

**People with Learning Difficulties and Their  
Healthcare Encounters**

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## **Abstract**

This study aims to explore the healthcare experiences of people with learning difficulties and their carers. This area has become highly topical as a result of recent national health and social care policies that have emphasised the social inclusion agenda and the right of individuals to have a say in decisions that directly affect their health and wellbeing. This study exposes tensions between individual and social models in accounting for the healthcare experiences of people with learning difficulties.

The decision-making process is complex and traditionally many people with learning difficulties have been judged incompetent to make their own healthcare decisions. However, the recent Mental Capacity Act 2005 proposes that people with learning difficulties should, like other people, be presumed to be competent (to make decisions) unless there are strong contra-indicators. This proposition is tested in the study.

To capture the voices of people with learning difficulties, particularly those with limited articulacy and no speech, ethnographic and narrative methods are used to include voices that may otherwise remain unheard. These methods were informed by a constructivist approach that involved working as closely as possible with informants in order to reach a shared understanding of their experiences.

Recent policy proposals suggest that all parties within the healthcare encounter need to work 'in partnership' and 'collaboratively' to provide a more 'person-centred' healthcare encounter for people with learning difficulties. An attempt is therefore made to deconstruct these ideas and to examine what light they shed on the lived experiences of people with learning difficulties in relation to their healthcare encounters in mainstream and specialist services.

The study can be seen as adding to the growing literature about the lived experiences of people with learning difficulties, to narratives about their everyday lives, to a questioning of tacit assumptions by staff about capacity and best interest, and to the power struggles people with learning difficulties continue to face in their everyday lives. The findings also demonstrate how situational and contextual factors mediate experiences, re-emphasising the importance of the social model of disability.

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## **Background of author**

I grew up in a shop. My father was undoubtedly an influence with his unjudgemental approach to people. In the 1960s he was employing people who were a bit 'slow', because he said that everyone deserved a chance in life to earn, as he put it, 'comfort money'.

I left school at seventeen and became a dental nurse, taking the National Examinations for dental surgery assistants after eighteen months, rather than the required two years. I progressed from private dental practice to the community dental service, working with people with learning difficulties, elderly people and children. I then worked in a dental hospital, and general infirmary, in all the specialist clinics, rather than having a set department, because I enjoyed the variety. I worked in a 'dental care clinic' for people with learning difficulties. I remember intensely disliking the dentist who ran the clinic. This particular dentist raised his voice and used terrifically long words to explain treatment. I did not understand much of what he said, and felt sorry for the patients. He undertook treatment without giving a local anaesthetic because he used to say: "where there's no sense there's no feeling". These sessions have remained engraved on my mind to this day.

From dental nursing, I moved into teaching, medical sales, and back to dental nursing in Saudi Arabia. I had children, and with their birth came the realisation that I needed to do more. I took three 'A' Levels in a year and gained a place on a degree course reading Psychology. Being a mature student made me question the aims and origins of psychological teaching, and I chose to take a critical pathway. At the same time, I became involved with parent support groups for children with ADHD, ADD, Aspergers, autism, Tourettes, obsessive compulsive disorder, and 'challenging behaviour'. I also worked part-time supporting people with learning disabilities and difficulties with their college courses. My dissertation was about the social construction of ADHD, where I challenged professional

constructions of the label, and looked at how infrequently parents were included in decisions concerning their children.

After the degree had finished, I took a counselling course, counselled voluntarily and started to question the construction of mental health. I counselled people with severe mental health problems, disliking the way that some people were excluded by professionals in decisions about their own health. I felt that I wanted to look more at marginalised groups who appeared disempowered.

My inquisitiveness led me to look at how people with learning difficulties were involved in their healthcare, if at all. I wanted to know whether they were included in the process of decision-making. With the advent of 'Signposts for Success' (DOH 1998b) and 'Valuing People' (DOH 2001b), which recommended making services more responsive to the preference of people with learning difficulties and their carers, I knew I wanted to explore the process further. The ESRC awarded me a Case Collaborative Scholarship to investigate my interests. The morning I handed in my thesis for its first reading, I attended an interview for a research post. I was successful, and am now working, perhaps ironically as a researcher at the Charles Clifford Dental Hospital in Sheffield. The same week, the General Dental Council appointed me as a voluntary lay member, mediating for private practice disputes. My work history appears to have come full circle, placing me back in the dental field, with greater knowledge than when I first started out as a seventeen-year-old dental nurse.

Within the following pages are the results of my study, which I hope you enjoy reading as much as I enjoyed writing.

## Foreword

It is widely reported that people with learning difficulties are less likely than the general population to have their health needs fully met (Powrie 2001, 2003, Lennox et al. 2001, Whittaker and McIntosh 2000, Hogg et al. 2001, Evenhuis et al. 2001b, Thorpe et al. 2001, WHO 2001). In addition, people with learning difficulties have traditionally remained uninvolved in their healthcare decisions because of the dominance of professional knowledge within the healthcare encounter (Lancioni et al. 1996, Charles et al. 1997, 1999, Stewart et al. 2003), and wider beliefs regarding competence (Lovett 1996, Jenkins 1998, Morris 1996, Booth and Booth 1994, McCarthy 2001). Professional knowledge has been used over the years to justify the marginalisation of people with learning difficulties, by making treatment decisions in their 'best interests' (Lovett 1996, Edge 2001, Beamer and Brookes 2001).

Despite research which identifies that people with learning difficulties have traditionally remained uninvolved in their healthcare because of the dominance of professional knowledge (Lancioni et al. 1996, Charles et al. 1997, 1999, Stewart et al. 2003), there appears to be little research from the perspective of people with learning difficulties. Recent policy proposals refer to the social model of disability (Abberley 1987, Oliver 1990, 1996). Disabled academics and researchers (Abberley 1987, Morris 1994, 1998, Oliver 1990, 1996) suggest that the social model focuses research on the disabling barriers within society to explain marginalisation. However, there is a tension between the social model and recent policy proposals because medical knowledge is scientifically driven and intimately related to power structures, which marginalise other types of ('non-medical') knowledge in policy recommendations.

Keywood et al. (1999) suggest that many people with learning difficulties need support from family and paid carers to negotiate the healthcare encounter.

Browne (1999), and Williams and Robinson (2000) argue that it is important to involve carers accompanying people with learning difficulties at all times because they can facilitate the communication process, especially for some people with limited articulacy and no speech. Additionally, the Norah Fry Research Centre (2004) has issued guidance on methods for involving people with learning difficulties who do not use speech. In their research with people with learning difficulties, Booth and Booth (1996) identify that one of the main problems for the researcher is trying to communicate with a person who lacks the facility of speech. Furthermore, it is well documented that many people with learning difficulties have some form of communication disorder (Beange 1996, Lennox and Kerr 1997, van der Gagg 1998, and Bigby 2004). Within the healthcare encounter, Charles et al. (1999), and Stewart et al. (2003) propose that for the professional, diagnosis is mainly dependent upon the patient being able to give an accurate description of their symptoms. This tension between a person with a communication disorder or lacking speech and the professional requiring an accurate description of symptoms problematises the healthcare encounter.

An important thrust of the national strategy 'Valuing People' (DOH 2001b) concerns person-centred planning (PCP), or putting the person at the centre of the process of planning support services (Sanderson et al. 2002). However, there appear to be a number of unanswered questions about the nature of participation and partnership relating to people with learning difficulties and hence about the characteristics of a person-centred service (Cambridge and Carnaby 2005). The possible ways in which participation can and should take place are likely to be related to the health context, the capacity for self-advocacy, and the values brought to the service relationship. It may well be that these 'intervening variables' are important indicators of 'good' participatory practice.

MacKean et al. (1999) suggest that professional groups need to work in partnership and communicate with one another, in order to understand individual contributions to care and treatment. However, Dalley (1993) questions the nature and existence of partnerships within an inter-

professional framework. Alternatively, Keywood (2003) raises a different issue, in relation to family and paid carers of people with learning difficulties, in that they can experience different and conflicting roles, placing a burden on them.

Therefore, the main research question for this thesis is:

- **To what extent are people with learning difficulties, and their paid carers, involved in the healthcare encounters of people with learning difficulties?**

Linked questions to the main research question are as follows:

- What can we learn from people with learning difficulties themselves about their healthcare encounters?
- Are the perspectives of people with learning difficulties on their healthcare encounters necessarily shared by staff and supporters?
- What can we learn about people with learning difficulties who do not use speech in their healthcare encounters?
- How can we best support or involve people with learning difficulties who do not use speech in their healthcare encounters?
- What are the factors that make healthcare experiences positive for people with learning difficulties?
- What can we learn from paid carers about the healthcare encounters of people with learning difficulties?

**Thesis structure:**

## Chapter 1: Introduction to the study

In this chapter I introduce a biography of the actors (the people with learning difficulties involved in my study). Then, I describe the location and homes where the actors live, before presenting a brief overview of my study.

Chapter 2: **Professional knowledge, policy and the individual model of disability**

This chapter provides an outline of policy recommendations relevant to people with learning difficulties. It also introduces the individual model of disability and its links with medicine. I argue that there is a tension between policy recommendations and the medical model of healthcare. I conclude that there is little guidance as to what constitutes the healthcare decision-making process, suited to the needs and circumstances of people with learning difficulties.

Chapter 3: **Lay knowledge, the social model of disability and policy**

This chapter introduces the social model of disability and lay knowledge. I argue for different types of knowledge within the healthcare encounter in order to enhance the competence of people with learning difficulties and simultaneously achieve patient-centred or person-centred outcomes.

Chapter 4: **The Case for an Interpretive Research Approach**

This chapter seeks to establish the case for a qualitative research approach in studying the experiences of people who have limited verbal articulation. I argue that traditional qualitative methods can exclude the voices of people with limited verbal articulation, or no speech. I conclude that narrative methods can add to existing life history research by employing the methods as a tool for people with limited or no verbal utterance.

Chapter 5: **Methods**

This chapter outlines and justifies the methods employed in my study, from literature search to analysis. I give examples of problematic interviews and their handling. The chapter concludes with a discussion of how ethical issues were handled.

## Chapter 6: **Person-Centred Services**

This chapter examines ‘person-centred’ thinking, linking it to ‘patient-centred’ issues that arise within the healthcare context. I argue that interactions between medical professionals and people with learning difficulties contrast with the proposals for person-centred planning. I conclude that important carer knowledge, that could positively influence the outcome of the healthcare encounter, remained unused.

