, http://hdl.handle.net: Accessed 5.12.09.

Sayers R., (2006*), Principles of awareness-raising: Information literacy, a case study,* Bangkok, UNESCO.

Seifert C., Yukl G., McDonald R., (2003), Effects of Multisource Feedback and a Feedback facilitator on the Influence Behaviour of Managers Towards Subordinates*, Journal of Applied Psychology*, Vol.88, (3), pp561 – 569.

Shepsle KA., (1972), The Strategy of Ambiguity: Uncertainty and Electoral Competition, *The American Political Science Review,* Vol. 66 No. 2, June, p555-568.

Shinn G., (2002), 15 Waste Scenarios, *Quality Progress,* pp67 -73, http://asqcincinnati.org/Library/change/15WasteScenarios.pdf: accessed 7.12.07.

Sim J, (1998), Collecting and analysing qualitative data: issues raised by the focus group, *Journal of Advanced Nursing*, Vol. 28, p345 -52.

Snelgrove-Clarke E., Scott-Findlay S., (2005) Foetal Health Surveillance: The use of research evidence in practice*, Association of Women's Health, Obstetrics, and Neonatal Nurses (AWHONN) Lifelines* Vol.9 (5), pp 400-403.

Solesbury W., (2001), *Evidence Based Policy Making: Whence it Came, and Where it's Going*, ERSC UK Centre for Evidence Based Policy, Queen Mary University of London.

Sooben R.D.(2004). 'Valuing People' with learning Disabilities in the Context of the Human Fertilisation and Embryology Act 1990: Social Policy and Legislative Incompatibility, *Journal of Learning Disabilities* Vol. 8, pp 107 – 112.

Spiegelberg H., (1975), *Doing Phenomenology,* Dordrecht, The Netherlands, Martinua Nijhoff.

Stetler C.B., Legro M.W., Ryecroft-malone J., Bowman C., Curran G., Guihan M., Hagedorn H., Pineros S., Wallace C.M. (2006), Role of 'external facilitation' in implementation of research findings: a qualitative evaluation of facilitation experiences in the Veterans Health, Administration, *Implementation Science,* Vol.1, (23), pp1-23.

Strang D., Baron J.N. (1990), Categorical Imperatives: The Structure of Job Titles in California State Agencies, *American Sociological Review*, Vol. 55 (4) pp. 479-495.

Statistics Finland, (2006), Social Capital in Finland – Statistical Review, www.stat.fi/socialcapital: Accessed 12.02.10,

Sudha X., (2008), Transformational, transactional and laissez-faire leadership, *Journal of Health Organization and Management* Vol.22, (6) pp. 599-613.

Swartz D., (1997), Culture and Power: The Sociology of Pierre Bourdieu, Chicago, The University of Chicago Press, p75.

Szreter S., Woolcock M., (2004), Health by association? Social capital, social theory, and the political economy of public health, *International Journal of Epidemiology,* Vol.33, pp 650-667.

Talib F., Ali M., (2003) Impact of Quality Circle—a Case Study, *Institute of Engineers Journal,* Vol. 84, pp 10-13.

Tan B.C.Y., Wei K., Lee-Partidge (1999), Effects of facilitation and leadership on meeting outcomes in a group support system environment, *European Journal of Information Systems*, Vol.8, pp233-246.

The Care Standards Act (2000), London, Her Majesty's Stationary Office.

The Department of the Premier and Cabinet (2000), *The Queensland Policy Handbook*: *Governing Queensland Good Policy Content,* Queensland Government, Australia, www.premiers.qld.gov.au: Accessed 12.11.06.

The Disability Rights Commission Act (1999), Chapter 17, London, Office of Public Sector Information.

The Health Act (1999), Section 31, London, Her Majesty's Stationary Office.

The Human Rights Act (1998), Her Majesty's Stationary Office, London.

The National Health Service Plan, (2000), London, Her Majesty's Stationary Office.

The National Health Service and The Health Care Commission, (2007), *The 'Better Metrics' Project, Version 8,* London , Health Care Commission.

The Race Relations Act (1976), London, Her Majesty's Stationary Office.

The Race Relations (Amendment) Act (2000), London, Her Majesty's Stationary Office.

Thomson K., Gripton J, Lutchmiah J., Caan W., (2007), Health facilitation in primary care seen from practice and education, *British Journal of Nursing*, Vol.16, (18) pp1156-1160.

Toulmin S. (1958), *The Uses of Argument*, Cambridge, Cambridge University Press.

Van Manen, M., (1990), *Researching lived experience: Human science for an action sensitive pedagogy,* New York, SUNY Press.

Warner L., Ford R., (1998) Mental health facilitators in primary care, *Nursing Standard*, Vol. 13 (6) pp36-40.

Warnke B., (1987), *Gadamer: Hermeneutics, Tradition and Reason,* Cambridge, Polity Press.

Watts D.J., Strogatz S.H., (1998) Collective dynamics of 'small world' networks, *Nature,* Vol. 393 pp440-442).

Webb J., Schirato T., Danaher G., (2002), *Understanding Bourdieu*, London, Sage Publications,

Wells P., (2007), New Labour and evidence based policy making: 1997-2007, *People, Place & Policy Online* (2007): 1/1, pp22-29, http://extra.shu.ac.uk/ppp-online: Accessed 10.11.09

West E., Scott C., (2000), Nursing in the public sphere: breaching the boundary between research and policy, *Journal of Advanced Nursing,* Vol. 32, pp817 - 824.

Williams J., (2009), The Profound and Multiple Learning Disability Network (2009), pmldnetwork@ldforums.org: Accessed 4.06.09.

Williamson A., Johnson J., (2004), Improving services for people with learning disabilities, *Nursing Standard*, Vol.18 (24), pp43-45.

Wilson B., Karlin D., (2005), *Don't Hate Meetings, Make Them More Effective,* www.businesslistening.com: Accessed 23.08.06.

Woolcock M., (2001) The Place of Social Capital in Understanding Social and Economic Outcomes, *ISUMA - Canadian Journal of Policy Research*, Vol.2 (1), p11-17.

Yardley Honess A., (2010), Frances Buss and Edward Thring: Teachers, Professionalism and Organisation, *Reflecting Education,* Vol. 6 (1), pp. 39-48.

Zabid M., Rashid A., Sambasivan M., Rahman A.A., (2004), The Influence of organisational culture on attitudes to organisational change, *Leadership and Organization Development Journal,* Vol. 25 (2) pp161-179.

Zimring F., (1994), *Carl Rogers (1902-1987), Prospects: the quarterly review of comparative education*, Vol. XXIV, No.3 /4, Pages 411-422.

Zott C., Huy Q.N., (2007), *How Entrepreneurs Use Symbolic Management to Acquire Resources*, Technology, Innovation and Institutions Working Paper Series, University of Bergen.

