Can people labelled as having learning difficulties and high support needs design and plan the services that they use?

A case study report of the Kirklees User Involvement Network

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Abstract

The paper addresses issues pertaining to the inclusion of people with the label of learning difficulty and high support needs in the design and planning of the services they use. The paper takes as a basis a Network of User Involvement groups in West Yorkshire which the author works within. Through using a social model analysis and through exploration of user involvement theory and the self advocacy movement the author examines how the guidelines in the recent government white paper Valuing People not only encourages consultation with people who uses services on all levels but also creates barriers through restrictive deadlines to meaningful involvement being achieved.

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Chapter 1

Introduction

The Kirklees User Involvement Network is a Network of people and groups of people who have the label of learning difficulty. It has a specific remit with respect to consultation and as such encourages and supports Network members to be involved in the running and management of the Network.

The Network aims to ensure that people who have the label of learning difficulty have the opportunity to participate in the development, planning, commissioning, service delivery and evaluation of health and social care services. The Network aims to support people throughout this process.

The Network aims to empower people who use services. It aims to ensure that the process of consultation and participation is effective and reflects the views of a cross-section of people who have the label of learning difficulty and who live in Kirklees.

My involvement with the Kirklees User Involvement Network has changed during the course of the research. My initial role was to act as a facilitator in the consultation process, preparing material for consultation in formats that were accessible to the members of the network and organising meetings where people could get together and discuss consultation documents. This role has altered since the Co-ordinator of the project left. It is now my role to both co-ordinate the consultation process and to act as facilitator.

People labelled as having learning difficulties and high support needs

The purpose of this paper is to examine facilitation of the consultation process for a specific group of people within the group of people labelled as having a learning difficulty. The medical professions use the term profound and multiple learning disabilities to refer to this heterogeneous group of people. This term is used by the world health organisation (WHO, 1992), and is defined using normative testing criteria and a list of the persons perceived limitations and impairments. This use of terminology is negative and individualistic. Through stressing only the perceived limitations that the person has it disregards the persons abilities and the fact that society is the main oppressing force, not the body (this will be further explored in chapter 4).

I will be using the term people labelled as having a learning difficulty who have high support needs, as this label, I feel, best demonstrates that the barriers to the person participating in society are lack of a supportive, inclusive society and not individual limitation. For clarity I will further elaborate that the term high support needs refers to people who may not use words or conventional communication methods to communicate. They may have physical and sensory impairments in addition to a label of learning difficulty. They may have additional labels such as challenging behaviour or autism (PMLD, 2000). This use of terminology is in line with Values Into Action advice (Beamer, 2001) and is consistent in part with the social model of disability.

Many other labels are ascribed to this section of the population and there is little or no consistency regarding which word or groups of words are chosen. The PMLD Network (2001) identified that within the white paper Valuing People at least nine different terms are used which are assumed to refer to the group of people who have high support needs. This lack of consistency of terminology can only serve to increase the exclusion experienced as confusion arises in whom is being referred to. Recommendations from people who are concerned that people with high support needs are at risk of exclusion are that it is necessary to agree on terminology (e.g.. PMLD Network, 2001; Beamer, 2001, Naken et al, 2002) so that everyone is clear who is being included in policy and service provision. In a truly inclusive society it would not be necessary to label people to emphasise difference. However for so long as people are marginalised because of their differences it is of fundamental importance that they can access the support that they require to reduce exclusion.

Of course it will take more than consistent labelling to reduce the degree of exclusion experienced by people with the label of learning difficulty and high support needs. It is essential to identify the organisational and procedural barriers to inclusion in addition to assumed attitudinal barriers. As will later be discussed, work to remove these barriers may need to take the form of training for organisations in identifying what these barriers are and in the development of policies which are people led, not time and money led.

Why look specifically at people who have the label of learning difficulty and high support needs?

Studies of the experiences of people in long stay institutions suggested people who used limited or no verbal communication were generally considered the least ’intellectually’ able, and received less support than people who could speak up for themselves (e.g. Tilstone et al., 1998). As a result people labelled as having learning difficulty and high support needs often led lives described variously as unfulfilled, lonely or bored (e.g. Sanderson et al., 2002). People with this label are amongst the last people to be discharged from long stay institutions (Lacey, 1998) and on discharge are given the least choice over where they live, who they live with, and the manner of support they receive (PMLD, 2000)

As previously discussed the marginalisation of people with the label of learning difficulty and high support needs is considerable within the population of people who have the label of learning difficulty. This mean that people who have this label are the most marginalised in society (PMLD, 2000). Despite this recent government initiatives (DoH, 2001) aimed at reducing the barriers to inclusion by people who have been labelled as having a learning difficulty set no specific objectives for this hugely oppressed group of people. Chapter 3 discusses the department of health’s 2001

White Paper '*Valuing People: A New Strategy for Learning Disability in the 21st Century' in* more detail.

Given that people who have the label of learning difficulty and high support needs appear to be sidelined within government policy it is pertinent to look at statistics to explore how many people have this label. Searches of the internet and recent literature uncovered no recent surveys of adults with this label, most literature coming from education of school age individuals (e.g. Male, 1996; Lacey et al, 1998; Lacey, 2001).

In 1984 a study by Friars of school age children found 1 in 1000 to have a label of learning difficulty and high support needs (PMLD, 2001; Friars not cited in PMLD references). It is generally agreed amongst professionals working with people who have the label of learning difficulty that people with high support needs are the largest growing section of the population. The reason for this increase in the population is assumed to be linked to advances in medical science which have lead to more premature babies surviving and more people living longer with the aid of assistive technologies (Carpenter, 2000).

In summary:

1) People with the label of learning difficulties and high support needs are the most marginalised section of the population,

2) People labelled as having a learning difficulty and high support needs are amongst the largest growing sector of the population.

Thus I can justify dedicating this piece of writing to examining the involvement of people who have this label in the services which are provided for them.