## Chapter 7: **‘Partnership’ and ‘Collaboration’: the prioritisation of knowledge**

This chapter aims to deconstruct ‘partnership’ and ‘collaboration’ because they appear to take different forms. I argue that if people with learning difficulties are to be included in their healthcare encounters then non-medical knowledge needs further acknowledgement. I conclude that supporting people with learning difficulties in their healthcare encounters is a complex process and that just because partnerships are formed it does not mean that they work effectively.

## Chapter 8: **Narratives of Competence: Support, Choices and Decision-Making**

This chapter explores whether there is a difference between mainstream and specialist learning disability services as a context for decision-making. I suggest that there is significance attached to the issues concerning how constructions of competence within the healthcare services affect choice making within the decision-making process. I conclude that the lack of medical knowledge of the staff carer or person supporting an individual with learning difficulties could sometimes be a barrier to the decision-making process.

## Chapter 9: **Roles and Consent: confusion and conflict**

This chapter examines the decision-making process, in which discourses about risk and roles engage as key factors. My study indicates that staff carer roles change and can be conflicting, but additionally have negative and positive dimensions. I conclude that staff carer roles appear to become more conflicting and complex with people with more profound impairments.

## Chapter 10: **Conclusions and Recommendations**

My study reveals inconsistent evidence of involvement of people with learning difficulties in their healthcare encounters. Furthermore, people with learning difficulties themselves report positive and negative experiences in their healthcare encounters. Paid carers of people with learning difficulties reinforce these perspectives, but they additionally struggle with the complexity of the conflicting roles that they undertake on a daily basis. Coupled with the conflict and complexity, there appear to be unwritten assumptions concerning the competence of staff to understand medical knowledge. My own experiences as a researcher indicate that narrative methods are useful when attempting to include the voices of people with learning difficulties in research. However, I suggest that these methods may also be usefully employed in healthcare encounters to include people with limited articulacy, or no speech.

I conclude with a critique of my study, review the implications for policy and practice, and recommendations for further research and development.

## Chapter 1:

### Introducing people and places

#### 1.1 Scope

This chapter introduces the people, the location of the study and the homes where people live. I have presented this chapter first, and in this way because I feel that it is important for the reader to gain a sense of who the individuals are and the context of their everyday lives, to facilitate building a fuller picture in later chapters. Descriptions of people with learning difficulties are deliberately positive in order to move away from their stereotypical negative images, as portrayed by the general dental practitioner in Chapter 6. I have also employed literary devices used in the humanities, for example metaphor, to enable readers to form a pictorial image of individuals and settings. The descriptions are journalistic in style to make individuals appear more real to the reader (Denzin 2001), and attempt to forge a bridge between the social sciences and humanities by using literary devices (metaphor, rhetoric) used by the humanities in constructing narratives (Bennet and Royle 1999). I have used the term 'people with learning difficulties' because this is the name that they have chosen to describe themselves. There are multiple voices represented in the stories in this thesis. The main voice however is that of the author because some people with learning difficulties lacked the verbal articulacy to represent stories in their own words. I used different tactics to secure meaningful narratives wherever possible, and this is a key feature of my thesis elaborated in chapters 4 and 5.

**In order to protect individuals and preserve their anonymity, names, locations and descriptions have been changed or altered.**

#### 1.2 People in the aggregate - my sample

I chose a purposive sample of thirty-one people with learning difficulties with an age range between twenty-one and eighty-two years. All

respondents lived in homes in the Brancaster Trust catchment area. Of the thirty-one people, six lived in secure hospital-based units, twelve in registered care homes and ten had supported tenancies where permanent staff carers provided twenty-four hour support (see Table 1.1). The three remaining people lived independently, one in her own home, one with a landlady (in accommodation arranged and supported by Social Services), and one in a 'key-ring' home.

The key-ring home is a new scheme run by a Housing Association; an individual lives, to all extents and purposes, in a flat or house, independently in the community but there is a key worker who lives within a certain radius of the homes who can be accessed eighteen hours a week, at set times, if problems occur.

The sample is not intended to be representative of the wider population of people with learning difficulties in Brancaster. It does however constitute a sample that is fit for the purpose of this study. For example, I decided to differentiate the population in terms of people who regularly accessed healthcare services for recurrent healthcare interventions and treatment, and sporadic users accessing services for six monthly dental check-ups and visits to the GP for colds, flu, and everyday complaints (similar to the general population). There is some evidence to suggest that people with learning difficulties have higher healthcare needs than the general population, but that these needs often go unmet (Powrie 2001, 2003, Lennox et al. 1997, 2001, Whittaker and McIntosh 2000, Hogg et al. 2001, Evenhuis et al. 2001b, Thorpe et al. 2001, WHO 2001).

In addition to the thirty-one people with learning difficulties, I interviewed:

- 12 staff
- 13 learning disability nurses
- 2 psychiatrists
- 1 psychologist
- 1 chiropodist

- 3 dental surgeons
- 2 GPs
- 2 advocates
- 2 family members

I explained to all interviewees (both people with learning difficulties and practitioners) that I was interested in how people with learning difficulties accessed healthcare, what support they received and what additional support might be needed. For staff, I asked what they thought about healthcare, what they considered good practice and what they felt needed to be improved.

For people with learning difficulties I explained that I was interested in their visits to the doctor, nurse, chiropodist, dentist, hospital and clinics. I asked them if they felt they could tell me what happened when they visited, whether they had to wait, felt they were treated kindly, and how treatment was explained. I explain my fieldwork methods and the problems I encountered in more detail in chapter five.

**Table 1:1 Sample characteristics**

N	Regular users of services.** (n=18)	Sporadic users of services. *(n=13)	Total (n=31)
<b>Gender</b>			
Male	17	7	24
Female	1	6	7
<b>Age (years)</b>			
Mean	49.3	54.5	52
Median	47	57.5	48
<b>Current Residence</b>			
Own home	0	1	1
Registered care home	7	5	12
Supported living	4	6	10
Social Services accommodation	1	0	1
Secure accommodation	6	0	6
Key-ring home	0	1	1

\*\* Regular users defined as those under active treatment for medical/psychiatric interventions.

\* Sporadic users defined as those accessing services when required (e.g., six monthly dental check-up).

### Sampling considerations

In order to enable the full scope of healthcare issues to be explored, a purposive sample was employed (Robson 2002, Cohen et al. 2000). This differs from convenience (accident/opportunity) sampling because this type of sampling chooses the nearest informants, regardless of typicality, until the

required sample size is reached (Cohen et al. 2000). In purposive sampling, the researcher handpicks the individuals to be included in terms of how typical they are for the specific needs of the study. As the name suggests, the sample is chosen for a specific purpose. I wanted to talk to a range of people with learning difficulties about their healthcare experiences.

Although the sample was purposive in relation to the range of healthcare encounters to be explored it does not reflect the population of healthcare services users with learning difficulties portrayed in the literature (Prasher et al. 2002, Davidson et al. 2003, Bigby 2004).

In my sample, people in registered care homes accessed healthcare services with a lower frequency than those in supported living. This was largely due to the percentage of men with forensic histories housed in the community. These men were able to take care of themselves. With the help and support of the learning disability staff they had begun to integrate into the community. They were still undertaking active treatment with the Consultant psychiatrist for their mental health problems, but were not seen by the medical profession as a risk to themselves, or the community. People in secure accommodation were usually sectioned under the Mental Health Act and had additional psychiatric needs that were closely monitored.

All informants were white Europeans. Within the community homes, there were only two people of Afro-Caribbean descent and no people of Asian or Chinese descent. However, this reflected the population distribution in the Brancaster area.

### **1.3 The People**

It would be unfair to launch any reader into a study without first familiarising them with the actors. If we consider the Ancient Greeks and their influence on modern day narratives, context was the first principle and characters, or actors, held the second place. The actors are people with learning difficulties whose stories have built this study from the foundations, removing the walls that were unnecessary, and providing windows into a world that only they

knew intimately. For this reason I chose to present the people first and their living situations second. **The names of all the informants in the summaries, and some of their circumstances, have been changed in an attempt to ensure confidentiality and preserve anonymity.**

I built the pen pictures of each individual from information they provided themselves, coupled with my observations, and knowledge from peers and people who knew them the best.

### 1.5 Biographies

#### Jack

Jack is a karaoke king; he has a passion for music, possessing an extensive knowledge of music lyrics, and he is a gifted artist with a prolific portfolio of artwork. He enjoys writing his diaries and interacting with people. He was admitted to St. Francis' hospital at the age of seventeen. Two events precipitated his entering the long stay hospital; the death of his beloved mother and his unstable mental health. Jack remembers his family life vividly. He has step-brothers and sisters who visit him regularly. He is now in his forties and resident in a hospital-based 'secure unit', detained, in his words, 'by the Home Office'.

#### Elisabeth

Elisabeth is in her thirties. She has always lived in the same community, firstly with her parents and then in her own flat with her husband. She is a quietly spoken young woman with a gentle air about her. She prefers not to work, finding daily life difficult enough. For the past eighteen months, she has lived in a hospital-based unit for people with learning difficulties, under a sectioning order of the Mental Health Act. The order started with her ill health towards the end of her second pregnancy, when she had what appeared to be a stroke. After Elisabeth gave birth, the baby and its older sibling were placed in the care of social services, being put up for adoption. Elisabeth did

not consent to the adoptions, and she is still struggling to come to terms with the loss of her children and the loss of her status as a mum.

### Mary

Fun oozes from every pore of Mary's being. She is bright, bubbly and lives alone in her own house. Mary is now in her late fifties. Her mother had learning difficulties and they lived with Mary's grandmother. Her mother predeceased her grandmother, leaving Mary alone with her. Mary is perhaps unique in many ways because her grandmother had the foresight to provide for her financially before she died. This financial freedom means Mary owns her own home (mortgage free) and can live where she pleases. Within reason she can afford a holiday and clothes when she chooses. She loves shopping, walking around the shops, not always buying, and just being in contact with people. Her worst enemy is loneliness. Selling her old terraced house in a gloomy narrow street, and moving to a light-filled detached house on a wide tree-lined avenue, has added a new dimension to her life because she can now visit her friends nearby and attend the church services. She attends the women's groups at the local vicarage and has become part of the community.

### Edward

Edward was admitted to hospital when his mother's health began to deteriorate. He was nineteen at the time. He is now fifty. He was originally housed in the long-stay hospital and can remember being frightened, attacked and stabbed by a resident. He still bears the scars of his institutional years and is very wary of new faces and people around him. He has lived in three separate homes in the community with other residents whom he has known since he was nineteen. Both his parents died whilst he was in the hospital. He was not allowed to attend their funerals because 'it might upset him'. He has since attended a funeral of a member of the staff. He found it upsetting but he recovered and understood that this was life. Edward has since made a

will and arrangements for his own funeral. Thinking about death has made him happy to be alive and he packs as much as possible into his days.