APPENDICES

West Midlands Multi-centre Research Ethics Committee

Chairman: ***Dr J Rao***
Co-ordinator: ***Mrs A McCullough***

27 Highfield Road
Edgbaston
Birmingham
B15 3DP

Tel: 0121 245 2544
Fax: 0121 245 2519

26 July 2005

Mrs. C.Glynis Whitehead
Adult Health Team Leader
Learning Disability Service Burnley
Pendle and Rossendale PCT
Balladen House, Rossendale Hospital
Rawtenstall
Lancs. BB4 6SL

Dear Mrs. Whitehead

Full title of study: **A phenomenological examination of the role of health facilitation in learning disability services.**
REC reference number: **05/MRE07/49**

The Research Ethics Committee reviewed the above application at the meeting held on 20 July 2005.

Ethical opinion

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

No local investigator status

The Committee agreed with your declaration that this is a "no local investigator" study. Site-specific assessment is not required for sites involved in the research and no information about the study needs to be submitted to Local Research Ethics Committees. However, you should arrange for the R&D Departments of all relevant NHS care organisations to be notified that the research will be taking place before the research commences.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Application	4.1	24 June 2005
Investigator CV	1	24 June 2005
Protocol	1	24 June 2005
Covering Letter		24 June 2005
Copies of Advertisements	1	24 March 2005
Participant Information Sheet Interview	1	24 March 2005
Participant Information Sheet Reference Group	1	24 March 2005
Participant Consent Form Interview	1	24 March 2005
Participant Consent Form Reference Group	1	24 March 2005
Basic Data Form	1	24 March 2005
RGEC Approval Letter		10 January 2005
Research Design Template	1	24 March 2005

Research Itinerary	1	24 June 2005
Recruitment Screening Tool	1	24 March 2005
Supervisor's CV	1	24 June 2005
Serious Untoward Incident Policy	1	24 June 2005
Trust Approval Letter	1	24 June 2005
Topic Guide	1	24 June 2005
Research Protocol Flow Chart	1	24 June 2005

Management approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research at a NHS site must obtain management approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Membership of the Committee

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

Notification of other bodies

The Committee Administrator will notify the research sponsor that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/MRE07/49	**Please quote this number on all correspondence**

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

Your sincerely

Anne McCullough [Mrs] *on behalf of*
Dr Jammi Rao
Chair

Email: anne.mccullough@bbcha.nhs.uk

Enclosures:

Attendance at Committee meeting on 20 July 2005
Standard approval conditions

SF1 list of approved sites

Burnley, Pendle & Rossendale

Primary Care Trust

INFORMATION SHEET

(Interview)

1. Study Title

A Phenomenological Examination of the Role of Health Facilitation in Learning Disability Services

2. Invitation

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. The purpose of the study

Glynis Whitehead, a PhD research student at Salford University, under the supervision of Professorial Fellow Dr. Duncan Mitchell, is conducting this study. The study stems from a personal interest in people with learning disabilities; their health; social policy, and its interpretation by practitioners. It intends to focus on the how the concept of 'health facilitation', as introduced in the 'Valuing People' White Paper (2001), is being interpreted by those professionals who have a health facilitation role. By identifying and describing particular interpretations of health facilitation, it is anticipated that the study will make a valuable contribution to the body of knowledge around the health facilitation model and the perceived effects of the 'Valuing People' policy upon this particular area of service provision.

4. Why have you been chosen?

You have been chosen as a prospective participant in this research project for a number of reasons:

- You have been identified as having experience of health facilitation via the Valuing Support Team in your region, one of the Learning Disability Networks, or you have responded to an appeal for participants made in the Learning Disability Press.

- Health facilitation is either whole or part of your current role.
- You are currently practicing in one of the 'Valuing People' Support Team regions.

5. Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

6. What will happen to you if you take part?

You will be asked to participate in a semi-structured interview that will be taped and later transcribed for analysis. It is anticipated that the interviews will last for approximately 1 hour and will take place in your own locality. The interview questions will be open in nature and based on a topic guide that will be sent to you prior to the interview taking place.

7. What are the possible disadvantages and risks of taking part?

There are no anticipated risks related to this study. It has achieved Ethics Committee approval and will be supervised throughout. Participation will be purely voluntary and you will have the right to withdraw at any time. Post interview, you will have the opportunity to ensure that the themes emerging from your interview accurately reflect the views you expressed. If any problems do occur however, the researcher will refer and/or consult with appropriate resources, up to and including the researcher's advisor.

8. Will there be any possible benefits in taking part?

You may benefit both personally and professionally from your participation in this study as a result of engaging reflectively on your practice. The information obtained from this research may make a valuable contribution to the body of knowledge around the health facilitation model and the perceived effects of the 'Valuing People' policy upon this particular area of service provision.

9. Will my taking part in this study be kept confidential?

All information collected about you during the course of the research will be kept strictly confidential. All researched data will be anonymised and stored securely within a locked filing cabinet in the researcher's place of work. Access will be restricted to the researcher, the researcher's supervisor, who will check on the accuracy of the researcher's transcription. No information that could identify you will be released and at the end of the study all tapes and transcripts will be destroyed.

10. What will happen to the results of the research study?

The results of the study will be written up and made available to the study's participants. It will be also be accessible to health facilitators, service users, carers, and health and social care practitioners on request. It is anticipated that aspects of the report may be offered for publication both locally and nationally via journals and conferences. No one participating in the study will be identified in any report or publication.

11. If you are having difficulty in understanding any aspect of this information sheet what should you do?

If you are having difficulty in understanding the information in this information sheet, please telephone me on 01706 233214 and I will endeavour to provide the appropriate assistance.

12. Contacts for Further Information

If you have any questions related to this study, please address your questions to the following people:

Glynis Whitehead (Research Student)
Tel. No. 01706 233214
E-mail: C.G.Whitehead@pgr.salford.ac.uk

Dr. Duncan Mitchell (Research supervisor)
Tel. No. 0161 295 2372/2426

Dr. Nancy Lee (Advisor)
Tel. No. 0161 295 2372/2426

Thank you for taking the time to read this information sheet and considering taking part in this study. The information sheet is yours to keep and a signed copy of the consent form will be given to you should you agree to take part in the study.