The primary research question: “Can People Labelled as Having Learning Difficulties and High Support Needs Design and Plan the Services they Use?” will be answered through examining the following secondary topics:

Chapter 3 will outline the social policy background to the research. Looking specifically at the government white paper Valuing People (DoH, 2001) I will explore how it supports people with the label of learning difficulty in general, and with the label of learning difficulty and high support needs in particular to live inclusive lives through.

In Chapter 4 the theoretical background to the research is introduced, drawing heavily on the literature from disability studies I look at the relevance of social model theory to the lives of people labelled as having a learning difficulty. I then draw on my experience and research to examine some of the barriers experienced by people with the label of learning difficulty and high support needs in the design and planning of services. Aspects of social model theory are then utilised throughout the text to highlight where societal barriers are occurring.

Chapter 5 introduces the wider concept of User Involvement, outlining the history of User Involvement in theory and practice. Within this chapter the key arguments regarding User Involvement as raised by disability studies academics are discussed with respect to the Kirklees User Involvement Network. Here I will demonstrate that whilst many of the arguments levelled at User Involvement in general do not apply to the Kirklees User Involvement Network there remain significant barriers to people who have the label of learning difficulty and high support needs being involved in planning and design of their services.

Chapter 6 looks at the self-advocacy movement, and at some practical and legal considerations regarding decision-making. I look at the polarisation of people who are labelled as having learning difficulties within the self-advocacy movement. Here I specifically consider the participation of people who do not use conventional communication methods within the movement.

In Chapter 7, the conclusion I bring together the preceding discussions to answer the primary question “Can People Labelled as Having Learning Difficulties and High Support Needs Design and Plan the Services they Use?” I will demonstrate that whilst people with this label can design and plan the services they use, the barriers present in organisational structures and prevailing negative attitudes are preventing this participation. I argue that it will involve a shift in the way that services are designed, planned and run before meaningful participation can be achieved by all who wish to participate.

The following chapter sets out some of the methodological techniques used to explore the research question.

Chapter 2

Methodology

Ethnographic approaches

Ethnography is an approach related to social anthropology. It uses three main methods of study: participant observation, unstructured interviews and document analysis. It is used as a tool for analysis of a culture rather than as a tool to generate a theory (Lacey, 2001). It is therefore a useful approach to analyse the participation of people labelled as having learning difficulties and high support needs within the Kirklees User Involvement Network.

As with any approach the ethnographic approach has weaknesses. Its strengths lie in its realism, the researcher becomes a part of the culture, but it's this narrow realism which is also a weakness. The ethnographer becomes the primary source of data, (Massey, 1998). Again this is both a strength and a weakness. The ethnographer is able to focus on the aspects of the culture being studied, and will have as data more than his/her field notes. In addition the issue of (mis)interpretation of data is minimised, as it is interpretation of one's own notes. The weakness is, however the potential lack of objectivity (Massey, 1998; Lacey, 2001). Through an ethnographic case study, observations are limited in their generalisability; the researcher is bound to be subjective.

In the current situation, my role as participant observer is worth some discussion. As the person responsible for facilitating the consultation process I am exploring my own working practice and looking at where it is lacking in terms of consulting with people labelled as having learning difficulties and high support needs. Just as introducing a researcher will effect the environment to be studied, so will increasing the level of reflective practice. An increased awareness of situations within the network where barriers exist to people labelled as having learning difficulties and high support needs being included will prompt me to find new ways to overcome these barriers. Thus a complementary analysis of the organisational structure and the time constraints that I work within will be necessary in order to determine what level of consultation is possible.

The participation of an ethnographer in the culture being studied is assumed to finish when the researcher has collected enough data (Massey, 1998). Thus ethnographic studies should be to a varied time scale. In this instance the research has a fixed time scale, and my involvement with the culture will continue, when the research period is over. This will undoubtedly effect the research, and my working practice.

Hamel et al (1993) sees participant observation as the key to good ethnographic case study analysis. Here participant observation is described as the gradual integration of the researcher into the culture.

Can this style of research be emancipatory?

A prerequisite of emancipatory research is that the ‘subjects’ control the research (Barnes, 2003; Kierncan, not dated). In the current example the user involvement network dictated the research question and dictated to a large extent how it should be answered. By this I mean that the research question was generated through observation of where the social unit was failing to include members, and the method of research was dictated by the access I had to the network, and the time scale. Thus although the research was researcher led and not ‘subject led’ it was undoubtedly internally driven. By working to a strict time scale it is not possible to conduct emancipatory research, it is the nature of internally generated research that it generates its own questions and therefore necessarily requires a flexible time scale.

Furthermore, whilst the outcome of the research should directly benefit the participants, insomuch as it will effect my working practice, the main beneficiary is myself as the researcher, who will potentially be gaining a qualification through it.

It has been argued that all research is empowering by virtue of the data generated (Barnes, 2003) and that whenever research results in representation of the voices of ‘unheard’ peoples to a larger audience this is a political act (Massey, 1998). Thus in this instance the research has emancipatory aspects through representing an oppressed group and through the generation of data about this group. Were the research conducted in greater consultation with people with the label of learning difficulty and high support needs it would be closer to an emancipatory approach, with researcher as activist, representing the voices of the marginalised group. As will become clear, this research looks at how the voices of people labelled as having learning difficulties and high support needs can be more effectively listened to on the policy and organisational level. Thus it examines how to represent the voices of others or how they can be supported to advocate for themselves, as opposed to representing the voices of the people who have the label of learning difficulty and high support needs per se.

The Research Process

As discussed an ethnographic approach was taken to see how the Kirklees User Involvement Network is successful or otherwise in its inclusion of people with the label of learning difficulty and high support needs and to explore in what ways it can be improved.

I have used my reflective practice notes dating from January 2003 to July 2003; this covers a total of 10 Network User Involvement meetings. I also attended a conference entitled Not For Us, With Us. This was organised by Values into Action and was advertised as a conference to explore ways to support people labelled as having learning difficulties and high support needs in self-advocacy. During this conference I took detailed reflective notes, with the aim of learning new ways to improve facilitation of consultation for people with the label of high support needs and learning difficulties. In addition I asked at the conference for examples of good practice, where meaningful inclusion is occurring with people with the label of learning difficulty and high support needs.