### Sam

Sam lived with his parents until his twenties when they both died suddenly within a short space of one another. He is now thirty. He reports that he has no living relatives remaining. Social Services (or the SS as he calls them) intervened and housed him with a landlady who is not particularly accommodating. He does not have his own kitchen or lounge and has to share with the landlady's family. Furthermore, he does not have a key to the house, and when returning from a trip out he frequently has to stand outside waiting for the family to return and let him in. Sam has problems with epilepsy, which is not very well controlled, and he has fits that frighten him. He has friends locally and is an active member and leader with support groups for people with learning difficulties. He travels the country going to conferences and meeting others, hoping to raise awareness concerning people with learning difficulties.

### Sandy

Sandy is forty. He is a genial man with a definite idea of his likes and dislikes. His main passion is horse-racing. He loves horses and watching them race. He enjoys the hustle and bustle of the track meetings, and the change of seasons that herald the change from flat racing to sticks (jumps). Sandy travels around the meetings, following the various trainers and jockeys, watching their form closely. His eyes light up and his face becomes animated as he discusses some of the recent meetings attended. Sandy lives under the supported living scheme, in a terraced house, with another gentleman, and outside help. He does not mention any family apart from his race meetings and the staff carer who assists him with meal planning and his daily living and health needs.

### Lisa

Lisa is a young woman in her twenties with profound physical impairments. Despite her physical impairments, she is a happy, attractive, outgoing young woman with an active social life. She lives in a local authority home, staffed by learning disability nurses and staff carers who attend to her extensive physical support needs. Finding a time when Lisa was available for interview was a problem. Lisa attends college and has a part-time clerical job, which she enjoys. Her family are regular visitors and supporters of everything she attempts.

### Anne

Anne is partially sighted and does not speak. However, Anne makes up for the vocal lack of communication in many other ways. She manages to communicate her needs and choices forcefully and assertively. Anne was institutionalised from an early age and now lives in a local authority home, with other people with learning difficulties. Anne came from a religious family. This link with religion has remained with her to this day and she delights in pictures of the Sacred Heart and the Virgin Mary. Anne has a documented photographic history of her life in an album, which she clutches fiercely. It is her most treasured possession.

### Austin

Austin is a 'gentle giant'. He speaks slowly but he has a fluent conversational ability. He enjoys sports, cycling and music. He has lived at home with his mother all his life and has recently been placed in a hospital-based 'secure unit' with men who have forensic histories, because of his temper outbursts. His home life is chaotic; one of his brothers is a drug addict and frequently steals Austin's CDs, selling them for drugs. His mother is struggling to cope with his brother and pregnant younger sister, so Austin sometimes gets 'forgotten'.

## Gordon

Gordon is a pensioner who relishes the fact he no longer has to work. He lives in a hospital-based forensic unit, because of his violent outbursts. His previous carer was an ardent walker and Gordon developed a passion for the outdoors, walking and taking his dog out. He misses his dog now that he is living in the unit and his staff carer has changed so he no longer goes out walking. He is trying to join the ramblers association but it is difficult if there is no member of staff to accompany him.

## Arthur

Arthur and his brother were both placed into a long stay hospital on the death of their parents. When the hospital closed they were housed separately in community homes with other people with learning difficulties. Arthur enjoys watching the television and this is from where he derives most of his news and information. Arthur is now in his late sixties. He is, however, very interested in his health, having had a heart attack a few years previously. His mobility was impaired after the heart attack, but he still manages to walk to the local shops where he buys his Guinness. Arthur loves gadgets and 'boys toys'. Anything fiddly and new draws his attention.

## William

William lives in his own council house, next door to a community home for people with learning difficulties. He has some support from carers and nursing staff. He has had a chaotic past and suffered a great deal at the hands of his stepparents. He is in his early twenties, attends college and has a part-time job. He frequently becomes anxious and nervous, especially in a new situation. High levels of anxiety make it difficult for him to relate and cause him to 'shut down' and block out the world. He loves cycling, gardening and being outdoors.

## Bernice

Bernice lives in a community home with other people with learning difficulties who are not as able as she. She is thirty (a mere baby next to me she said) and has a forceful personality. Bernice knows what she wants and makes sure her choices are listened to, and understood. Bernice has educated her carers into allowing her the autonomy to make a drink when she wishes. Bernice showed me how to make a drink for her friends whilst I was visiting, making sure it was not too hot so 'they didn't burn themselves'. Bernice likes fashion and knows a great deal about the styles of the moment, but says she would not like to wear some of the clothes that models wear because she would be frozen!

## Callum

Callum is another young man with a chaotic past. He has been in and out of prison, lived alone in a flat, and had a full-time job. He was moved to a hospital-based secure unit from a local prison. The prison, and the staff, could not cope with him and thought he had mental health problems. A psychiatrist, who specialised in learning disabilities, eventually saw Callum. On testing, his IQ was found to be below 70, giving him the label 'learning difficulties'. He also had mental health problems and was diagnosed with schizophrenia. Without these labels, he would still be in prison. If he had initially received more support, and a correct diagnosis for his mental health problems, many of his difficulties may have been avoidable. He is an engaging young man, loves the outdoors and knows a great deal about nature. He worked for the local council in parks and gardens for a period, and later in an abattoir. He knows a great deal about nutrition but says he would not know as much if he had not been to prison because the staff and inmates taught him a lot.

## Kieran

Kieran's smile is infectious. He has a very relaxed air about him. The smile is, however, at odds with his gaze, which can be quite disconcerting. He watches people intently, hungrily 'drinking in' their movements. He is thirty-five, having spent his teenage years in and out of the local long-stay hospital. He now lives in hospital-based accommodation. He knows he will be moving soon but does not know where to. He loves working and has City and Guilds qualifications in catering and food hygiene. He is aware that for most jobs these days you need qualifications (even to sweep the floor). He loathes inactivity and cycles everywhere to keep fit.

## Anthony

Anthony moved to a hospital-based community home on the death of his mother. He attended her funeral but could not understand why she left him. He still struggles with the loss so his advocate takes him to visit her grave regularly. His father blames him for the death of his mother, and Anthony feels this rejection keenly. All he wants to do is to go and live in his home with his dad. He does not understand why his father does not want him there. Anthony is now in his fifties and in the process of being relocated, but he has no idea where and does not want to move. He repeats himself frequently and needs constant reassurance.

## Derek

Derek is tall and slim. He loves his bike, the outdoors, and being with other people. He lived in a community home but moved to a key-ring home. This is a flat in a neighbourhood with other people with learning difficulties housed nearby. They all have access to seven hours support a week (Monday-Friday) from a designated flat staffed by health care workers. He has very few survival skills and needs to learn how to do things for himself. He is coping but admits he struggles, finding life lonely at times.

## Nigel

Nigel lives in supported accommodation with two other men of a similar age. He is in his late twenties, is a keep-fit fanatic, plays golf regularly, runs, takes part in marathons, and walks dogs part-time for the RSPCA. Nigel does a great deal of voluntary work because he says he likes to feel useful and feel as though he is 'putting something back in'. He would love a paid job but says nobody wants him. He is reserved, speaking only when he feels it is necessary and when he has something that is worthwhile to say.

## Dennis

Dennis loves attention. He loves company and wants to chat to everyone. He is waiting for his flat to be finished so he can move in. He enjoys his own space and resents living in a hospital-based secure unit. He moved to the unit because he has frequent violent outbursts. Dennis loves travelling by train, coach and bus. Seaside visits are his favourite; a mere sniff of the sea air makes him feel good. Being brought up by the seaside with happy memories of his parents means he returns to the areas where he felt happiest. Both his parents are now dead and he misses them sorely. He was involved in a road traffic accident when he was a child and this left him with epilepsy and residual brain damage. He remembers life before the accident vividly, describing his happy home life and his parents. He is now in his forties, still travelling and exploring places. His idea of heaven is to take a journey on a bus or train and explore when he reaches his destination.

## Joe

Joe is in his eighties. He remembers the war, and the subsequent change in the area where he lives. Joe went into hospital when he was eight with a severe chest infection and never came out. He transferred to the long-stay hospital where he grew up, and later moved to a community home when the hospital closed down. A carer became interested in him, and because Joe is a devout Catholic, she went to the local priest to see if he could trace any

living relatives. It transpired that Joe had a large family living nearby who had presumed he had died when he was in hospital. At this stage, Joe had been living in institutions for over fifty years. His family visited him until one-by-one they died. Joe has nieces and nephews but they choose not to keep in touch.

### Haydn

Haydn is a frail man of pensionable age. He is a wheelchair-user and feels frustrated by the confines of the hospital-based unit that he lives in. He was moved to the unit because his epilepsy has worsened and he needs constant nursing support. He would like to get out more but his mobility is a problem. His brother-in-law visits when he can and takes him out but he has a family to care for. Haydn visits his sister's grave and lays flowers for her on her birthday, Christmas and the anniversary of her death. He still works at the poly-pipes factory (which is a small unit employing people with learning difficulties to manually join sections of plastic pipes together) because he likes to feel useful and admits to boredom, he also likes the contact with other people who are more alert than the other people he lives with.

### John

John's appearances are deceptive. He is eighty, a wheelchair-user, and appears to be uninterested in the world. How wrong our assumptions can be! John has a wicked and keen sense of humour. He is an astute observer of life around him and can weigh people up very quickly. He is aware of his rights, preferring to be spoken to directly, not through the person aiding him with his wheelchair. John lives in a community home with other people with learning difficulties who have varying abilities. He is interested in sport and takes part in the annual disability Olympics. He enjoys old War and Western movies. John Wayne is his favourite actor.

### Paul

Paul is another pensioner. He has an encyclopaedic *memory concerning* music from the sixties which was, in his words, 'the best time for music'. During his teenage years, from Monday to Friday, he lived at the long-stay hospital whilst his mother worked. When she died, he no longer 'went home' at weekends. By this stage, he had been transferred to a community home with other people with learning difficulties. He started to run away because 'he could'. It is probably significant that he chose the weekends to 'run away'. He has had three bone fractures; the latest was a hip. Now he walks with a frame and his lack of mobility prevents *him from running* anywhere. He has recently moved (under duress) to a large bungalow with four other men who have mobility problems and learning difficulties. The bungalow is miles from anywhere. There are no local shops to walk to, or people who know him with whom he can spend the time of day. Instead, he stays in his room and listens to his music, chatting to whoever will listen.

### Roger

Roger is in his forties and lived in community homes nearly all his life. He is a wheelchair-user, but this does not prevent him from going out and powering around the community home he in which he resides with other people with learning difficulties. His passion in life is Country and Western music. He is prepared to talk at length and play sections of music to anyone who shows an interest.