Burnley, Pendle & Rossendale

Primary Care Trust

Centre Number:
Study Number:
Participant code:

CONSENT FORM
(Interview)

Title of Project: A phenomenological examination of the role of health facilitation in Learning Disability Services

Name of Researcher: Glynis Whitehead

Please initial boxes

1.I confirm that I have read and understand the information sheet dated ..... for the above study and have had the opportunity to ask questions. ☐

2. I understand that the interview will be recorded on audiotape to facilitate the collection of information and that all information I provide, will be held in confidence and I will not be identified in the thesis, summary report, or publication. I understand that I may withdraw this consent at any time, without penalty, by advising the researcher. ☐

3. I agree that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous. ☐

4. I understand that my participation is voluntary and that I am free to withdraw at any time. ☐

5. I understand and agree that the tape recordings made at the time of the interview and the subsequent transcripts, may be examined by individuals approved by Salford University, or other regulatory authorities, where relevant. ☐

4. I agree to take part in the above study.

Name of Participant:

Signature:

Date:

Name of Researcher:
C. Glynis Whitehead

Burnley, Pendle & Rossendale

Primary Care Trust

PARTICIPANT INFORMATION

(Reference Group)

1. Study Title

A Phenomenological Examination of the Role of Health Facilitation in Learning Disability Services

2. Invitation

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. The purpose of the study

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4. Why have you been chosen?

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- You have been identified as having experience of health facilitation via the Valuing Support Team in your region.
- Health facilitation is either whole or part of your current role.

5. Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason

6. What will happen to you if you take part?

You will be asked to participate in 2 reference group meetings during which you will be asked to consider a number of themes relating to health facilitation for people with learning disabilities. It is anticipated that each of these meetings will last approximately 1 – 1½ hours. Meetings will be recorded on audiotape, a summary of which will be given to each member of the group.

7. Are there any possible disadvantages and risks involved in taking part?

There are no anticipated risks related to this study. It has achieved Ethics Committee approval and will be supervised throughout. Participation will be purely voluntary and you will have the right to withdraw at any time. If any problems do occur however, the researcher will refer and/or consult with appropriate resources, up to and including the researcher's advisor.

8. Will there be any possible benefits in taking part?

You may benefit both personally and professionally from your participation in this study as a result of engaging reflectively on your practice. The information obtained from this research may make a valuable contribution to the body of knowledge around the health facilitation model and the perceived effects of the 'Valuing People' policy upon this particular area of service provision.

9. Will your taking part in this study be kept confidential?

Your participation in this study cannot be kept totally confidential given that you will be participating as a member of a Reference Group along with a number of other people. However, confidentiality in relation to the content of Reference Group meetings will be an issue addressed within the group. All information collected by me about you, and your contributions during the course of the research will be kept strictly confidential. All researched data will be anonymised and stored securely within a locked filing cabinet at my place of work. Access will be restricted to me, and my supervisor. No information that could identify you will be released.

10. What will happen to the results of the research study?

The results of the study will be written up and made available to the study's participants. It will be also be accessible to health facilitators, service users, carers, and health and social care practitioners on request. It is anticipated that aspects of the report may be offered for publication both locally and nationally via journals and conferences. No-one participating in the study will be identified in any report or publication.

11. If you are having difficulty in understanding any aspect of this information sheet what should you do?

If you are having difficulty in understanding the information in this information sheet, please telephone me on 01706 233214 and I will endeavour to provide the appropriate assistance.

12. Contacts for Further Information

If you have any questions related to this study, please address your questions to the following people:

Glynis Whitehead (Research Student)
Tel. No. 01706 233214
E-mail: C.G.Whitehead@pgr.salford.ac.uk

Dr. Duncan Mitchell (Research supervisor)
Tel. No. 0161 295 2372/2426

Dr. Nancy Lee (Advisor)
Tel. No. 0161 295 2372/2426

Thank you for taking the time to read this information sheet and considering taking part in this study. The information sheet is yours to keep and a signed copy of the consent form will be given to you should you agree to take part in the study.

Burnley, Pendle & Rossendale

Primary Care Trust

Centre Number:
Study Number:
Participant code:

CONSENT FORM
(Reference Group)

Title of Project: An examination of the role of health facilitation in Learning Disability Services

Name of Researcher: Glynis Whitehead

Please initial boxes

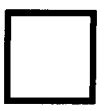
1. I confirm that I have read and understand the information sheet dated ..... for the above study and have had the opportunity to ask questions. ☐

2. I understand that the meetings will be recorded on audiotape to facilitate the collection of information with the understanding that all the information I provide will be held in confidence and I will not be identified in the thesis, summary report, or publication. I understand that I may withdraw this consent at any time, without penalty, by advising the researcher. ☐

3. I agree that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous. ☐

4. I understand that my participation is voluntary and that I am free to withdraw at any time. ☐

5. I understand and agree that the tape recordings made at the time of the reference group meetings, the subsequent transcripts and summaries, may be examined by individuals approved by Salford University, or other regulatory authorities where relevant.



4. **I agree to take part in the above study**.

Name of Participant:

Signature:

Date:

Researcher Name:
C. Glynis Whitehead

Burnley, Pendle & Rossendale NHS
Primary Care Trust

A Phenomenological Examination of the Role of Health Facilitation in Learning Disability Services

Recruitment Screening Tool

Criteria	**YES**	**NO**
In which of the following Valuing Support Team Regions? ▪ North East ▪ Yorkshire & Humberside ▪ East Midlands ▪ Eastern ▪ South East ▪ London ▪ South West ▪ West Midlands ▪ North West		
Is the potential participant currently undertaking health facilitation as part, or, whole of their role?		
Which of the following applies to the potential participant? ▪ Male ▪ Female ▪ From a minority ethnic background		
What is the potential participant's occupational background?		
How long has the potential participant been involved in Learning Disability Services?		

Checklist for Preparation for Interviews

When preparing to conduct interviews you should feel confident about answering 'yes' to the following questions:	
Is the interview method appropriate in terms of: • The topic of the research? • The need for detailed information? • Access to informants? • Enough time allocated for the interviewing?	
Do I have a clear vision of the issues to be discussed during the interview?	
Am I confident that 'self' and personal identity (age, gender etc.) will not prove a major obstacle to getting informants to respond openly and honestly during interviews?	
Have I obtained authorisation from the appropriate authorities to conduct the interviews?	
Am I clear about what criterion has been used for the selection of informants?	
Has a suitable time and place for the interview been arranged?	
Is there a time limit for the interviews and are all parties aware of this limit?	
Has consideration been given to the most suitable mode of self-presentation?	

TOPIC GUIDE

(INTERVIEW)

a. The model of health facilitation used when working with, and on behalf of, people with learning disabilities.

b. Understanding of the role of 'health facilitator'.

c. The practice of 'health facilitation'. What does it involve?

d. Influences on the ideas about the way health facilitation should be practiced.

e. Measurement of the health gains and outcomes of health facilitation.

f. Establishing the client's own experience of health facilitation, and their perspective on its impact on their health.

g. The impact health facilitation has had on the commissioning process.

h. Challenges presented by health facilitation and how these have these been overcome.

i. The impact of health facilitation on the health of the individuals with learning disabilities.

j. The impact of health facilitation on mainstream health care provision.