As will later become apparent whilst a lot of useful contacts were forged, and my creativity towards my work was stimulated, it was difficult to find pockets of good practice in terms of supporting people with the label of learning difficulty and high support needs in service planning, delivery, design or review. I thus attempted to gather information about good practice through contacting the valuing people support team. The feedback from this correspondence is used throughout the text.

In the spirit of ethnographic research, I also examined national policy documents which impact on the lives of people with learning difficulties and high support needs on the macro level, and looked at whether barriers to meaningful inclusion were created through restrictive job descriptions, time scales for consultation, or budgets on a micro level.

I undertook a programme of extensive reading into the background of the self advocacy movement, and tried to focus my reading to examine the inclusion or otherwise of people with the label of learning difficulty and high support needs within this social movement.

Thus I have been able to study the micro-social units known as the North Kirklees User Involvement Network, and the Huddersfield User Involvement Network, and have situated these Networks, within the local and national policy structure.

The Kirklees User Involvement Network is person centred. Changes to the Network are made through the Network committee which consists of people with the label learning difficulties. It is, however, part of the job descriptions of both project staff to “ensure the voices of people with profound and multiple learning disabilities are heard.” Thus, should the Network Committee make decisions which in some way exclude people with the label of learning difficulty and high support needs, it is my duty to advise the committee of this and seek to reach more inclusive options, or whether a parallel, inclusive solution is possible. This has meant that through the research process, discovering alternative ways to support people who have the label of learning difficulty and high support needs I have been able to discuss the practicalities of implementing theories and have gradually been able to alter the working practices of the Kirklees User Involvement Network to reflective inclusivity.

The advantage of researching one’s own working practice is the opportunity of being able to use the research as it arises, thus the research can have a direct effect on the case study. Clearly issues of objectivity arise, and I must concede that there are bound to be issues which I have missed due to being too closely involved in the project. This being accepted, I suspect that I have also been super-critical of where inclusion is not being achieved. I do not see this as a research failing, as I believe that there are no compromises to inclusion.

This chapter has addressed some of the theoretical and practical possibilities and limitations of the research design. The chapters that follow address the major political and theoretical structures underpinning the research and apply each structure to the case study.

Chapter 3

Valuing People: A New Strategy for Learning Disability in the 21st Century

This chapter outlines the policy framework that the Kirklees User Involvement Network exits within.

The launch of the white paper *Valuing People: A New Strategy for Learning Disability in the 21st Century'* (DoH, 2001) was the first major strategy designed specifically to improve the lives of people labelled as having learning difficulties since Better Services, 30 years previously (DHSS, 1971). Better Services recommends a move away from the containment of people with the label learning difficulty and towards support in the community. It suggests that public sympathy needs to increase for this to occur successfully. It clearly regards people who have been labelled as having a learning difficulty as in need of care, and it has as an appendix a section on the prevention of impairments which can result in a person being labelled as having a learning difficulty. It thus implies, albeit implicitly, that people are not valued; not entitled to a place in society. Unlike Better Services, Valuing People was formulated in consultation with a team of people with the label of learning difficulty.

Valuing People recognises that disability is a social construction and seeks to remove disabling barriers through working in partnership to provide the support that people want (Grant et. al., 2002). It recognises that people who have the label of learning difficulty have the right to live as equal and valued members of society.

Valuing People is a rights based strategy. It states that people with learning disabilities have the same rights as everyone else, that people with learning disabilities should be independent and have choice in how they live their lives. It states that everyone should be included in this process. It states that each local authority should develop a ’learning disability partnership board‘.

Each learning disability partnership board should consist of representatives from the people who are labelled as having a learning difficulty who live in the area, from parents or carers of people with the label learning difficulty who live in the area and a range of representatives who are involved in providing services for people with the label learning difficulty. This last group includes mainstream service providers, local employers and community groups. The guidance for how the partnership boards should function is clear and is designed to ensure that people with the label learning difficulty feel comfortable and able to play a full part in all decisions that are made by the board. My experience of supporting people who have the label of learning difficulty to attend partnership board meetings is such that language used was often inaccessible, no time was given to discuss topics as they arose and meeting agendas were sent out so late, that discussion with the people who have the label of learning difficulties prior to the meeting was not possible. This has highlighted a growing need for training to be given to all people on the Board around removing barriers to participation. Such training, based around social model theory, has been piloted with the Bradford partnership board, and is being developed to help other organisations think about barriers to participation.

Valuing People sets out targets to ensure that people who have the label of learning difficulty get the support that they want and are able to access any services that they want to. The lack of consistent terminology regarding people who have the label of learning difficulty and who have high support needs has resulted in a lack of identifiable targets to ensure that further marginalisation of people with this label does not occur.

As with all policy the strength of Valuing People is determined by how well it is implemented, a factor, which is surely as dependant on the attitudes and beliefs of the people charged with implementing it as it is on time and money. Indeed the warning that the move towards empowerment *of* service users *by* professionals may be no more than a substitute for action has been made, with reference to previous strategies to facilitate empowerment through involvement (Dowson, 1997).

With respect to people labelled as having learning difficulties and high support needs this appears to be true, there is talk of supporting people with this label to be empowered and included yet very little action is evident. The level of involvement is not stipulated clearly in valuing people, and therefore the level of autonomy given to people in terms of decision making regarding services is reliant on how much power the ‘professional decision-makers’ are prepared to relinquish. People labelled as having a learning difficulty and high support needs are more likely to experience barriers to taking power on their own, and may need support to do this, this means people are reliant on taking only the power that they are given (Dowson, 1997). This is far from empowerment and far from inclusion! This is, of course a cynical view, and there will undoubtedly be people who do not work in this negative way. But history shows that people are unlikely to release power unless it becomes costly to retain it. The perception of people labelled as having learning difficulties and high support needs is often that of ‘not capable, not responsive’ it is unlikely that those with power to give out will pass it to people with this label.

In my experience implementation teams can become focused on working to the deadlines, of getting a plan out on time and thus not focus on quality and inclusiveness. This is a major limitation of Valuing People. The timetable is restrictive and often prevents the meaningful consultation it is meant to promote.