### Seamus

Seamus misses his family. He is thirty-six. He dislikes living in community homes although he is very happy in his current residence, which is a supported tenancy. He attends college on a daily basis. He is a helper for people with physical impairments and an advocacy worker. Seamus likes people and he enjoys being with different people. He is also good at keeping house, cooking, ironing and looking after himself. He takes pride in his

appearance. Seamus changes situations where he feels his rights are infringed; if a healthcare worker is offhand he questions them. If he does not receive satisfactory treatment, he moves to someone who treats him with respect.

### Dave

Dave loves football and indeed any kind of sport. He is in his thirties and lives in supported living accommodation, enjoying the relationship he has with the staff. He feels supported and trusts his key workers. This has given him the confidence to try to be a member of the community in which he lives. Dave has his own allotment and tends this with a next-door neighbour who has helped him grow his own vegetables, which he brings back for his friends to share. Dave attends college and the local gym to keep fit. He feels good about himself and likes being occupied and doing different things.

### Irene, Susan, Noel, Liam and Mike

This group is inseparable, although Mike now has the chance to move into his own flat. They all live in the same community home, a detached council house on an estate, two minutes walk from the local shops and bus stops. Mike is the spokesperson for the group. They all look to Mike for the answers. Each member of the group, apart from Mike, is a pensioner; some members are in their eighties. Mike is the youngest, in his early forties. It was difficult to gain an ‘understanding’ of each separate member, apart from Mike, because they all appeared to ‘speak as one’.

## **1.6 Commentary**

In relation to the focus of my study - healthcare encounters – it is important to bear in mind the varied living situations, and differing levels of support of people with learning difficulties. Some people with learning difficulties are extremely articulate and live independently with minimal support. Others have complicated medical histories or mental health problems and need one-

to-one support from a staff carer. They live in community homes or secure units. I am interested primarily in health-care decision-making, issues around capacity, autonomy and how people with learning difficulties are supported to make decisions. Context becomes crucially important when I start to look at how people with learning difficulties in hospital-based and forensic settings make decisions, in comparison to people with learning difficulties in their own homes or in other community based residences.

The next section provides information about the living accommodation of the people with learning difficulties in the study.

### **1.7 Brancaster 'The Field'**

To protect the anonymity of the people in the study I have changed the area and street names. The following description of Brancaster was taken from the 2001 Census.

The population of Brancaster has declined since the 1990's because the heavy and extractive industry characteristic of this area has significantly reduced.

There are high percentages of people in Brancaster who are either on long term sick or in poor health. Nearly a tenth of the population are permanently disabled and receiving disability living allowance or attendance allowance which is 3% more than the national average. The highest areas for long-term illness are in the former mining areas. This places Brancaster as the fourth highest in the whole of England in terms of percentages of members of the community with long-standing illness or disability.

Brancaster also has fewer people in professional occupations than the national average but more people in skilled or service occupations.

Brancaster is 2% lower than the national average for owned property, communal group homes are 3.2% above the national average. Housing association homes are also 0.7% higher than the national average. The most

common types of accommodation are semi-detached houses, followed by terraced, detached houses, and flats. Private nursing and residential care homes are also 8.2% higher than the national average.

On the next page, Table 1.2 depicts the areas and homes that I visited.

**Table 1.2 Profiles of areas and homes visited**

<u>Area</u>	<u>Male</u> %	<u>Female</u> %	<u>White</u> %	<u>Asian/Black</u> %	<u>Employed</u> %	<u>Retired</u> %	<u>Disabled</u> %	<u>O*</u> %	<u>M*</u> %	<u>C*</u> %	<u>Ot*</u> %	<u>Homes</u> <u>visited in</u> <u>this area</u>	<u>RM*</u>	<u>RF*</u>
<u>Furby</u>	49	51	99	1	58	16	13	23	31	34	12	Babylon Lane/Steel Rd	12	6
<u>Candle</u>	47	53	99	1	67	14	11	25	37	30	8	Hurley St	13	3
<u>Spelsby</u>	50	50	93	7	46	20	17	4	5	74	17	Band/Tyke St.	15	0
<u>Trottingly</u>	46	54	96	4	70	22	6	36	40	15	9	Robins Rd	0	8
<u>Bookton</u>	48	52	99	1	70	16	9	30	38	22	10	Troutbeck Dr.	5	8
<u>Outwell</u>	49	51	96	4	65	17	8	28	33	31	8	Ardoyne Rd/Lee St	5	3
<u>Pointon</u>	51	49	90	10	69	15	7	30	38	6	26	Vicarage Walk	5	4
<u>Albertsfield</u>	48	52	98	2	76	16	5	35	50	6	9	Birch Ave	2	6

**Key:** O\*-home owned outright, M\*-home owned with mortgage, C\*- home rented from council, Ot\*-any other form of accommodation, RM\*- number of male residents per home, RF\*- number of female residents per home.

## **1.8 A brief description of the homes and living environments**

At the time of the fieldwork, there were thirty-five homes for people with learning difficulties located in and around the Brancaster area. The properties included some 'ordinary' houses, or semi-detached and detached houses on streets in residential areas, bought by and maintained by the local NHS Trust. Other properties were purpose-built bungalows, owned by a housing association, and registered with the local authority. Some houses were rented from a Housing Association and there was one registered bungalow, which was a joint venture between the Trust and the local authority. These homes were staffed by an assortment of paid carers, learning disability nurses, and a home manager or team leader. For ease of reference, I shall refer to them as 'community homes'.

In addition to these community homes were six purpose-built bungalows and three semi-detached houses in the grounds of St. Francis' Hospital. St. Francis' Hospital is the old long stay hospital that was closed in the 1970s when the people with learning difficulties who had resided there were resettled in the community. Four of the bungalows are for people with profound learning difficulties, people who needed monitoring due to recent health changes, and for people for whom there is nowhere else to go. The other two bungalows are linked by a communal hallway, but are classified as 'secure' and used to accommodate people with forensic histories. Forensic units tended to have higher staffing levels compared to the other units.

There are three houses on Burntwood Drive, near to St. Francis' Hospital, which are halfway houses for people ready to live in supported accommodation. Supported accommodation is a flat or house that is either shared with another friend of choice, or occupied by one individual. Support is provided according to assessed need. For example, if an individual is able to cope with everyday personal care and shopping then they would access a support worker at a known address in the community, if any problems arose requiring assistance. For people who require higher levels of support, paid

carers or learning disability nurses would be present daily. The houses on Burntwood Drive, for some unexplained reason, remained absent from the lists that the nursing staff gave me. People living in the secure units alerted me to their presence and I visited them later in the study. Burntwood Drive and the purpose built bungalows are staffed by a mix of male and female learning disability nurses, general nurses, and paid carers, working on a rotational shift pattern. The homes are immediately identifiable by their personnel uniformity; different coloured shirts denoting seniority, red for senior members of staff, or head of the unit, green for qualified nursing staff, and blue for unqualified carers, all worn with navy trousers. Additionally, these units ran like mini-hospitals with hospital-based routines, regimes, and staff on a hospital shift rota. Within this study, these homes are referred to as 'hospital-based units'.

In total, the assorted homes housed approximately 201 people diagnosed with learning difficulties. I use the word approximately because the Trust was in flux during the study and people were being allocated to different homes and flats in the community. Burntwood Drive and Steel Street (a home in Furby, housing 8 people) were in the process of being closed altogether.

I will briefly describe the homes, and the surrounding neighbourhoods that I managed to visit during the fieldwork. I endeavoured to visit as many homes as possible but time constraints and geographical distances prevented me from visiting every home in the area.

### Band Street.

Band Street is a purpose built Local Authority bungalow. It is a joint venture between Brancaster Trust and Brancaster Metropolitan Borough Council. Having two landlords causes difficulties when routine maintenance work is needed on the building; Brancaster MBC is responsible for the structure and drains, Brancaster Trust is responsible for interior repairs. However, there are times when the status of a repair overlaps. This causes arguments, and leaves the home in limbo. You approach the Band Street bungalow through

a housing estate; the surrounding houses are a mixture of council and private tenure. The area appears well kept, and the bungalow has a large car park attached. Entering the bungalow is like entering any other private home; doorbell, papered hallway, carpeted floor, mirror on the wall, and pictures depicting rural scenes. One of the first rooms off the hallway contains a floor to ceiling glass tube, the circumference of an old tree trunk. The tube is filled with water and soothing bubbles are passed through it. This is a therapy room where gentle music is played, and relaxing activities take place. There are various other rooms off the corridor with a kitchen, staff toilet, and main toilet. There is also a bedroom/office for the member of staff sleeping in the bungalow in the evenings. Within the office is a locked medicine cabinet containing medication for the eight residents who live there. The residents are all profoundly impaired with high individual communication needs. They do not share a common system of communication. They also have a diversity of health problems. None of the residents were in paid employment, and many spent their days in the day care centre at St. Francis' hospital. The residents were registered with different GP's because the local practice would only take on a limited number of people with learning difficulties. This created problems when more than one resident was ill and different practices needed to be attended; there was one vehicle and this meant that a driver plus another member of staff was required as an escort. Logistically, this meant losing two members of staff and the transport, which occasionally meant cancelling booked fun days out for the residents.

### Babylon Terraces.

These are two purpose built bungalows. A Housing Association provides the bungalows. The approach to the bungalows is through a mixture of council and privately owned property. There is a small village centre with shops and a main bus route. Each bungalow has a back garden, used infrequently by the residents. The bungalows are a cross between a hospital ward and a home; they are large and impersonal. The lounges are 'L' shaped, and dominated by a large television screen, and an eating area. Both bungalows have the same physical layout and house six people. The staff comprise

learning disability nurses and paid carers, working rotational shifts. People living here have mixed abilities; some are physically impaired but they possess greater cognitive skills than their peers at Band Street.

None of the residents were in paid employment and many attended the day care centre at St.Francis' Hospital. Once a week the local community hall was hired, and an exercise facilitator came down to do movement to music. The level of communication differed from person to person, but most people were able to articulate verbally. People that lacked verbal fluency had their own system of communication that staff interpreted, until the other party in the communication environment felt confident enough to take a lead. Health requirements were mixed; some residents required regular medication, struggling with fluctuating good health. Residents in the bungalows all attended the local GP. Even though the GP is a mere twenty yards away, confusingly there are access problems. The staff reported difficulty in obtaining appointments for residents. Apparently, they have to telephone before half past nine in the morning. If they call later than this they are given an appointment for the next day, or the day after. Additionally, some doctors at the practice refuse to see the individual, instead asking for a report from the learning disability nurse. They then make their diagnosis from this report.