The order of the questions will flexible allowing you to develop, and me to follow up issues within the list of topic or subject areas.

Topic Guide – Reference Group Meeting

Influences of role interpretation
The professional background, age, years of experience, and level of education of health facilitators, influences the way in which they interpret their role.

Many health facilitation posts are temporary in nature, and therefore time constraints can influence the facilitators' priorities.

Poor or constantly changing management is a feature in the lives of health facilitators and affects how they see their role.

Health facilitators have experienced:
Some degree of difficulty when expected to function at both a strategic and a person-to-person level.

A degree of confusion at the 'person to person' level in relation to:
* The role of the health facilitator
* The differences between 'health care' and 'nursing care'.

A lack of sufficient authority to bring about changes in practice within primary care settings.

Difficult working relationships with community nursing teams..

Health facilitators think that:
When working at a strategic level, that they would be best placed, and more effective, within a generic Primary Care Trust environment.

The concept of 'person centredness' is not fully understood in relation Health action plans.

Little support is available to those people with learning disabilities who are not in receipt of supported services, in order to help them achieve, and maintain healthy lifestyles.

Encouraging GP practices to take on board the 'Valuing People' targets on board has been mostly ineffective.

There is a currently a lack of serious monitoring of the impact that health facilitation has made to date on: the health and well being of people with learning disabilities; to the primary and secondary care sector, and the commissioning process.

Code Number: T15

Interviewed by: Glynis Whitehead

Transcribed by: Glynis Whitehead

Side 1

R: I've given you a bit of information about me, so it would be really helpful if you could tell me about your background, and how you've got from where you started, to be working in the area of health facilitation, if that's alright?

P: That's fine, just to clarify that, today I'm not working as a health facilitator, my secondment ended September last, I'll go back to the beginning, I'll start off by, I trained as a learning disability nurse in the _____ *(locality)* worked in _____ which was our learning disability hospital, then came out, got a community post, and worked in some residential and went back into community. I always retained an interest in health, and we were one of the first areas to go into an integrated service, but it wasn't particularly well managed it was all, one day, you know, we were all still based in the building with social workers, so it was almost like, well one day you're just working together, and the next day you're integrated you're an integrated service, you know the single assessment, there were benefits to that but there were some negatives. And some of the negatives were that as nurses we felt we were losing our health focus. What I tried to do, at that time, which was a few years ago was to get like minded nurses together to have kind of some focus groups just to retain a professional interest in health and health services, and we'd do things like, erm, share good

practice, and maybe if we'd done some good work with GPs anyway, what the kind of current research was, what the themes were coming out, it was just an interest group, because we thought we were in danger of losing some of that. Because social services have the lead now, they are the lead agency. So from that I kind of, you know when I was hearing about *Valuing People* and health facilitation, I found that it was very much an interest for me. _____ then became one of the sites that was chosen for the project around access to health and _____ *(name)* was part of our project support team, and they set up a erm, a steering group, if you like to steer that project. And I was aware of that going on but didn't really have any contact with it other than, (*short pause)* they did have a focus group for nurses to find out from nurses locally, learning disability nurses that is, what they felt *Valuing People* would do for us, how it could be interpreted, and what our response would be, what we thought about it etcetera etcetera. So that was kind of my first exposure to the project if you like, and erm, from that point on people decided that they needed to put someone in post on the ground level to carry out some of the aims and objectives from *Valuing People* and then from health facilitation. So they advertised, it was a year's secondment initially, and it was open to community nurses if I remember correctly and they would be answerable to this steering group while the project was going on from the King's Fund. So I applied. I was successful in getting that, and it was erm, it just felt when I look now at the job description, it was so very big, but as was everything, as was the guidance. Erm, so it was very much left to me to make it my own and my initial thoughts were *how do you start?* But I had the steering group behind me, so we then decided we would, because we had *Valuing People* we had a Valuing People

Officer in post as well, so we agreed that we would have another health group, another health task group and I was the lead on that and that would be kind of a way of getting things together and we that would be the start point for us, looking at a framework, the health action plans, and health facilitation. So that was kind of, that's how I got there, and that was kind of my starting point for my secondment. The secondment, it was a joint funded post between health and social services erm, and because our Trust was all for integrated teams, social care and health, I'm still employed by the Trust as well. So it was joint funded, and for a year initially. We then started going through the PCT, planning and performance profiles just to put in bids for money the post? We weren't successful until the third year I think it was, in getting some funding and then it was only (*unclear on tape*) so it felt like an on-going battle really. We're very much left in the hands of social care and health to fund the post, and then we basically ran it until September this year. And we felt like we'd done some kind of work in the task group to make it more, we knew my post wasn't going to be everlasting if you like, but it felt like it was cut short, it felt like there was still so much to do. So in the first year, it was (*short pause)*, I suppose it was just me getting to grips. _____ and _____ *(localities)* had six PCTs, and six localities and integrated teams. _____ *(locality,* although part of the Trust, is an independent authority. Erm, and I, eventually, initially I worked into _____ as well, but they agreed then, part of the learning disability Partnership Board that they were going to do their own work.

R: Are they a Unitary Trust?

P: Yes, they are, so I still have links with _____ but they are going to go on and do their own thing. So I worked across the five PCTs and localities in our area. Until September that was kind of the focus of my work, around the access to mainstream erm, working with the acute trust, the university hospital, and working with our own learning disability service to make health facilitation and health action plans tangible really. Initially I would say, it sounded quite focused, it sounded quite easy, but the more I got into it I found more things that I was being drawn into.

R: Right, such as?

P: Erm, anything to do with health whatsoever, absolutely anything to do with health. I literally did it all from being involved in pulling the framework together, to consultation with service users, my role was also interpreted as doing all of the health action plans for every single person we had, which was just impossible, erm, education and training, anything at all, that had anything to do with health at all, even when it came down to continuing health care funding for the PCT, somebody from the PCT would say *Oh is that _____'s job to do?* So it tended to keep, whenever, if learning disabilities and health was mentioned, you know, in the same sentence, it kind of came to myself, so it was difficult to keep thinking *hang on get this focus back.* So although there was a focus on the King's Fund Project, it then just became a bit wild after that, it was kind of *it's your remit to carry out the Valuing People objectives.*

R: And where did that come from?

P: That really came from, from our Partnership Board if you like, that I would do the lead on those. Yeah, so now I'm back in my substantive post as a

community nurse, but I've managed to agree that, within my capacity, that I have a special interest in and take the lead within my particular patch, which is now _____. So it's still doing it but in my own locality if you like, which, perhaps is a bit more manageable. It was almost a strategic post, but it wasn't advertised as that, I think we kind of, it was shaped as we went along really the post. I don't think there was a lot of thought went into it initially, or direction initially either it was kind *of we need some help we need someone to do the job.* I wasn't quite sure what the job was going to look like at that moment in time.