Valuing People acknowledges that “it is important to enable people with profound and complex needs to exercise as much control as possible over their lives” (DoH, 2001 p101). However most mentions of people labelled as having learning difficulties and high support needs are in respect of the need for specialist medical care. This puts overemphasis on the person’s impairments. Whilst there is a need to ensure that the NHS directive “All means All” encompasses all disabled and non-disabled people, there need to be specific objectives to ensure that people with learning difficulties and high support needs are recognised as active decision makers.

The valuing people support team lead officer who's responsibility it is to ensure that people who have the label of learning difficulty and high support needs is Stephanie Baulcombe. As part of my research process I contacted Stephanie to discuss the inclusivity of valuing people. She explained that valuing people includes everyone who has been labelled as having a learning difficulty. Everything should be available to everyone regardless of ascribed impairments, gender, and ethnicity. For this to be achieved she believes there should not be different services, just more thought, planning and creativity, and sensitivity to human rights built into services in a top down fashion (Baulcombe, 2003 personal communication). Thus service providers need to create an ethos of inclusivity. This thinking is in line with a social model framework that it is the structures, not the people with impairments who need to change. Hopefully the work of the valuing people support team will ensure that such thinking is top down, and that it becomes second nature to service providers, instead of an after thought.

The purpose of the above discussion is to highlight the relevance of the Kirklees User Involvement Network. As valuing people set targets to be achieved through the learning disability partnership boards, so equivalent consultation takes place through the Network. Thus before a plan or strategy is passed by the Kirklees Partnership Board the Kirklees User Involvement Network discuss it and submit their comments. This is where deadlines dictated by Valuing People become a barrier to effective consultation. It is not always possible to undertake meaningful consultation with people with the label of learning difficulty and high support needs within tight timescales. People need time to think about the issues, they may need time to communicate, they may need to experience different situations to inform their decisions. This is not possible when we are working to government prescribed deadlines. It becomes the responsibility of the Partnership Board to either ignore consultation or ignore government set targets and deadlines.

The next chapter looks primarily at the social model of disability, a model which asserts that disability is caused by societal structures, which oppress people who have biological impairments.

Chapter 4

The Social Model: The inclusion of people labelled with learning difficulty in social model theory

Models of Disablement

The social model of disability is a phrase coined by Oliver in 1983 to describe how disability is fundamentally a product of the way in which society is structured. This concept had its roots in the work of Hunt (1966) and others who demonstrated that the experience of disability is an interaction between material wealth and the perceptions of others based on cultural schema (Barnes 1997). This is in clear contrast to the individualistic, medical model of disability, which sees impairment (the medical condition) causing the disability.

In the mid 1970's a dialogue developed between the Union of Physically Impaired Against Segregation and the Disability Alliance. The cause and result of the dialogue was to develop clear distinction between the word impairment and disability. This distinction underpinned the fundamental principles of the Union of Physically Impaired Against Segregation. They demonstrated that impairment is a biological condition, and disability is a situation, brought about by social conditions leading to the oppression of people with impairments (UPIAS & The Disability Alliance, 1975). The importance of these definitions in the creation of disabled peoples solidarity is crucial, not least because the definitions were the product of discussions between disabled people, whereas hitherto definitions had been created by medical professionals (Barnes, 1997).

The aforementioned social conditions, also known as disabling barriers, incorporate a wide range of socially created situations, including political and economic structures, segregated education, employment and living conditions, the attitudes of society towards people with ascribed impairments and physical environmental barriers. Thus it is the failure of society to address the needs of people with impairments, which is the major disabling force (e.g. Oliver, 1990; Barnes & Mercer, 1996)

Understanding of this distinction, and of the presence of barriers created by society is central to an understanding of the social model of disability.

An important aspect of the social model and one which has often been misunderstood (c.f. Crow, 1996 & Barnes 1996) is that whilst it places emphasis on disability as a social construct, it does not suggest that impairments or medical interventions should be ignored. The Union of Physically Impaired Against Segregation (1976) advocated for the ‘right kind of help’ by welcoming alliances with medical professionals but stressed that this alliance will only be useful when the professionals are guided by the disabled people (also Finklestein, 1999).

The social model offers a realistic antidote to the medical model by demonstrating that disabled people can influence their own lives and exact change. Indeed the social model emphasises those aspects of a persons experience which are changeable (e.g. Barnes, 1996). The medical model views the person as a sum of their impairments. Within this model the disabled persons’ life is guided by what professionals think is best.

It is argued that the medical model supports a proliferation of professionals and experts who are authorities on disability/impairment (Finklestein, 1999). Like UPIAS the medical community make a distinction between disability and impairment but here disability is defined in terms of the person’s functional limitations. This classification system is tripartite, making a distinction between disability, impairment and handicap (WHO, 1980) (definitions made by professionals, not disabled people). The implication inherent in this definition, with its use of the word ‘limitations’ is that there is a level past which the person cannot achieve. (An example of the medical model can be found in Hunt, 1966.) The medical view is impairment centred, and concentrates on interventions to lessen the person’s limitations, rather than environmental adaptations to lessen the impact of disabling obstacles. Thus it is often referred to as an individualistic model, the emphasis being on the individual changing, instead of society. Subsequent refinements by the international community resulted in the International Classification of Functioning (WHO, 2002) which has a much stronger emphasis on ability and environmental barriers.

The social model enables people with impairments to reclaim a disabled identity. People are proud to be called disabled, as it highlights the struggle against the oppressors.

People labelled as having a learning difficulty

The terminology chosen by the self-advocacy movement is in contrast to the social model although the rationale behind the terminology compliments it. Thus the self advocacy movement People First have opted for the term people who have been labelled as having a learning difficulty (Aspis, 1998).

The people who use the label chose the term learning difficulty over the word disability. They felt that this emphasised that the difficulties exist only in the absence of support, that difficulties can be overcome and that disability was permanent (Mason, 2000). The use of the word disabled in the context of the social model of disability emphasises that the situation of ’being disabled’ exists only in the context of a society which creates barriers to inclusion. Thus the terms are comparable; the absence of support referred to in the definition of the label learning difficulty is a socially constructed barrier to inclusion.