### Hurley Street.

These are four late 1970s town houses in a large estate, supplied by a housing association. They have tiny rear gardens, just big enough for two deckchairs, all open plan, with a large communal grassy area behind. The approach to the houses is through a run down council estate. The car park behind is littered with broken glass. The whole estate appeared heavily littered with rubbish and dog excrement. I felt distinctly unsafe walking down the street towards the houses. Inside, the houses feel small and cramped. The staff are learning disability nurses and paid carers, working rotational shifts, the homes house sixteen older people with learning difficulties, with a mixture of abilities and communication problems. Nobody was in paid employment and most residents attended the day care centre at St.Francis' Hospital. The health of

some of the people was closely monitored. Any severe change in health meant a move for the individual because the homes belonged to a housing association and could not be adapted for anyone with a severe health problem. This is contrary to the 'ageing in place' policy of the NSF for older people (DOH 2001c). The staff reported that the main problem was being unable to provide a safe area for the residents to wander about freely.

### Steel Street.

This home closed in 2003 because it did not comply with the 1990 NHS and Community Care Act.

### Church House.

This house is owned by Brancaster Trust. The approach is through a private residential area, comprising a mix of terraced, semi-detached houses and detached houses. Shops are within walking distance from the houses. Church House has a small well-kept garden. First impressions are that the house is uninhabited because there is no movement within, and the closed blinds prevent the inside of the house from joining the outside. Stepping inside I felt like an unwelcome intruder. The lounge was big and impersonal; divided into a lounge and dining area. Again, a large television screen dominated the lounge, but there was very little that made the house a home. The blinds made the room dark; it felt like a sick room, although there was little evidence of anyone being ill. The kitchen was galley style and off the lounge. There was a downstairs cloakroom and the bedrooms and main bathroom were upstairs. The houses accommodated four people, some with profound learning difficulties and impaired communication. Most people used a simplified version of sign language (Makaton) that they had adapted so they could talk to each other but their carers still found it difficult to understand them. Nobody was in paid employment and most people attended the day care facilities at St. Francis' Hospital. The houses were staffed by male and female learning disability nurses and paid carers,

working rotational shifts. The local GP's were happy to take all the residents onto their list and the practices appeared reasonably accessible.

### Lee Street.

There are two adjoining 1950s semi-detached houses on Lee Street, owned by Brancaster Trust. They are jointly accessed from the rear. Each house has its own driveway and private garden. The houses are in a small cul-de-sac of privately owned houses, each with their own neat garden. The approach is through a private residential area, similar to any other suburban residential area outside a main town. There are shops within walking distance of the houses. Stepping inside the houses is like stepping inside the home of a favourite aunty. They felt homely and safe. The layout is similar to any other semi-detached house; lounge, dining room (doubling as a staff office), kitchen, sunroom, and upstairs are the bedrooms and bathrooms. Eight people with a mixture of communication disorders and behavioural problems live between the two houses. Nobody is in paid employment and most people attend the day care at St. Francis' Hospital.

Staff mentioned how they did not like to 'rock the boat' and challenge the psychiatrists if they failed to turn up at a designated appointment. The reasoning was that they thought they would get a better service if they stayed quiet, avoiding being labelled as troublemakers. The local GP was not particularly understanding or accommodating and appeared to be frustrated by the nursing staff when they reported raised temperatures but could not give a full diagnosis of an individual's problem. The local pharmacy ran a system for delivering the medication.

### Ardoyne Road.

These are two adjoining 1950s semi-detached houses in a narrow suburban residential street. The houses are owned by Brancaster Trust. Each house has its own garden, but whenever I visited the residents were always indoors. The approach is through a residential housing estate, laid out in fifties style,

not far from a large park and shops. Each house has a lounge, dining room (doubling as staff office), and kitchen. Bedrooms and main bathroom are upstairs.

The houses provide homes for eight people. Some have part-time jobs at the local fast food outlets, and others attend the day care and poly-pipes at St.Francis' Hospital. Poly-pipes is a work placement for people with learning difficulties. The work consists of fitting sections of plastic pipes together, for approximately £3.20 per hour.

The group living in the homes are between mid-forties to early seventies, and there is much diversity between individuals in relation to their abilities, health, and levels of communication. Most people living in the house have known each other from St.Francis', before its closure. The atmosphere within the houses is relaxed. The staff are a mixture of learning disability nurses and paid carers, working rotational shifts. Each individual is assigned a named carer.

### Birch Avenue.

These two homes were extremely difficult to find and are located on the outer reaches of the Brancaster Trust catchment. The properties are approached through fields and there is a small council estate nearby. A housing association provides these purpose- built homes. A low fence surrounds a small garden, enclosing the properties. Externally, the appearance of the larger property is one of a modern clinic. Internally, at the entrance is a staff office. The layout reinforces the 'clinic' feel. A corridor leads to a large lounge dominated by a television, and a smaller lounge where people can sit if they do not want to watch the television. There is a kitchen, which remains locked, and then further down the corridor are the bedrooms and bathrooms.

Eight people live here. They have varying abilities and additional communication impairments. Nobody is in paid employment and most

people attend special education centres and St. Francis' day care facilities. The staff are a mixture of male and female learning disability nurses and paid carers, working on a rotational shift pattern. The staff feel that one advantage of the layout of this particular house is that should a resident become terminally ill then the home can be easily adapted to nurse the individual in their own surroundings.

### Tyke Street.

There are three town houses on this street, all owned by Brancaster Trust. These houses feel and look like ordinary homes. They all have a lounge, dining room (doubling as a staff office), and kitchen. Bedrooms and bathroom are upstairs, and outside, at the rear, is a small, enclosed garden. This is a well-established residential area. Most of the houses are privately owned. Shops, GP, dentist, and optician are all within close walking distance. Seven people live here. They are aged between thirty to their early fifties, and all have different health needs. All the people living here are verbally articulate. Everyone here participates in voluntary or paid part-time employment; nobody attends the day care facilities at St. Francis' Hospital. The staff are male and female learning disability nurses and paid carers. Additionally, a group of volunteers assists with finding diversionary activities in the local community.

### Troutbeck Gardens

These are two purpose-built bungalows, leased from a housing association. They are in the middle of a run-down council area. The approach is through a mixed residential area that just 'stops' and is replaced by houses that are in various levels of disrepair. There are no shops or facilities nearby. The buildings resemble new health centres and the layout is very similar to the other purpose-built homes in the Brancaster area. There is a therapy room and a treatment room. The buildings house thirteen people who have a range of profound physical, cognitive and communication impairments. Most people attend the day care facilities at St. Francis', or the local Social

Education Centres. The staff are male and female learning disability nurses and paid carers. The local GP surgery attends to any routine health requirements, referring people on to relevant consultants when more specialised advice is required.

### Vicarage Walk

This is a large Victorian house on a main road with a pleasant garden at the rear. Most of the houses are privately owned. There are open grassy areas nearby. From the outside, the house is large and imposing. The interior feels the same. There are two lounges, both dominated by a large television screen, a kitchen and dining room, staff offices and various other rooms. The house gleams, is clinically clean, and is home to eight well-scrubbed people with a range of physical, cognitive, and communication impairments. Nobody is in paid employment, and the majority of people attend day care at St. Francis' Hospital. The home is staffed by male and female learning disability nurses and paid carers, working rotational shifts.

### Robina Road

Five minutes walk from the local shops in the middle of a large residential estate, this house has a large garden and from the outside looks like the other houses nearby. It is owned by the Trust. Inside, the house feels like a home; the lounge was divided in two, with a dining area adjacent to the kitchen. Six people live here, some work part-time; others attend day care at St. Francis' Hospital. The people have a diverse range of cognitive and communication impairments, and varied health needs. The staff at the home are male and female learning disability nurses and paid carers, working rotational shifts.

### Sansiveria Road

This large detached bungalow is owned by the Trust. It is located in a private, well-manicured, residential area. There are houses for miles, but no shops or leisure facilities. Transport is essential to reach these facilities.

Four people live here with varying physical, communication, and cognitive impairments. One person works part-time and attends the local college of further education. All people attend day care at St. Francis' Hospital. The home is staffed by male and female learning disability nurses and paid carers.

### **1.9 Experiencing the homes**

I was a privileged outsider to the homes. My main intention was to listen, observe and identify people who were willing, and able, to discuss their healthcare experiences. In her study of residential homes, Atkinson (1998, pp20-21) talks about making 'creative leaps' about what it would be like to live in a particular place. These creative leaps are based on intuitions, impressions and subjective experiences of a home. Like Atkinson, I noted how many staff used the analogy of 'family' to describe the relationships, everyday working, and atmosphere of the homes. One member of staff at Tyke Street even likened herself to a mother to the people living in the home.

Another member of staff at Steel Street called the people her 'extended family'. At Babylon Terraces, a staff member reported that choosing a holiday (for the people in the home) was like any other family choosing a holiday. Many people with learning difficulties privately said that there were people living in the home that they did not like and would not be their choice of friend. Thinking of people as a family rather than individuals can lead to what Booth (1993, p.161) calls 'unthinking compliance'; because everything is decided and done by other people. Furthermore, Booth argues that this can also lead to a kind of enforced helplessness because people do not feel free to express their thoughts as individuals. Additionally, a carer projecting a parenting role, albeit intentionally as a caring function, reduces the other adults to the status of children, denying their right to operate as autonomous individuals.

Babylon Terraces adhered rigidly to the 'family' approach. On one visit, a resident whom I had called to see had barricaded herself in her bedroom, refusing to come out. The home manager said it was a 'bad day', and that

just like the rest of us, people with learning difficulties could have a bad day. I listened and watched, and discovered that the 'bad day' was a stand against having to go to day care, with everyone else, in the same bus, at the same time, to do the same thing. Every resident here had to wear a plastic apron at meal times. The individuals living at Robina Road reminded me of 'The Borg' (a group of life forms from the science fiction series Star Trek who operated as a single unit, each thinking each other's thoughts); they ate, talked, and appeared to think 'as one'. Even when I visited to talk to them, the staff called everyone to the table together so I effectively had a focus group that only functioned as a unit, not as a result of individual interactions. Similar to 'The Borg' these residents had been 'assimilated'.

Alternatively, staff who encouraged autonomy, individuality, and risk-taking were more likely to involve people in everyday choices. Band Street had a new resident who had taken to lying on the floor in her previous home, refusing to move. The staff at Band Street discovered that this particular individual was very anxious about change. Their solution was to allow the resident to remain in the home if she felt too anxious to leave. The person concerned no longer lies on the floor or refuses to move.

The staff at Tyke Street, in particular, encouraged and supported people to develop individual interests, go on outings, and develop lifestyles that they enjoyed. There were still group outings, but usually these were for activities that needed group interaction like ten-pin bowling.