R: What would you say the influences were then on how it shaped up, and where did they come from?

P: They came very much from; we've got a good learning disability Partnership Board. We had good leadership on the board, and it was well represented with service users, and carers, so there was a lot of influence from them. We also in _____ *(locality)* set up ..... (*trailed off*). The Partnership Board recognised that it often failed to do some of the hard business, although there was recognition that everything should come through Partnership Board all decision making .... (*short* pause) was almost all the realism about ..... (*short pause)* we talked about the finances, and we talked about budgets, and we talked about the kind of big issues where people have to make a bigger decision. There needs to be a core group that does that and the independent head of commissioning services, PCT leads all sit on that board, so they also influenced and shaped my role. My line manager was the county wide commissioner, and although she erm, managed the learning disability integrated service she was also trained as a learning disability nurse so I felt

like she had some understanding of some of the issues and was very well versed. So it was really kinda of, I would say between the Learning Disability Partnership Board, the *Valuing People*l ocal officer _____ *(name)* who is our *Valuing People* Regional Officer, and the integrated service core group and the PCT leads.

R: Quite a lot of fingers in that pie then?

P: There was yeah, yeah. And then of course there was like the huge issue of consultation with service users and carers as well. We had some kind of representation groups set up so I would kind of dip into to those. The first ... (*short pause*) one of the first things that I did, because I just felt *where's the direction?* And *what, what do I do first? How do I start first?* Erm we asked _____ *(Colleague from another area)* to come up and do a day with us as an external facilitator really, and we invited _____ who was the PCT lead. When I talk about leads I'm talking about Learning Disability leads from each PCT. We invited all of those. We didn't get one of them to attend I have to say. We got a couple of the commissioning managers to come, and service representation came, how many of those did we get? We had one GP with a special interest came. We just kind of, our in house providers came along. We tried to get representation from everyone across county _____ *(locality)*, if you like, who, had a part to play in ensuring health for people with erm, and carry out health facilitation, we tried to get all those together for a day. We did a bit of like a SWAT analysis then we kind of looked at what we could build on, what we needed to go back to, and that was really, really helpful. We kind of

used that as a focus for our framework really, that, that, was the building blocks of that.

R: That's really interesting. What I'd like to move on to now _____ is how it's panning out on the ground floor.

P: My 'strategicy' bit, part of my role was then to make it happen.

R: How did you make it happen? What did you do?

P: We, from that day we'd kind of then looked at where erm, where people accessed health and what services we had in place currently to support people with their health. And we felt like we couldn't, just kind of, go down the one shop route and say *this is how we will offer people health action plans, this is how we (unclear on tape)* it felt too big to just do it that way. So we kind of looked at what we already had, and we had a one PCT which was willing to go down the annual health check route and to an enhanced payment scheme for that. That's the area I'm in now. Erm, we had erm, we had interested groups who wanted some education, we had some district nurses and groups of people with some forums and people ere *saying come and tell us how we can make changes.* Erm, then we had our care co-ordination model, which is our integrated model we do a single assessment whether it be social work or nursing and offer people a care plan. Ad we also had some very interested service users groups who wanted to kind of spread the word and do some work amongst themselves and have their own health conferences. So those kind of, were the areas we thought *Right, we can go in and make something happen within those.* What I also kind of quickly recognised was that I couldn't do everything there was no extra money. So I had to make some links with at least

five localities. Erm, so what I agreed with the team managers, learning disability integrated teams, was that I had one link nurse in each locality who would kind of fit under me with the work that would come out of the task group and [they] would help to filter that information through and would be a point of contact in their locality, for PCTs, with the GPs. We did flyers letting every individual practice know that this person from the learning disability team. It didn't mean making referrals necessarily to the services but they would be a point of contact and if the practice wanted help that was the way to do it.

Erm, the care co-ordination, we actually built into the care co-ordination document, erm, the offer of health action plans, initiating, within the initiation step, we filled in a kind of a very basic health assessment, but it had to be done, not only by nurses or other health professionals, but also by the social worker as well, because of being an integrated service. So we looked at the ten key points and made sure that our basic first initial assessment covered those and would then signpost. We were trying to get the message across that it wasn't, that facilitation wasn't implementation, but it was signposting the people in the right direction and supporting people. So that's the kind of the big messages we were trying to get through. We also had a around the same time of my post, erm, had someone come into post to lead on person centred planning and set some priorities around erm, day services modernisation. And we also had re-provision from our posts. So I felt we had to tap into that as well and kind of try and make everything fit together. So I worked very closely with the person centred planning co-ordinator and we built into the person centred planning training an element of health action planning awareness as well. And again, not saying to people *you are a health facilitator, you can do all of this*, but to make

sure they, you know, were aware where to signpost people to. Erm, you know I then gave out some packs, some information packs, with some proformas around *this is what it looks like.* I left some examples around, supporting evidence, if you like. Erm, the re-provision at _____ at the time was very, much alive and GPs, receiving GPs of people coming into community were a bit anxious that there was a lot of people coming onto their books that they knew very little about. Erm, they were being passed over with not particularly good medical records, and not good health histories. So we all saw that every single person that was re-provided for coming out of _____ had a baseline health assessment. We used the OK health check at the time, and then developed a Health action plan for them, and that was great 'cos I could, I had some influence over that but it wasn't my responsibility to do it. We had two nurses working with the health staff at the hospital to do that work. And all of that information went off to the receiving GP before they moved out, so it was to kind of give them a baseline. And we got into, I got in to a few GPs practices on the back of that to *say these are the issues that people with learning disabilities have* (*unclear on tape*) *one to one if you're ready for education sessions.* Erm, you know, (*unclear on tape*) I felt a bit like kind of bible bashing at times, like knocking on doors saying *We're here* and *this is how we can support you* and try alleviating some of the fears. So it was all of those things really _____ *(researcher's name)* it was just trying to erm, recognise what we had at a ground level, kind of recognise where people accessed health services and to try and tap in to all of those things. I think we are still very conscious that we don't, well (*short pause)* God, that was the other thing we were trying to do, erm, that's what I was initially tasked to try and do, develop the register of

people with learning disabilities. And although we have a social services data base here it's very, it's, it was optional for people to be on the register, the learning disability register, erm, and it wasn't particularly well managed, information about the data, 'cos I thought when I came into post I'll be able to go out and say, *here's what we've got*, and make sure that (*unclear on tape*) register to GPs. You know at the end of my post I was still doing that work, I started trying to do these three years ago and it still felt like a chore. Read codes and everything I thought *Oh my Lord, it's a nightmare*. Erm, but you know, we still recognised that we don't know all of the people in _____ *(locality)* we don't know that we've hit all the people. But we did some big publicity things around putting stuff in *Carer's Echoes*. Erm, putting things in local PCT newsletters, the big PR around my post, what I was hoping to achieve, inviting anyone who had had good experiences and bad experiences whatever to contact me. And the service users, they had like, an annual conference that they organised themselves, that they agreed and decide the focus, and for two years running the main focus was around health. And so, so that was another good platform, if you like, to inform people about health action plans. Erm, I'm still not sure that we, it seems to have to be an on-going thing, and I think kind of part of the worry about having a person in post was that everything got passed my way, but having lost that post that's my concern now, that role, where is that going? And how do you keep up the continuity and the (unclear on tape) But we put a few things in place that hopefully will help.