The term mental handicap was rejected, by people with the label learning difficulty and professionals in the field as it was felt to imply the existence of unsurpassable limits which are not considered real (Mason, 2000). It is considered to be offensive.

> “We are people with learning difficulties, not what

> people used to call us, I wont say the word"
>
> (Kershaw, quoted in Goodley 2000)

The department of health continues to use the label learning disability. This decision was taken on the advice of Brian McGinnis, who is Mencap's Policy Advisor. The decision to utilise the term learning disability in preference to the term learning difficulty was based on the following premise: learning difficulty is used within the learning sector to refer to specific barriers to learning, learning disability refers to a serious global condition. The international term of Intellectual Disability was not used, as it was not felt that people in the United Kingdom knew the term (McGinnis, 2003 personal communication).

People labelled as having a learning difficulty and the social model

So, although the terminology 'people labelled as having a learning difficulty' is not entirely consistent with a social model of disability, does this mean that the model does not apply to people so labelled? That the social model neglects people who have the label of learning difficulties is a matter of some contention. Chappell et al (2001) argue that people with the label of learning difficulty have been tagged on or included as an afterthought in the academic debates surrounding the social model, and certainly a cursory glance through papers by leading light academics show only limited mention of people who have this label (e.g. Oliver, 1990, 1996).

The argument that consideration of people who have been given the label of learning difficulty has always been an afterthought in the disabled peoples' movement and in social model discourse is not a unique argument. Morris (1996) makes a similar argument regarding the inclusion or otherwise of disabled women in the movement. Yet the social model is no more than a theoretical framework, based on the shared experiences of people whom society oppress by virtue of an ascribed impairment. If it is accepted that people who have the label of learning difficulty are oppressed by society on this basis the social model must be applicable to their life experiences. Given that people with this label are least likely to be in paid employment, least likely to live in the community and most likely to experience abuse (DoH, 2001) it would be hard to argue that people labelled as having a learning difficulty are not oppressed by society.

I will take the above arguments and aspects of social model theory along with later discussion of user involvement and the self advocacy movement, to demonstrate that organisational and structural barriers are excluding many people with the label of learning difficulty and high support needs from contributing to the planning and design of services.

The next section is a brief exploration of the complexity of User Involvement, taking the social model as the underpinning construction. I will look at some of the main academic arguments regarding User Involvement, and will discuss the possibility that the motivation behind getting involved may have impairment specific influencing factors.

Chapter 5

User Involvement

The purpose of a section on User Involvement theory within this paper is to try and put the consultation of people with the label of learning difficulties and high support needs into the context of consultation with the wider population of disabled people. I will attempt here to demonstrate where the Kirklees User Involvement Network fits into the key arguments.

Participation and Normalisation

The theory that people with the label of learning difficulties should be central to the design of the services they access is by no means a novel one. In his landmark work *The Principles of Normalisation,* Wolfensberger (1972) declared that involvement in organisational decision making was the right of every person. Wolfensberger’s work was influential in the shaping of community services and normalisation became the buzzword in services for people labelled as having a learning difficulty (Chappell, 1997). Yet the involvement aspect of Wolfensberger’s work appears to have been lost, at least in community services, for people who are labelled as having a learning difficulty. Certainly my experience of supporting people who are labelled as having a learning difficulty in community settings would suggest that more emphasis was put on individual choice and control than encouraging a user-led service. This was perhaps due to the emphasis of O’Brien’s 5 Accomplishments for Service Provision (see for example O‘Brien, 1989). The service accomplishments were fundamentally service directed and as such were aimed at improving service delivery. However O’Brien emphasised the importance of choice only with a focus on limitation. There was an underlying assumption that some people would, on account of an impairment, be unable to make decisions on anything, least of all service delivery:

> People unable to make decisions for themselves because of age or extent of disability will have a strong personal relationship with a guardian who manages only those areas of life in which the person is incompetent (O’Brien, 1989 p20)

Clearly if this is the underpinning philosophy of services the barrier to inclusion becomes part of the organisational scaffolding. By starting from an assumption that some people are unable to make decisions an attitudinal barrier is in place to user involvement.

Is there such a thing as a representative person?

User Involvement is part of the rhetoric of providers *of* services for disabled people, and the arguments around user involvement are multi-faceted and open to much academic debate. The major argument I will address here is the issue of how representative the ’users’ are. This argument is fundamental in exploring the current experiences of people who have the label of learning difficulty and high support needs. As I will later argue there may be issues around how people choose to take part in the user involvement network.

So, why is representation such a big issue? In a 3 year review of user involvement within the statutory and voluntary services Croft and Beresford (1990, 1991 cited in Beresford & Campbell 1994) identified that services were concerned that the people who were becoming involved were not representative of the overall population of service users. Service users who took part in the review also said that this was a criticism frequently levelled against them. This criticism leads ultimately to the service users feeling degraded and demoralised (Beresford & Campbell, 1994). This suggests that service providers are making an assumption that the people acting as representatives are in fact voicing their own opinions only, and that their opinions are not worthwhile as they are not the opinions of a hypothetical ’typical’ service user.

To bring briefly into context the example of the Kirklees User Involvement Network I will explain that here, rather than asking for a small number of volunteers to represent people who have the label of learning difficulty, we draw on as large a pool of people as are willing to take part, not only by consulting people in specific meetings, but also by mailing questions, visiting people in their own homes, visiting people in day centres, places of work etc. People who have the label learning difficulty elect, on a 6 monthly basis people who will represent them on the learning disability partnership board. These elected representatives have a key role in collecting information about what their peers think and present this information to the partnership board. It is my role within this process to support people in their role of representative and I do this in conjunction with an independent advocacy service.

Criticisms of User Involvement

Referring further to the review of User Involvement by Croft and Beresford criticisms were made by service users to the service providers, summarised as follows:

- involvement is tokenistic
- involvement excludes minority ethnic groups
- members of disabled people's organisations are discouraged from taking part
- disabled people are asked to speak for themselves, not for groups
- professionals do not have to be 'representative of their profession'

I will look at each of these statements in the context of the case study.