#### **1.10 Differing care regimes**

I observed that staff attitudes differed from home to home. Some staff appeared supremely organised and efficient and 'in control'. The homes gleamed, there was nothing out of place, and even the people living in the homes appeared 'ironed into place'. Vicarage Walk, in particular, smelt of furniture polish as I entered the house.

Other staff members in different homes were more relaxed; shoes and umbrellas in the entrance hall, sports kits packed ready for the off, magazines and books on tables, the odd CD lying around, personal possessions of the residents on tables or mantelpieces. These were little things that made a home feel 'lived in'.

Rather than adhere to a rigid routine some homes attempted to break with routine at weekends. I turned up at Troutbeck Gardens, early on a Saturday morning and helped with preparing and serving the breakfasts. The staff broke with routine at the weekend and the people living in the homes had a lie in, and a late cooked 'brunch'. Friday night was activity night and people went to bed when they were tired, rather than at a set time.

The stark contrasts came from the hospital-based units where, despite a fully functioning kitchen, meals were delivered from St. Francis' Hospital in a meal trolley and had to be ordered one week in advance. Some units tried to 'think round' this system and had bread, cheese and tins of meat and fish in the kitchen, in an effort to accommodate everyone's needs. Medicines were dispensed on a spoon (even if the person was capable of self-administering their medication) at a set time. There were washing machines and driers in the bungalows, but laundry was collected and delivered by the hospital at a set time. Meals were all at a set time. People started their mornings and went to bed at the same time, the staff changed shifts at a set time. Staff meetings were held in the same room, on the same day, same time. The community dentist and chiropodist visited the homes and saw people for check-ups, and treatment at the same time. All paperwork was in quadruplicate, meaning that the staff spent a great percentage of their time filling in charts and reports rather than interacting with the residents.

Five minutes after I arrived at one hospital-based unit a resident became distressed. This affected all the other residents and every member of staff was pushed to the limit trying to restore order and calm. I sat on the floor with one resident, singing his favourite song with him. After restoring calm, a detailed report had to be made out in quadruplicate by the senior member

of staff. Whilst in the process of writing out the report, another incident occurred, requiring yet another report. There was little autonomy for the residents here, but the administrative work and form filling appeared to take time away from the active support of the residents.

### 1.11 Summary and Conclusion

My overall impression, based on visits and conversations with staff carers and residents, was that the few homes that took a more individualised approach appeared to offer a more varied life for individuals. These homes attempted to build choice and decision-making into everyday life for people; risk-taking was encouraged, as was learning from mistakes. This appeared to result in more positive outcomes for both staff and residents. Everyone's views were valued in these cases. 'Family' or group approaches appeared to be the catalyst for individual dissatisfaction because of the rigidly enforced routines, coupled with lack of choice and autonomy. There was also conflict between residents who did not enjoy the company of people they did not like. The regimes of these homes meant that residents were 'stuck' with one another nearly every waking moment of their day.

However, these are snapshot impressions based on three or four visits to each home. Visits on different days with different staff teams could have produced different impressions. My depiction of the homes is comparable with the descriptions of residential care by Atkinson (1998). However, some of my depictions run counter to policy expectations within 'Valuing People' (DOH 2001b). Sansiveria Road is one example of people with learning difficulties housed miles from anywhere and in need of transport to access any facilities, making them totally dependent on staff carers. Furthermore, Valuing People recommends housing people with learning difficulties in smaller units, counter to my observations at nearly every home apart from Tyke Street. Additionally, there appeared to be little choice for some people as to where they lived.

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In addition to changes in how people with learning difficulties live, Valuing People recommends modernising large institutional day centres. The majority of homes that I have described were reliant on the large day centre in the grounds of St. Francis' Hospital which provided a limited contribution towards promoting independent living or social inclusion for people with learning difficulties. Only Tyke Street appeared to make an effort towards promoting independent living by using the local colleges, community facilities and using voluntary support workers (usually from the immediate area) to assist residents with integrating into the local community.

## Chapter 2

### **Professional Knowledge, Policy, and the Individual Model of Disability**

#### 2.1 **Scope**

In this chapter I seek to outline the progression of policy recommendations concerning healthcare, and introduce the medical deficit model of disability and its links with medicine. I intend to look upon medicine as a body of knowledge based on 'objective' scientific principles, linking it to the grand narratives of biomedicine and epidemiology, arguing that medical narratives have often been used to persuade people of 'the way things are'. Persuading people of 'the way things are', means that professional knowledge is used to define what is 'normal' and therefore this knowledge is used to diagnose and treat a disorder, or derivation from what is 'normal', as a 'case' (Brown et al. 2003). I intend to adopt the approach used by Davey and Seale (2002) in using 'professional', 'case', 'medical', and 'biomedical' knowledge interchangeably.

In contrast to case knowledge are 'patient', 'person', and 'communicative' knowledge, where the individual will have a more meaningful understanding of their health (Liaschenko 1997, Mead and Bower 2000). I will explain and examine these different types of knowledge in greater depth in Chapter 3. Using case knowledge to define what is 'normal' also defines the type of relationship in the healthcare encounter which is traditionally practitioner-centred (Stewart et al. 2003).

However, contemporary policy argues that the healthcare relationship should be more person-centred. This appears to mean that different types of knowledge need considering to facilitate this approach (DOH 1998b, 2001b, 2003a&b). I will argue that there is a tension between policy recommendations and the medical deficit model of disability because medical knowledge is scientifically driven and intimately related to power

structures that can easily marginalise other forms of knowledge and experience.

This tension between policy recommendations and the medical deficit model focuses on the relationship between professionals and people with learning difficulties in the healthcare encounter. Previously, healthcare encounters have been traditionally practitioner-centred and professionals made all decisions, with little or no reference to, or inclusion of, the individual (Lancioni et al. 1996, Charles et al. 1997, 1999, Stewart et al. 2003). In many situations, people with learning difficulties have been treated 'in their best interests'; with little identification of whose interests decide what is 'best' (Lovett 1996, Edge 2001, Beamer and Brookes 2001). For example, Booth and Booth (1994, 1998) produce research evidence of the forced sterilisation of people with learning difficulties, and many of those who have managed to escape sterilisation and have children the outcome has often been the removal of their children, with all the personal and social consequences that this brings.

Over the past 40 years, there has been a gradual move away from institutionalised care towards the inclusion and participation of people with learning difficulties in the community. Early ideas were influenced by the philosophy of normalisation (Wolfensberger 1972) and latterly by ideas about independent living (Holman and Bewley 2001). However, many decisions were still based on the judgement of individual capacity, rather than offering the person support to make a decision for themselves (Edge 2001, Beamer and Brookes 2001). Beamer and Brookes (ibid.) argue that people with learning difficulties are offered little choice in decisions about their lives. Arguably, deciding what to eat on a daily basis carries far less practice implications compared to deciding whether to have a major operation. It would therefore appear that the significance and personal implications of decision-making warrants consideration in relation to healthcare in terms of the seriousness and irrevocability of a decision.

Keywood et al. (1999) argue that people with learning difficulties need other parties who know them well (usually their main caregivers) to help them make decisions in healthcare encounters. Helping people with profound learning difficulties may mean interpreting their method of communication, raising as it does, the issue of intermediaries. Keywood (2003) identifies issues in relation to main caregivers who may experience overlapping and conflicting roles as gatekeepers, decision-making proxies and advocates. I will revisit the roles of staff and decision-making in Chapter 9.

In this chapter, I describe professional knowledge and introduce the individual model of disability and its links with professional knowledge. I also include a table of the recent changes in healthcare policy that are reflecting a paradigm shift in patterns of knowing and types of knowledge, and highlight the policies that have particular relevance for people with learning difficulties. I conclude by looking at emerging policy themes and the nature of decision-making and identify the parties involved in healthcare decision-making processes, and their roles.

## **2.2 Professional Knowledge and the Individual Model of Disability**

*‘The work and approach of the medical profession are based on the scientific method, defining science in the strictest sense of the word, namely the systematic observation of natural phenomena...As an integral part of the society in which we live, scientific methodology is generally held to be an acceptable basis on which to set reliable judgement....’* (British Medical Association 1986, p. 61)

This statement from the British Medical Association implies that medicine is a body of knowledge based on objective scientific principles. However, the foundations for this biomedical model of health and disease were laid in the early nineteenth century (Brown et al. 2003). This was when biological principles joined with the practice of medicine, and practitioners employed the scientific process of observing objective facts used to deduce the nature of an organism, to discuss the body. Clinician-pathologists used signs and

symptoms from their clinical enquiry, linking them to the descriptive data of morbid anatomy, and a classification system began to emerge. Pasteur and Koch's discoveries gave the predictive value of using this system more scientific credibility because they identified specific causal agents in the disease process. Disease can therefore be isolated, treated, and cured because it is something located within the body and separate from the person.

Since the early nineteenth century, biomedicine has developed its own language and associated practices that reinforce the discourse of medicine. As an illustration, Stewart et al. (2003) give examples of medical practitioners in training, transmitting knowledge and learning about people as 'cases'. They describe the process of learning about the person as a case as follows; a presentation consists of a perfunctory description of the patient, followed by the history of the present illness, past medical history, any associated family medical pathology, patient profile and findings of the examination of the body. Next are the usual investigations, blood tests, x-rays, pathology reports etc., then a list of potential diagnoses and a treatment plan. This process transmits medical knowledge quickly in clinical settings, and during oral presentations in front of peers and senior medical personnel. It is also a way of socialising young practitioners and reinforcing a particular type of knowledge. This particular knowledge is heavily dependent on scientific language. Using this type of knowledge does not necessarily require the voice of the person it concerns. The process is merely one of gathering information to construct a category that will inform treatment and guide prognosis.

Case knowledge uses deductive approaches and formulates a hypothesis about the patient from factual or objective information, from the medical records, or examination of the patient (Fairhurst and May 2001). The result is that the practitioner presents a unilateral set of medically oriented facts about the person, but the interpretation of the facts may not necessarily be shared with, or by, the individual concerned. The individual becomes a classifiable, describable, analysable object.

The general problem of health in populations became, broadly speaking, a problem for governments in industrialised nations because there was a need for the preservation and upkeep of a labour force (Rabinow 1984). The population became a problem, an object of surveillance, analysis, modification and intervention. Foucault (1973) argues that the population became a technological project as demographic estimates, life expectancies, levels of mortality, population growth, birth rates, reciprocal relations in growth of wealth and the growth of the population, alongside training and education emerged as a means of developing and improving the existing population.