R: That's a great shame. How did you evaluate what you had done? You were given this list of things to get on with, were you able to say what you'd achieved?

P: Not specifically in terms of health outcomes. I found that really difficult to do, I mean and the area in _____ *(locality)* where we, were we had the LES it was only really came into place at the beginning of this year, January this year, so I'm kind of working with both practices still to look at how many people, it wasn't just for learning disability, they also did it for mental health, erm, to find out how they invited people in, and what about people with complex needs, what about those who didn't respond to an invitations, erm you know, what about those people with very complex health needs and physical disabilities, what did they do about that? None of those questions have really been answered yet. They've agreed that we can do some on-going work, but at the minute the kind of outcomes we're getting are *Oh we've done so many health checks*, but there's not really enough data in that to find out what has been beneficial, what difference has it made, what things have you picked up? Erm, so I did find the outcomes very difficult the only things I think we could do is kind of look at our framework and look at the things we wanted to have achieved and I think we kind of, it was very much qualitative rather than quantitative it was you know, service users would come and knock on my door, or would make a call, or people would contact me, carers would get in touch erm, they were very supportive continuing the course so if there was messages in that itself, that way. But in terms of actually hard evidence, I found it extremely difficult to do. I mean what we did, what I did manage was to try and hopefully get (*pause*) the people that we did, you know, about registers, GPs and people that we erm, that we were aware of to make sure of that that GPs where aware, that they knew that they had a learning disability erm, and we kind of we did a lot

around the education so we felt that almost leaving a bit of a legacy, as much as erm, any real hard outcomes.

R: Tell me _____ in what way were you able to tap into the public health agenda at all, in terms of the NSFs and, you know, the stopping smoking and what have you?

P: In that there was a lot of people around who had provided information erm, who would perhaps talk to groups, and they would listen to me, like they very much invited me to go and talk to them, but I didn't see any difference in practice as a result of that, they would take on board the issues for people with learning disabilities and there was, I think that was the thing, I don't think there has been anything across the board. There's been a couple of individuals who have took a really keen interest in said *Oh, my goodness, the evidence around us, this is terrible, we must do something about that*, and have gone out of their own ways to influence, and to take that information back and to maybe look at how the information they were giving out needed to be made it a bit more accessible or ensured that you know, health professionals working with learning disabilities have access to their services, but there's nothing that I'm aware of where there's been a real change in practice. I used to find it quite astounding, I remember going to the PCT and seeing how large the public health departments were but found that we weren't having any slice of the action really, whatsoever. They say *Oh well there's information here* but it's still inaccessible. The one area that was very good was our (*unclear on tape*) public health, the health promotion department. They were very good in getting resources for us and buying things in that we'd recommended, circulating their

resource lists for us to make people aware that there was this information out there. Erm, but in terms of coronary heart disease I'll send out any bit of information that I could glean that gave evidence about people with learning disability I would send ,but I don't think, I think our numbers were so small that it just didn't hit them hard enough really. I mean it was really surprising to find that when it starts affecting the star rating that when the thing for the registers came out that was all of a sudden there were so many calls, and that was in my last couple of months in the job and it was like you know, these are the things that we've been trying to home in on, erm, but all this time and I think that's kind of been one of the big, (*pause)* I think we've all kind of, oh you know, (*short pause) Valuing People* and the guidance around Health action plans, it just didn't seem to have those teeth that we needed to make a difference really, it all felt very much down to good will and getting to know, getting to know personalities and the people that you could chip away at. That's very much how it's felt to me, kind of chipping away and I know we made some small differences for individual people and but in terms of it being really hard hitting, I don't think it has been, and I know the guidance was written with intent that it would be flexible enough so you could mould it and shape it, but I don't think it gave us anything to kind of bash people over their heads with really.

I mean I did feel a little bit at the time that my post was kind of tick in the box and the PCTs were like, *we've got a health facilitator* and it's like, you're just not getting it, you know. I have to say that there were some very good individuals that kept taking things back. Certainly a lot of the leads were trying desperately to look at, they really felt the GPs would go for the incentive scheme that was on offer. I struggled, morally and ethically, I really struggled with that, but I kind

of came round to the way of thinking well, if we get someone a health check and that picks up things then it gets the GP practices to recognise people, and then maybe ask for some help and it's a way forward, and that just seems to be the way of the world. 'Cos we've promoted that quite a bit and as I say one PCT managed to erm, to look at it's funding and agree to that payment mechanism. But the others were very keen on it they just couldn't get the funding. And I've left them with, you know, they've all got written proposals to do that should they now be in a position to reapply for funding. But now of course there's the issues of the PCTs merging now and so it feels like it's gone by a little bit again.

R: It would be such a shame if all that was to get lost due to PCT mergers. In terms of commissioning services then for people with learning what has been achieved? How have you been able to influence commissioning decisions?

P: I don't think we have, I think we've been, there's that feeling of being listened to, and patronised almost, you know, kind of patting us on the head and saying *Oh, we're hearing you, we're hearing all the problems but we're not in a position to do anything about it.* As I say, I think it's kind of very much been around good will and individual achievement really, you know, having someone who's really, interested to take it on board, and I guess that's where it kind of, you know the day to day, one to one health facilitation has worked. Erm, I feel like I've had a ... (*short pause*) I really questioned my post after three years it was difficult to kind of keep putting bids in for funding because I kept thinking *what evidence have I got to say I'm making a difference?* You know, people are being invited to all of these meetings and I'm going along, I felt like you know (*trails off).*

_____ *(name)* of the _____ network was a Godsend

because anything I got through, I was sort of sifting through, trying to summarise it, send it out erm, you know it felt like just a constant flow of information, but it rarely felt like anyone went *Oh, this is interesting, what can we do with this?,* you know. Erm, that's not to say some or some practices were like, *Tell us how we can work better* you know? The _____ hospital we set up, and I still attend, a specialist interest group, but we had to do that on the back of a couple of complaints, they had been so badly treated and that was kind of the way of getting through the door, but I became quite ruthless really, I just think, well, you know, hit them with this and see if they get something. That was the only way, but they've continued that and they've now got the head of patient experiences who takes the lead on that, and they are trying to develop better services but even (*unclear on tape*) mandatory training. We have to keep coming back to we're quite small population, and the only time we seem to really hit hard at the PCTs is with the continuing health care funding, and they are expensive packages of care, and that seems to be the only time they ask any questions. Erm, you know, compared to our mental health services we're really small, you know what they are saying, the PCTs are kind of saying *Oh you've all this re-provision going on where we're doing so much now for people in the community, we can't possibly take any more on, and we're barely managing what we've got.* The district nurses are struggling, and it just felt like we're always last in line.