Attempts have been made to ensure such criticisms cannot be levelled at the Kirklees User Involvement Network, although often with limited success.

Involvement is tokenistic

It is my aim to ensure that involvement is not tokenistic, and that plans are developed for services in full consultation with the people who use them. My employment position is such that if service providers are asking only for what for ease of terminology, I will call lip service consultation I am in a position to push for a fuller consultation. Thus if I suspect the purpose of the consultation is to tick a box at the beginning of the plan saying ‘service users were consulted’ I am able to suggest that meaningful consultation would be more productive in the long run.

Involvement excludes minority ethnic groups

Regarding the second criticism of user involvement, that people from minority ethnic backgrounds are excluded, this is a situation not peculiar to User Involvement but is mirrored throughout all services for people who have the label of learning difficulty. Speculation is rife on why this happens. The major reasons being cited are: racism within ’white’ disability services and lack of appropriate information on services available to people from minority ethnic backgrounds (e.g. Evans et al, 2001; Chamba et al., 1999). The Kirklees User Involvement Network does support people from some of the minority ethnic groups who live in the area, however it is apparent that this is not in proportion to the population. To attempt to address the above issues the members of the Network who represent the ethnic minority groups are working together with the

Kirklees Working In Partnership Team to put on an information event for carers and people with the label of learning difficulty. The purpose of this event will be to talk about what it means to be a person labelled with a learning difficulty, and to let people know what support is available to people with this label and their carers should they desire it.

Members of disabled peoples' organisations are discouraged from taking part; Disabled people are asked to speak for themselves, not their groups

These two statements regarding disabled peoples organisations would appear, from a cursory glance at the membership list of the User Involvement Network to be true. Attempts are currently being made to link with the local people first group, but to no avail. I can only suspect that this a result of years of the group experiencing barriers to participation in similar settings. The path to enlightened, participatory service provision is littered with the mistakes of the past!

Professionals do not have to be representative of their profession

I have assumed that this final statement refers to whether professionals are ‘typical’ of their profession, and without further study I am not able to comment on the applicability of this to the case study.

In terms of a User Involvement Project, I feel we can withstand the criticisms traditionally levelled at User Involvement. My major concern is whether people are being supported to choose whether they attend or whether other people are making the decision for them. Analysis of my reflective practice journal demonstrates that on one occasion a person attended a meeting, which he had told his support worker he did not want to attend. His support worker had ‘thought he’d change his mind.’ This is a demonstration of someone advocating for themselves and being ignored; a barrier to his further development of self-advocacy skills created by the belief of a support worker that ‘she would know best.’ Naturally arrangements were made for this person to return to the place that he wanted to be at. This is an alarming example of barriers created by staff in an attempt to represent someone’s interests, and it certainly left me wondering how much choice somebody without this person’s verbal skill if offered in choosing to attend the groups.

This concern was not unfounded. One man who attended the group had a communication impairment, and sometimes I infuriated him by not following what he was saying, but with patience and time spent together, I felt that I was understanding him better and better. He always appeared happy in the group and always made relevant contributions to the topics we were thinking about. He has been removed from the group by his keyworker, who thinks that he would benefit more from a communication workshop. Thus, rather than encouraging people to listen to him and understand him, or acting as a ’translator’ with new people to remove the barrier of lack of understanding the keyworker has decided he should change the way he communicates. This is a clear demonstration of individualistic medical model attitudes. After only a short period of time I was able to understand what he was saying, yet he is being asked to change because a ‘professional’ believes that his communication is a barrier to his inclusion, thereby perpetuating the medical model of disability and inhibiting the persons life opportunities. It is the attitude of society to people who communicate in different ways that needs to be addressed.

This can be seen, on a micro level, as an example of the barriers that professionals create. Here the barrier is the belief, by professionals, that people with the label of learning difficulty and high support needs are restricted by their ascribed impairments, and are therefore not capable of involvement in service planning or design. A belief illustrated earlier by the quote from O'Brien (1989).

So, for user involvement to be meaningful, people have to be listened to and respected, not doubted and consulted only on a limited number of aspects. The following section looks at the self advocacy movement, which is an international movement of people who have the label of learning difficulty, who promote, amongst other things the rights of people who have this label of learning difficulty to speak up, stand up and be counted. Within this context I will also look at how people with the label of learning difficulty and high support needs are often ignored when making decisions.

Chapter 6

The Self-Advocacy Movement

Self-advocacy, as a concept, involves standing up for your rights as a human being. The term self-advocacy has become synonymous with the movement of groups of people who have been given the label of learning difficulty and who meet to talk about rights, choices, personal relationships and many other topics. Whilst the term implies an individual speaking up for themselves, self- advocacy can occur through groups of people and can involve speaking up for other people as well as speaking up for oneself. (See Goodley, 2000 for a detailed account of the self -advocacy movement, the different forms self-advocacy takes and the experiences of self- advocates.)

The self-advocacy movement, regarded as a new social movement (Goodley, 2000), has it's roots in the 1960s when disabled people with good social and communication skills started to speak out against the services they were receiving (e.g. Hunt 1966). This marks the start of the disabled people's movement. For a long time it was dominated by disabled people who were not labelled as having a learning difficulty, and it was not until the late

1970s that the campaign for mentally handicapped people (who later became Values Into Action) saw people labelled as having a learning difficulty speaking out alongside professionals.

Within the campaign it was the role of professionals to support people labelled as having a learning difficulty to become a self-advocate. At this stage the self-advocacy movement continued to be dominated by people with conventional communication methods. Over 20 years on, this situation has remained the same. People who use conventional communication aids remain at the forefront of the movement. Studies of the movement have similarly focused on people who use words or recognised communication aids as a primary form of communication (e.g. Goodley, 2000). The self advocacy movement has been key in informing and developing Valuing People, but little equivalent consultation took place with people labelled as having learning difficulties and high support needs. It is thus of prime importance that people labelled as having learning difficulties and high support needs are not further left behind. The guidance of the charity Acting Up, is entitled “People with communication difficulties have lots to say” (Acting Up, 2002). It is of utmost importance that this advice is acted on in order to prevent further polarisation within the group of people who are labelled as having learning difficulties.