Davey and Seale (2002) suggest that an example of joining bio and behavioural medicine with policy is that of the smoking campaign, originally emerging in the 1970s, with doctors warning patients of the effects of smoking. The campaign gained prominence in the media. Cigarette packets and advertising carried a government health warning as to the dangers of smoking, and clinics emerged specialising in treating people to stop smoking. Medical knowledge became a powerful persuader in its position of authority regarding health care. Nevertheless, Oliver (1990) argues that the biomedical model was not originally concerned with prevention, and that since the twentieth century we have seen an increase in the medicalisation of society. He gives examples of doctor involvement in assessing driving ability, prescribing wheelchairs, determining allocation of financial benefits, selecting educational provision and measuring work capabilities and potential. Oliver (*ibid.*) questions why medical knowledge and qualifications should make a doctor the most appropriate person to be involved with these assessments, which really require very little medical knowledge.

However, Oliver's (*ibid.*) main objection is medicine's dominance in the lives of disabled people, and whilst he acknowledges the substantial gains from the medicalisation of disability, he criticises the negative and impartial view that accompanies medicalisation. Illich et al. (1977) give examples of medicalisation as; the retention of absolute control over technical procedures, the expansion of what in medicine is deemed relevant to the 'good practice'

of life, e.g., amelioration of disability, the retention of near absolute access to certain areas, e.g., pregnancy, emotional problems, ageing, drug addiction...etc., and the expansion of medicine's commitment from a specific disease model of health to a multi-causal model.

Oliver (1990, 1996) argues that the medicalisation of disability originates from the centrality of the 'expert doctor' in the lives of disabled people. From birth, the medical profession uses case knowledge to classify, describe, analyse, and objectify people with disabilities. The classification of people with disabilities means that they have a label attached to their particular condition e.g., cerebral palsy, Down's syndrome, spina bifida, paraplegia, autism, Asperger syndrome, Williams syndrome...the list appears endless. Accompanying the classification is a description of the individual's impairment that 'fits' the biomedical definitions of impairment, facilitating classification. The description is then analysed. Analysis involves investigations (blood tests, x-rays, pathology reports) confirming the diagnosis, and treatment interventions. The individual becomes a 'case', objectified, pathologised and ready for presentation. The whole process involves measurement against the biomedical account of what is 'normal' in the general population.

Deviation from the norm in turn creates a deviant body in need of treatment to return it to normality (McClimens 2005). The disabled person becomes a devalued passive object of intervention, treatment, and rehabilitation. One example of the devaluation of an individual with a disability is the Abortion Act (1967) that makes it possible to terminate a foetus up to full term if there is substantial risk of impairment. This implies that a person with disabilities is a burden, with few rights, to be disposed of at the soonest possible opportunity.

Although the dominance of biomedical knowledge offers a partial account of the medicalisation of disability, further explanations of the biomedical dominance over people with disabilities emerged during the rise of the institutions, through the segregation of non-working disabled people from the

rest of the working population (Finkelstein 1980). The medical profession became an agent of social control, employing classifications of people from biomedical descriptions, in order to justify the segregation and incarceration of people with disabilities. Oliver (1996) argues that using biomedical knowledge to control disability instead of treating illness creates problems. This is because *'disability is not treatable medically and is certainly not curable'* (p.36).

The individual model of disability locates the problem of disability within the person, and additionally sees the cause of the problem as stemming from the functional limitations, or psychological losses assumed as arising from the disability. If we return to the notion of healthcare, Williams and Heslop (2005) argue that medicine has a tendency to prioritise ill health rather than the person behind the label, with particular diagnoses leading to stigma and discrimination. This implies that stigma and discrimination can originate from using medical knowledge to classify and label certain groups of people who deviate from this Utopian ideal of 'good' health. Additionally, Davey and Seale (2002) argue that illness presents fundamental challenges to membership of the mainstream population and the ideology of 'normality', which if not legitimised by the 'sick' label, may be resented by people who expect the person to play a 'normal' role in society. Therefore, those who consider themselves 'normal' can use illness labels to designate inferiority in other people. One label that can lead to stigma and discrimination is the label of learning difficulties.

The International Classification of Mental and Behavioural Disorders (ICD 10, WHO 1992) categorises people with learning difficulties in terms of their measured level of 'intelligence' or Intelligence Quotient. For example, categorisation of a learning difficulty (disability), according to the world of medicine, means an IQ of 50-69 (mild), 35-49 (moderate), 20-34 (severe) and less than 20 (profound), alongside detailed clinical descriptions of each category. Any IQ measurement above 70 is within 'normal' limits. Using this categorisation of the term learning difficulty (disability) immediately medicalises the individual because we are using numbers and words to define

individual competencies and predict future capabilities (Dumbleton 1998). The limitations of performing an IQ test alone on someone with learning difficulties are recognised, so the UK employs additional assessments based on the individual's adaptive functioning (Mackenzie 2005). However, the label with its negative connotations relating to an impaired IQ (or reduced intelligence) remains and the person, and aspects of their behaviour, becomes interpreted in relation to their label. Diagnosing a person with learning difficulties separates them from the 'normal' population. Therefore, the mere practice of diagnosing is a dividing practice. However, the force of the stigma comes not from the label itself, but from the beliefs surrounding the label.

### **2.3 Learning Difficulties and Health Care**

For some people with learning difficulties, there are many associated medical conditions requiring frequent medical intervention (Prasher and Janicki 2002). These associated medical conditions can stem from genetic make-up to lifestyle determinants (Beange 2002). Factors reported to be associated with genetic make-up are epilepsy (Bowley and Kerr 2000), sensory problems (Evenhuis et al. 2001a), thyroid disease (Beange et al. 1995), osteoporosis (Center et al. 1998), breast cancer (Davies & Duff 2001), early onset menopause (Martin et al. 2001), Alzheimer disease (Cooper 1998).

Beange (ibid) identifies some lifestyle determinants, for example, obesity resulting from lack of exercise, or malnutrition resulting from difficulty in swallowing. Other factors associated with obesity and lack of exercise are; diabetes, heart and circulatory problems, and mental health problems resulting from boredom and inactivity. Additionally, there are problems related to the side effects of long-term medication, or inadequate medication reviews. However, many people with learning difficulties experience comparable rates of illness with the general population (Grant 2005), whereas for some genetic or syndrome specific conditions, rates are higher (Evenhuis et al. 2001b). Improved medical knowledge coupled with frequent intervention over the years, means that people with learning difficulties are

experiencing dramatic increases in life expectancy, raising new challenges and opportunities for healthcare services (Bigby 2004). One challenge is how to plan adequately for people whose needs fall between the learning disability services, healthcare and services for older people.

There is some research evidence to suggest that people with lifelong disabilities have higher rates of unmet health needs in comparison to the general population (Powrie 2001; 2003, Lennox et al. 1997; 2001, Whittaker and McIntosh 2000, Hogg et al. 2001, Evenhuis et al. 2001b, Thorpe et al. 2001, World Health Organisation 2001). There appears to be a tension here between people with learning difficulties experiencing a dramatic increase in life expectancy, resulting from improved medical intervention, and people with learning difficulties experiencing higher rates of unmet health need.

Bigby (2004, p. 81) identifies that '*...health is a complex interaction of a multiple of factors, stemming from the individual and their environment*' (my emphasis). Access to good quality healthcare is therefore not the only factor for maintaining health. For example, Beamer and Brookes (2001) argue that people who have learning difficulties and high support needs require additional help in healthcare decision-making. This additional help can originate through many media and I produce examples of these media (and their effectiveness) in Chapters 6, 7, 8 and 9. However, what remains clear in later chapters is that without the additional help in healthcare situations, people with learning difficulties will always experience higher rates of unmet health need.

Recent policy has identified that people with learning difficulties are not getting a fair deal and '*have much higher needs than the general population yet visit their doctor less frequently...Services need to be more sensitive to their needs*' (DOH 1998b p. i). Additionally, being sensitive to needs means being aware of individual rights, which were not really addressed in the UK until the introduction of the Human Rights Act (1998). The incorporation of the Human Rights Act (1998) into UK law is now a key part of policy. For example, Valuing People (DOH 2001b) uses the principles of rights,

independence, choice and inclusion. However, even when a government has genuine intentions that policy should enhance the lives of disabled people, practice can thwart those intentions through institutional structures, actively disempowering those whom policy seeks to empower (Drake 1999). Therefore, another part of this thesis will be to examine whether policy aspirations are reflected in practice.

The next section examines the progression of relevant healthcare policy, drawn up with the aim of supporting people in their healthcare encounters. I will be referring to the policy documents, in the table on the next page, throughout the thesis and have therefore presented a short précis of the aims of each. All policy documents are relevant to healthcare. However, the policy documents in **bold type** have *particular* relevance for people with learning difficulties.

**Table 2.1 At a glance table of the emphases in recent healthcare policy.**

<b><u>Policy</u></b>	<b><u>Emphases</u></b>
The New NHS (DOH 1997a)	Promoting partnerships and relationships, needs of patients as central, Health Improvement Plans, Primary Care Groups, and patient involvement in healthcare decision-making
Designed to Care (DOH 1997b)	Building 'trust' as a part of relationships, making patients better informed regarding health
Putting Patients First (DOH 1998a)	Person-centred planning
<b>Signposts for Success (DOH 1998b)</b>	Subjective views of service users important, person-centred care
Our Healthier Nation (DOH 1998d)	Partnerships, Health Improvement Programmes, collaboration as the key
<b>Once a Day (DOH 1999a)</b>	Attention to different communication needs, getting to know the patient as a person
Health Act (DOH 1999b)	Co-operation and collaboration
The NHS Plan (DOH 2000a)	Building relationships, Patient Advocacy Liaison Services (PALS)
<b>Valuing People (DOH 2001b)</b>	Principles of rights, independence, choice and inclusion
<b>Health and Social Care Act (DOH 2001a)</b>	Public involvement and Consultation
Strengthening Accountability (DOH 2003a)	Bottom up approach to planning
Building on the Best (DOH 2003b)	Information revolution, sharing knowledge

## **2.4 Policy Themes and Challenges.**

Policy has progressively emphasised collaborative approaches and partnerships based on co-operation, co-ordination, sharing information, and the involvement of individuals in decisions concerning their own healthcare. Policy documents contain considerable guidance on ‘collaboration’, ‘partnership’, ‘person-centred planning’, and ‘decision-making’. However, within the literature, there is a marked lack of clarity about what actually constitutes working ‘collaboratively’, in ‘co-operation’, and ‘in partnership’ (Cooper 2000, Tennyson 1998, Hutchinson and Campbell 1998, Carnwell and Carson 2005).