R: It sounds as though you are saying that it has been a bit disheartening?

P: Mm. But then, you would get a really good group of active service users who would say *we know more about health.* We make sure that, when I say we I'm

talking about myself leading the Task Group, you know, we made sure that we made a response to the Mencap consultation, to the Disability Rights consultation, erm, you know, to have a voice, that way, erm, and to be fair, a lot of our services users were saying *we're getting an ok service from our GP's*, you know. I think _____ *(locality)* was quite fortunate in that we didn't have big problems in terms of making sure everyone was registered, because we're quite small really, we're not a big city, erm, and fortunately, or unfortunately, most people with learning disabilities do get some kind of service from health or social care, so generally they're known and we have a fairly static population. Erm, in terms of, I've tried to do some work around ethnic minorities, we have a very big Chinese community in _____ *(locality)* and we're making some inroads into that as we speak, and I blame us as an authority for that because we tend to go *we don't have many people*, which is true, but it doesn't make it that the people we have don't have needs, you know. But you know, we don't have the same problems as say Manchester but it's been our get out as well.

R: Thanks _____, erm, I'm looking at our topic guide and I think we've covered all aspects of it. So let me see if I can sum up what you've been talking about up to this point. You've told me about your conferences, and your groups with clients and the individual feedback you've had about how your role as a health facilitator has made an impact. Erm, we've had a look at the commissioning process, we've talked about mainstream, hospitals and GPs. Have I captured everything so far?

P: Pretty much.

R: So let me ask you the how do you think health facilitation has impacted on you as a practitioner?

P: I think in many ways really, I think one of the big ways was that I thought, you know, if and when, I go back to be a community nurse/care co-ordinator my practice would be very different. I think previously I tried to not be one of those types, but I'm sure I did erm, be very protective and think *this is my population I know best* and protect the mainstream because I think we've almost created this gap ourselves, you know, by going and I think as learning disability nurses we kind of go i*s this our role, is this our role?* So we filled in a lot of the gaps ourselves so I think we did some damage there. Erm and I think we weren't very transparent in what it was that we did do around health and promoting ourselves. I think as kind of going back as a practitioner into this role, my personal practice would be very different, and I think also that determination to influence the mainstream, to look at hard evidence, which again I know I'm not very good at, I can give anecdotal evidence, but I don't think I ever kind of saying, *do you realise that by not treating this person?* You know. And I don't think I was erm, oh, confrontational enough really erm, I've learnt, why I think we, I don't think I appreciated how primary health care worked, or how secondary health care worked, or how PCTs worked. I thought I did until I started working as a strategic health facilitator, or whatever you want to call it, and that was a massive learning curve for me. I thought I understood the NHS and I didn't at all and that, and I think that's kinda something that comes back to our local education centres. As learning disability practitioners come through we need to know more because we keep blaming other people that they don't understand us but I don't think we understand them.

R: We all understand our own bit don't we?

P: Yeah, sounds like we need to know more about that process works in order to influence. Erm, I think, looking at kind of joint working, and shadowing, and the forums very much differently. So it has had a massive impact in all kinds of ways both as a kind of going back to being a practitioner, but I think about understanding the needs of people with learning disability, and understanding some of the barriers to health care that I just didn't particularly pick up on.

R: What have been the biggest barriers you've faced?

P: Attitudes, attitudes and assumptions, people assume that someone else is doing the job erm, and this kind of diagnostic overshadowing because they've got a learning disability, I think those have been the biggies really. Erm, and there's some other stuff you know, around just kind of technology [in surgeries], that we just don't know what to even think about, you know, kind of: some of the ways of having this little diddy screens up in practices that rely on you to be able to read your name. They are put them there to preserve people privacy and dignity rather than holloring down the corridor you know, i*t's your turn.* It's just, you know, that's reliant on someone being able to read. And some of these complicated telephone systems that we have in place now; complicated appointment systems not being able to make appointments in advance for people and it's a lot of the things like, you just accept, and people just assume someone else is doing it, that facilitation if you like. And I think that's been part of the other thing about health facilitation and health action plans, a lot of it has been going on, and I think it threw a lot of people going into a panic about *Oh my God, this is something different and something new*, but hang on, if you kind

of look at how you work now, about what you do, you actually do some of this, you know. I was talking to some; I went to talk with a group of social workers the other day because they were tying themselves in knots about health care co-ordinators. They initiate health action plans and they signpost people and try and get someone to facilitate and I just think by the nature of it they're doing holistic assessments, by nature of looking at someone's health , by nature of you going saying to the consultant *this person needs a medication check*, I said *you're doing it*, you know, that y*ou're doing that work*, it's that. But, it's 'cos when you read the guidance, again I keep coming back and reading it 'cos I'm saying *have I missed something*, It's almost like so simple that it's complicated but it's not how we work I don't think in the learning disabilities services, I think it's how we fit into, I don't think we've kept up with the rest of the world almost. Erm, so we don't speak the same kind of language and I found that really these were the barriers for me, and the other thing I assumed that when I went to talk to a couple of the Chief Execs. of the PCTs who were very open to me talking about my post and what I was going to do and what they could do to support and (*unclear on tape*) Erm, I thought that the PCTs would kind of, there's this organisation where you would speak to the Chief Exec. and they would influence. What I hadn't appreciated was that it was like number of little businesses kind of carrying on under one roof and you have to go round them all and get into them all and none of them functions the same as the next door neighbour so it was like, oh, it was just so complex I found it difficult.

R: Your post has gone now, although it feels like, I mean you were in it three years and it sounds as though you've achieved a lot in three years, but what is there still left to be done?

P: I hope it's made into a substantive post. I do kind of hope and I think what makes me live in hope is I keep getting these little phone calls saying, *Oh _____ can I just?* I'm like n*ot really,* that needs to go back though the Task Group which I'm still part of but they kind of lead for that group has gone back to our *Valuing People* Officer who kind of has the lead for all of the task groups if you like erm,

R: Was that the commissioning manager?