All people with the label of learning difficulty have the right to be included in the planning of the services that they use. Being able to present your views, and thus self-advocate, requires an understanding of how planning occurs, of how services are running and of what the alternative services are. For people who use unconventional communication methods and for people who are labelled as having learning difficulties and high support needs the presentation of opinions, and therefore the process of self advocacy, regarding the planning, delivery and design of services becomes further complicated. As has been elsewhere discussed there may be a reliance on another person to interpret communication, yet this can still be a valid form of self-advocacy.

The Values Into Action Conference, Nothing For Us Without Us was described as a series of workshops to address issues pertaining to self advocacy for people labelled as having a learning difficulty and high support needs. The conference was for self-advocates and supporters. It was a deflating experience to discover that the majority of the people attending the conference including the partnership board representative who is a wheelchair user and has physical access barriers to attending the board meetings could only recount bad experiences of self-advocacy for people with this label.

The people attending the conference who related what they felt were positive examples of where people with the label of learning difficulty and high support needs were joining in ’self-advocacy activities’ were, in reality, attending the parties and not the meetings, others attending the meetings were not being supported to participate, leaving me to wonder whether the staff supporters really believed that it was empowering in some way to be present at a meeting where there are barriers to participation.

Within the conference the workshop held by the charity Acting Up, was in my opinion the only workshop that addressed effectively 1. that everyone is capable of supported self-advocacy and 2. that they were working on a project to support people in doing this. The following discussion is based on notes I made during the workshop and afterwards from an informal interview with John Ladle the Director of Acting Up.

Acting Up work with people who have the label of learning difficulty and high support needs and, using a technique called multi media profiling they support people to create their own ‘multi media filing cabinet’ showing new supporters how they communicate, how they like to be supported, what they like and what they don’t like. Using video to train staff the people with learning difficulties and high support needs are able to develop their own support packages. The video is also used to assess a persons understanding of who they are. It was noted by Acting Up staff that many people they worked with had no mirrors in their rooms and where mirrors existed they were too high. They therefore supported people to play back the video and using various computer technology people were able to pause video and make themselves stop and start on screen. Thus the people were taking retrospective control of their lives. It was hoped that this would give the people insight into the types of control they could have.

The Acting Up project is not going to be the answer to supported self-advocacy for all. However for people who engage with the media, it has proved a successful project. Across the UK multi - media profiling has been used in supported self-advocacy in East London and a project is being developed in York to examine how it can be utilised for consultation. There are barriers to the multi media projects succeeding. The first barrier is economic. The equipment is expensive and, although it is only one initial cost, local authorities are unwilling to prioritise the needs of those who shout the least. The second barrier to successful supported self-advocacy through the use of multi media is that it is reliant on the enthusiasm of the carers or supporters. Thus for the profile to be successful the implementation must not only be encouraged from a bottom up perspective but also needs to be reflected in the organisational structure, with enthusiasm from management to ensure its longevity.

A major issue of the self-advocacy movement is that it introduces the idea of self to people who have not been able to explore who they are. They argue that many people labelled as having a learning difficulty, and especially those with high support needs, are denied the opportunity to discover who they are. As discussed the multi-media project Acting Up supports people to commence the journey to discover who they are through the use of video (Acting Up, 2002). They argue that understanding that you are an individual is key to making choices about your life and to understanding that you can control your life.

This is a long process. We are asking people to plan and make decisions about their services when we have not taken the time to consider how they conceptualise themselves. The barriers created by organisational structures, and working to deadlines should be removed, and organisational structures need to be flexible in allowing people the time to take part and say what they think. Service plans will thus need to be left open to regular review, as better support is available to enable people to input into the planning process.

What are people given decisions in?

The promotion of choice was seen as a core principle of the movement from institutions to community living (O‘Brien, 1989). For staff supporting this move the temptation was to give people choice in all aspects of their lives without recognising that this involves a major conceptual change in the persons life (Smull not dated; Harris, 2003). Instead of supporting people to understand what it means to exercise choice and take control of their lives it was assumed that all people would understand the impact of the choices they made. Often people were left to make these decisions with no prior experience, having ’been moved’ from an environment where all decisions were made for them. This is by no means a suggestion that people with the label of learning difficulty and high support needs are not able to make such decisions, only that the support must be carefully developed for each individual to ensure that they do not experience barriers to decision making through the effects of institutionalisation (Smull not dated).

The stress by some on the use of collaborative decision making (e.g. Nakken & Vlaskamp, 2002) where it is assumed that some people are unable to make a decision on their own is one which is equally alarming. The key to all supported decision making should surely be that it is the persons behaviour, the person’s communication which is the decision, and it is therefore interpretation of that behaviour by people who know the person well which becomes the support of the decision making process (Beamer & Brookes, 2001). In this paradigm, there are still risks related to the interpretation of behaviour, but in a carefully monitored situation these risks are minimal. Thus if a wrong interpretation occurs, subsequent behaviour and communication would demonstrate this and corrections can be made to the original interpretation. This speculative method of supporting decisions has one potentially fatal flaw, namely that it relies on the honourable motivations of the people who are interpreting the behaviour. Conversations with local person centred planning co-ordinators have highlighted that ways of lessening the potential negative impact of people who have different agendas to the person they may be supporting are in the early stages of development. At least a basic level of awareness has been generated.

The concept of mental incapacity

While people are making decisions about their own lives on a daily basis the law often deems the same people as being without capacity. This means that legally the person is deemed incapable of making decisions about, say, personal medical treatment or entering into a sexual relationship, unless he or she can prove a logical and coherent approach to problem solving (Harris, 2003).

This holds clear contradictions with the ethos of Valuing People. The government clearly states that people who have the label of learning difficulty should be supported to be in control of their lives, and should be consulted in the planning, development and running of the services that they use. However, the legal system can and does rule over whether people can make decisions in many aspects of their lives. Valuing People address the issue of choice and control directly (DoH, 2001; ch4). It acknowledges the governments priorities since 1999 to address the lack of clarification on the word capacity to set clear guidance for assessing a persons best interests and to appoint a “general authority to act reasonably which will regulate day-to-day activities” (p52). It is not clear how they are going to achieve these objectives, who the ‘general authority would be, nor is it clear that the situation will improve when they are achieved.

This situation is due to change. The draft mental incapacity bill, launched on 26th June 2003 aims to make law the reality that all adults have capacity to make decisions about their lives (Mencap, 2003).

One of the clearest routes to planning and controlling the services you use is through the use of direct payments (see the Values into Action 2001 publication for a full discussion of the uptake of direct payment schemes by people labelled as having a learning difficulty). Many people labelled as having learning difficulties have not taken up this scheme. In autumn 2000 out of nearly 4000 people accessing direct payments schemes less than 300 were people who have been given the label of learning difficulty. It is a goal of Valuing People to increase services supporting people to access the direct payments schemes (DoH, 2001).

Other than the lack of support, there are other barriers to people accessing direct payments, noted by VIA (2001). One of the postulated reasons for this, which has especial resonance for people who don’t use standard communication methods is that it is seen as ‘difficult’ to obtain consent. The law originally said that the person has to be ‘willing and able’ to implement the direct payments scheme. The use of unquantifiable criteria such as ’willing and able’ have meant that retrospective consent is often given by an individual - that means that it is when the person experiences an option and is happiest with that option that consent is given. This is informed consent as experience clearly informs the decision yet this type of decision making takes time and resources and is neither accepted within the framework of direct payments nor within the framework of valuing people. Indeed willing and able suggests a decision that needs to be made *before* the direct payments scheme is initiated. This is a barrier to people who make decisions through their responses to situations.
Thus, people have been pushed to make decisions in the way that society considers ‘normal.’ Legally people have to conform to a

decision making protocol, and any deviation from this by a ‘vulnerable adult’ will mean that the person is deemed to be ‘without capacity.’

In addressing the primary research question, can people labelled as having learning difficulties and high support needs design and plan the services that they use? the above discussion on choice and decision making highlights an important factor. Organisations need to be aware that people make choices and decisions in different ways, and that people have different experiences of the decision making process.

In summary, so far this paper has explored different aspects of disability theory and current social policy to explore whether people who have the label of learning difficulty and high support needs can play an active role in designing and planning of services. It has been suggested that the oppression of people with this label has, to date, been a result of the social construction of disability, manifested in the institutionalisation of people with this label. Furthermore, I have addressed that people who have the label of learning difficulty and high support needs are marginalised within organisations of people who are labelled as having a learning difficulty and within services and policies for people with this label.

In the concluding chapter I will explore what the barriers are that need to be removed in order that all people who use services can participate in their planning and design and speculate on how these barriers could be removed.

Chapter 7

Can people labelled as having learning difficulties and high support needs design and plan the services that they use?

To conclude this work, I will return to the initial question, and look at how the preceding work combines to answer it.

The question “can people...” was chosen over “should people..” or “how can people.....” as I believe that all people have the capabilities to design and plan the services that they use and that society has constructed barriers which prevent people from so doing. Had the question been should people it would have been a rights based question, and national policy is currently clear (thankfully) that people have the right to influence their services. The question ‘how can people’ would have looked at practical solutions, but I wanted to argue for ‘the right kind of support’ which would be different for every individual. Thus the question “Can people labelled as having learning difficulties and high support needs design and plan the services that they use?” was chosen, to enable me to identify some of the structures which prevent people with this label from being involved in consultation regarding the services that they use.

This question was answered within the policy framework of Valuing People and the theoretical framework of the social model. It has been clear that Valuing People took as its philosophical basis a social model framework. It is, therefore, ironical that some of the largest barriers to inclusion come from Valuing People’s deadlines for strategies, plans and service designs to be written. In addition the barriers created by holding meetings aimed at people who use words to communicate, or holding meetings where people who are there in a supporting capacity are not given the opportunity to support are preventing some people from being involved let alone included in a meaningful way.

Whilst I have highlighted ways in which my working practice, and therefore the way in which the Kirklees User Involvement Network functions can be altered to improve inclusive working practices, much of this will rely on the honourable intentions and enthusiasm of other supporters. Moving to the larger scale can I influence the way that the Kirklees Partnership Board functions, to ensure that we have time to consult with people who have the label of learning difficulties and high support needs? To an extent, I can provide reports to the board explaining that meaningful consultation is not taking place and requesting that plans and strategies are left open for change.

Regarding representation and the arguments that disabled people who are involved in User Involvement are in some way not typical of the people they represent it is likely that I have been guilty of thinking in this way, and thus my insistence on consultation with people with the label of learning difficulty and high support needs. Yet I feel this is justifiable, insomuch as I believe that the experiences of oppression that people who have this label are having are considerably greater than the experiences of many other people who have the label of learning difficulty. That does not mean that I feel that one set of experiences is better, or more important than any other in this respect, but that the different experiences of people need to be considered to ensure that further oppression is not occurring.

Thus my answer to the primary research question, based on the above discussions is that

with the right support people with the label of learning difficulties and high support needs can plan and design the services that they use.

The right support would involve there being no barriers to participation. The barriers present including not just those of physical access to buildings but also of the attitudes of supporting staff and the attitudes of organisations. Not wishing to dictate how others should think I believe that organisations may need to scrutinise their recruitment and training programmes in order to address the attitudes of the people in supporting roles. As individuals access support through direct payments this barrier may lessen.

For successful consultation to occur with people who have the label of learning difficulty and high support needs society needs to believe that it is a realistic goal. I suspect this is a bottom up process wherein the more people with this label are involved the more acceptance that occurs in the wider society.

This research has at least allowed some changes to be made to the way that people with learning difficulties and high support needs are consulted within this small part of West Yorkshire. I have no doubt that people with this label can and will design and plan the services that they use, Rather than dictating the methods of consultation we need to slow down and start by supporting people with this label to design how they would like to be consulted. Then we can proceed in working in a person centred, user led manner.