P: Yeah. No, not the county wide commissioning manager, we actually had in post, we actually had in post a *Valuing People* Officer whose remit was just around implementation of *Valuing People* task groups. So it's gone back to him to kind of chair and lead on, but part of it, I keep thinking *no you must do it this way.* But by the very nature of getting those calls, erm, a guy from one of the PCTs rang me just a couple of weeks ago and said he'd been asked to do this work one day a week, could I kind of go through everything that I'd done previously? And I kind of put him in touch with the LD forum now and things like that. So it feels like, it's just that feeling that I'm just on the first rung of the ladder almost, and you know, because I never envisaged nor should I have had input forever. The idea was for everyone to be, you know, good health to be everyone's business with people with learning disabilities and I would sort of be playing a part in it. But it just feels like I hadn't quite got there. But we've still kind of got this notion of there being a link nurse if you like, from each of the integrated services in post. We're trying to set up a parliament system for service users. So we're looking at a kind of minister for health from that bit of work that's on-going. Erm, the Partnership Board, the service users on the

Partnership Board, wrote to the PCTs and you know said *really we want some answers about what happens now to this post. Who is going to carry it on*? And I think they'll be very good in not letting things lie, if you like.

R: That's excellent.

P: It's as long as we've got learning disability Partnership Boards you know, it's still feels very fragile. Erm, I, you know, I kind of think when we got *Valuing People Oh five years, we've got five years* and that just like yesterday. It's gone in a flash hasn't it, it's now nearly 2006.

R: Makes you think doesn't it?

P: Mm.

R: How do you think achievements will checked up on 2006?

P: Well that was the thing wasn't it with the whole health agenda, wasn't it? It was like, it was very much on goodwill because there was no incentive to particularly do anything, no-one was going to rap your knuckles if you didn't, so the PCTs were really quite honest in going *we just haven't got the capacity*, you know, *we haven't got the capacity* but the annoying thing was they, you know, it was relatively small funding for my post, I mean, The _____ *(locality)* kind of, their get out if you like was *well we've put money into the LES*.

R: What's the LES?

P: This local enhanced scheme, the incentive payment. So I'm like, *it's great that you've done that, however how are you going to make sure (unclear on tape) communicate particularly well, it may be with elderly carers who get very*

confused, and who's going to interpret that health check for that, and you know, how are you going to get a urine sample? It's like *hang on, who's going to do all of that?* Yeah you know, your GPs getting a hundred pounds, but who's going to do that kind of work? It's like well, won't the community nurses from the teams, you know they are care co-ordinators working in an integrated service, so it's like we're creating more gaps again.

R: How come your nurses got changed from nurses to care co-ordinators?

P: It was through the Health Act Flexibilities. As individuals, as nurses, we all kind of take that view you know, I'm trained as a nurse and if someone needs an epilepsy assessment, if they need some in-depth work doing round their behaviour, if it's around cognitive work, then that needs to be my focus. And I think we've now all got enough strength and I think now there's kind of, again when I was in my role strategic role, I kind of tried to say to nurses *this health facilitation could be very valuable to us and could be a way of strengthening the role of the nurses.*

Side 2

P: I just felt that it could be a really, you know, I had visions of it being something we could hold up of value really. And I'm disappointed in the way that hasn't kind of panned out. Er, the integration seems to have got better as we've gone on I have to say. It was horrendous at first we were all up in arms just 'cos .... (*trails off)* And then we then have our assistant director of nursing from the Trust came in post and we went to her and said we thought professionally er, we felt we were almost being fraudulent in signing up to be honest for our registration, because we're not doing nursing roles and tasks. We accept those

nursing roles and tasks have changed over the years and we need to work very differently, but we're not doing those things so we kind of we got some forums together and some professional development forums erm, and we said what we thought we should be doing as nurses and that was kind of gone back to the team manager, we are meant to be operational. We had a _____ *(name).*

R: I've heard that name, is she from the department of health?

P: Yeah. We invited her to one of our nursing forums, I think as a bit of a boost for ourselves, because a lot of the nurses in the Trust had become very worn down, and they just used to think *come in and get on with it, what's the point in arguing?.* Social services has taken over so what's the point. So we used that as a bit of motivation as well. Erm, and I think again with that it was kind of chipping away trying to do our role, chipping away and I think with regret, we're starting to see some of the backlashes if you like, you know our consultant psychiatrists are saying *we can't have community nurse input, why should that be?* So they're starting to ask some questions. So I think it's kind of ever evolving, that's all I can say for that, I think. At the outset we didn't have, (*pause*) morale was extremely low.

R: So if you've got this tension between care co-ordinators actually being a community nurse, what room then is there for health facilitation?

P: Well I've asked for that, you know, when I came back into the team I think about what I was doing, if you paid me at H grade for three years you know, if you

want to just let all of that go, all those skills and information go to waste then that's down to you. Erm, and I would suggest that we don't, and that has been taken on board, so I've pretty much got erm, I haven't got a reduced case load but they try to put the more complex health needs my way, if you like, within our allocations and erm, I've got a good enough relationship I think to kind of say to the team manager *this is what I'd like to do.* I'm not saying that it will always get agreed but to date it's kind of going ok, and I certainly asked for it to be put on the agenda of the local planning groups, and the lead for learning disability for our PCT comes along to that and for the December meeting I've asked if I can go and ask them *what's happening with this incentive scheme?*. You know we asked him to come and do a presentation to the Partnership Board, which he did, it's quite fortunate that I'm back in that area so that I can kind of say *well how can I support you,* you know.

R: So you are just going to have to find different ways of doing what you were doing?

P: Yeah, and do it smaller. In some way I kind of think, *should we have started smaller? Should we have tried to crack it in one locality, and then gone out to the five?* I think at the time we thought if we have a strategic post, if we get the top layer right, but it never worked out that way as you just got pulled into the operational and everything.

R: Thanks _____ you seem to have covered all the points I wanted to bring up. Erm, but is there anything that you wanted to tell me that I haven't asked you, I

wouldn't really want to bring the interview to a close and not having given you the opportunity to include all the points that are important to you?

P: No I don't think so. I think we've covered everything. I think like the big thing was the power issue. I think it was just that thing about not really having any power, I think that was the biggy, you know, I set out with great guns thinking *Oh, you know, you're getting to do all of these things*, I had to keep going thinking you know, *I have achieved you know, I have achieved.*

R: It sounds like you achieved an awful lot.

P: But it's just it feels like I haven't done enough and you feel like you kind of lost in the darkness really.

R: Somebody once said to me that they felt like pilgrim in a foreign land.

P: That's it exactly, and I think if I was coming into the post now it would be very different because as the three years have progressed there's obviously more posts similar to mine have been springing up erm, the _____ network meetings have been invaluable, but I wish we'd had some power behind it, and I wished we'd had some real influence, I wish there had been some real hard hitting messages from the Department of Health some must do's, rather than would you like to do's? It would have been nice.