Looking at the literature surrounding partnership and decision-making there is even more confusion as to what actually informs and facilitates the decision-making process in healthcare encounters (Charles et al. 1999, Georgiou and Robinson 1999). It will be argued that there is little or no identification relating to the constituents of the decision-making process, its implementation, who is included, and what training and key skills are required for planning the decision-making process.

A key proposal in recent policy documents is that of person-centred planning (PCP). PCP is itself a fundamental break with previous methods of planning (Mansell and Beadle-Brown 2004a). The precursor to PCP is the individual plan, but policy does not indicate why the IP failed and why it is being replaced. Additionally, Sanderson et al. (2002, p. 9) argue that PCP is a new and different way of ‘*seeing and working*’. This new way of working is known as a paradigm shift because another form of knowledge is challenging dominant scientific biomedical knowledge (Davey and Seale 2002).

If PCP is a new and different way of ‘*seeing and working*’ then what lessons have been learnt from the existing IP and what makes PCP so new and different compared to IP? Emerson and Stancliffe (2004) see this ‘new’ way of ‘*seeing and working*’ as unhelpful because it discounts prior knowledge

and experience about what works, negating historical continuity, rather than building upon it. A difficulty here is what constitutes different types of knowledge and challenges to the traditionally dominant scientific biomedical model? Additionally, how will this 'other' type of knowledge specifically benefit people with learning difficulties? Furthermore, what types of knowledge existed before recent policy, and have they been used as foundations on which to build new knowledge? I will return to these three questions in Chapters 6, 7, 8 and 9.

From present policy it can be seen that current services have somehow failed to positively engage with, and support, a substantial number of people. The assumption is that changes in planning methods, with a 'bottom up approach', or from the person to the professional (DOH 2003b), will automatically lead to changes in service practice and delivery. However, Grant (1997) in previous research on the existing IP (the individual plan), identifies problems in its implementation; if there was a previous change in planning methods, with problems in changing service practice and delivery, we can question why is there yet another change in planning methods specifically with respect to the relationship between individual and strategic planning.

Sixteen years ago, Smull (1989) argued that doing more of the same under a different name would not work without addressing previous problems, and examining why a particular plan did not work initially. It appears that assuming a change in planning methods will change service practice and delivery means policy may have fallen into the same hole that Smull cautioned against in the late eighties. I will return to the IP and PCP in Chapter 6 for a fuller explanation and analysis of their origins and progression since their implementation.

Making services more 'person-centred', including the person in decisions about their own health, and the shift towards 'collaboration' and 'partnership', stand in marked contrast to the inherited biomedical approach to healthcare.

## **2.5 Policy, People and Professionals**

Recent policy documents have singled out people with learning difficulties for particular attention because this group is viewed as one of the most marginalised in relation to healthcare (DOH 1998b). Historically, people with learning difficulties have been discriminated against and marginalised in many areas: from education (Simpson 1990), employment (Barnes 1991), the welfare benefits system (Oliver 1996), health and social services (Booth & Booth 1994, 1996, 1998, Grant 1997, 2005, Hogg et al. 2001, Prasher & Janicki 2002), leisure and social life (Traustadóttir & Johnson 2000), housing and transport (Kinsella 1993, Oliver 1996), and political life (Barnes 1991, Drake 1999).

Recently policy has sought to address the healthcare inequalities experienced by people with learning difficulties by changing planning methods (DOH 1998b, 2001b). The bottom-up approach means that initially, planning should start with the person, finding out their needs and preferences, and then fitting service delivery around the person, rather than utilising the present method of service delivery where the person has to 'fit' the services (Cambridge & Carnaby 2005). This style of service planning and delivery creates a tension between the traditional biomedical model of healthcare, where the professional is a '*culturally defined expert*' possessing the knowledge, skills and legislated rights, which are inaccessible to patients (Stevenson 2002, p.1103).

Stevenson (ibid.) argues that in this context, the authority still rests with the professional. It is a doctor-centred relationship, and the person's values are assumed to be consistent with that of the professional. Personal autonomy is therefore restricted to assenting to treatment because the professional has made an 'objective' diagnosis through closed biomedical questioning. The key to this biomedical approach is that illness coincides with an objectively defined pathological origin. Personal knowledge and subjective experience,

which for the professional may bear little relationship to the disease, takes second place.

If we relate this approach to people with learning difficulties, then learning difficulties have an objectively defined pathological origin; personal knowledge and subjective experiences bear little relationship to present circumstances for the professional. Barry et al. (2001, p.489) argue that this dominance of biomedical knowledge creates a power imbalance because the '*voice of medicine*' when used in its scientific context is seen as undistorted and superior, whereas subjective experience is seen as distorted and inferior. The result is a struggle between two very different voices within the same healthcare context, resulting in the professional retaining power and suppressing the voice of the patient. Barry et al. (ibid) do acknowledge that no consultation with a professional can take place without relying to some extent on the voice of medicine, because this is a communication tool for reaching a diagnosis. However, these authors suggest that a balance needs to be struck between the two voices, requiring more active work on the part of professionals.

Mishler (1984) suggests that if professionals were to adopt more ideal interactions with their patients then the resultant care would be more effective. He gives examples of more ideal interactions that include active listening, use of open-ended questions, simplified language, and negotiation of power sharing within the healthcare encounter. However, this analysis of the healthcare encounter is reliant on the patient being articulate, and someone who can adequately describe, understand, and account for their illness. In Chapter 8, I highlight the difficulties for people with impaired communication in the healthcare encounter, and the contrasting evidence for Mishler's (ibid.) suggestions for professionals to adopt more ideal (presumably dyadic/triadic) interactions.

Keywood et al. (1999) suggest that many people with learning difficulties require a third party who knows and understands them to explain and interpret their healthcare difficulties. For many people with learning

difficulties, because of third party involvement, the healthcare encounter is not the traditional dyadic encounter. Other voices add to the encounter. These can be paid carers, families, advocates, allies, and representatives. Third party roles can differ greatly, the role can be one of a proxy who informs the professional as to the wishes and needs of the individual and negotiates treatment on their behalf. Alternatively, the role could involve interpreting the style of communication from individual to professional and explaining treatment options from professional to individual.

Edge (2001) argues that this means that it is the responsibility of the caregiver or supporter to recognise how an individual communicates choice. Additionally, he suggests that the extent to which choices may be acted upon is dependent on whether the choices are recognised initially, and whether caregivers and supporters believe that something can be done. However, in chapters 3 and 9, I discuss the conflicts that these roles can reproduce. The healthcare encounter in this context is complex and relies on more than the voices of the professionals and patients achieving a balance. I revisit the patient-professional encounter in Chapters 6, 7, and 8 of this thesis.

## **2.6 Conclusion**

Throughout this chapter, a number of key themes have emerged. Whilst the biomedical account of health remains dominant, policy appears implicitly at least, to acknowledge different types of knowledge as important in healthcare encounters. These different types of knowledge originate from people with learning difficulties, and in many cases from the third party involvement of caregivers, families or advocates. What appears to be crucial is that using case knowledge and a practitioner-centred healthcare encounter actively serves to disable people with learning difficulties because they are marginalised within the decision-making process. Case knowledge is a prerequisite for many people with learning difficulties with compromised health, but simultaneous use of different types of knowledge would appear to broaden the scope for more active and potentially more meaningful involvement by the person with learning difficulties. I discuss different

types of knowledge, and their relevance to the decision-making environment, in Chapter 3. Within this chapter, I have discussed the parties involved in the decision-making encounter. Examples of decision-making can be dyadic with just the patient and professional involved, but with the professional making most of the decisions. In Chapters 3 and 6, I discuss a different model of decision-making with the person at the centre of the process being supported to make decisions.

The character of decision-making appears under question, or the seriousness of the decision in relation to healthcare and the irrevocability of some decisions. I have related the character of decision-making to the process of decision-making and the capacity of people with learning difficulties to make decisions. I will look at capacity and the law in Chapter 3, and examine constructions of capacity occurring in practice, and their effects on decision-making, in Chapter 8.

The disabling factors for people with learning difficulties where a practitioner-centred environment occurs are the exclusion from decision-making concerning healthcare, an assumption of incapacity to make decisions, and a reliance on the biomedical voice taking priority over the voice of the individual. In Chapter 3, I will examine using the voice of the individual in the healthcare encounter; providing patient, communicative and person knowledge in addition to case knowledge, equipping the healthcare professional with a more complete picture of the person. I argue in Chapters 6, 7, and 8, that this additional knowledge can strengthen the efficacy of a more inclusive model of decision-making.

## Chapter 3

### Lay Knowledge ,The Social Model of Disability, and Policy

#### 3.1 Introduction and scope

The preceding chapter has already considered case knowledge so in this chapter I intend to introduce different types of knowledge alluded to in recent policy documents and theorised in detail within the work of Mead and Bower (2000) and Liaschenko (1997) as ‘case’, ‘patient’, ‘communicative’ and ‘person’ knowledge. I suggest that the healthcare encounter needs these types of knowledge to become more ‘patient-centred’. However, there appears to be tension between the different agendas that inform case and different knowledges, stemming from the capacity of an individual to possess, and make a decision, based on ‘other’ knowledge.

Healthcare takes place in a variety of contexts for some people with learning difficulties, these contexts can be the home, day care, leisure, educational facilities, and within potentially any of the structures within civil society (banks, social clubs, shops and so on). I argue that the decision-making process is bound to the varying service contexts.

This chapter will firstly consider different types of knowledge within the healthcare encounter and how this knowledge is constructed. I will then outline the social model of disability and its relevance for the lives of people with learning difficulties. One of the problems is the issue of capacity when making decisions to consent to treatment, and I will consider these issues in light of the recent Mental Capacity Act (2005). From considering the Act, which addresses decision-making, I will proceed to examine the service contexts for the decision-making process and their linkage with person centred planning (PCP). Finally, I will examine some of the process issues within decision-making for people with learning difficulties, in relation to the knowledge requirements proposed by Liaschenko (1997) and Mead and Bower (2000).

### **3.2 People with learning difficulties and healthcare services**

Grant (2005) argues that we are still a long way from knowing about every factor that influences the health of people with learning difficulties. He proposes many reasons for this lack of information, including:

- Uncertainty about where many people with learning difficulties are to be found especially those with mild learning difficulties, so little is known of their circumstances
- The ‘disappearance’ of people into the community who are now successfully using mainstream services (although Grant (ibid.) suggests this is contentious)
- The ‘retirement’ of people with learning disabilities from specialist learning disability services and their assimilation into services for older people
- A lack of integrated case records so people become ‘lost’ in the system

For those people who remain ‘known’ to the services there are still barriers to accessing appropriate healthcare (McCarthy 1999, Bigby 2004). For people with learning difficulties there are perhaps more barriers than for people without learning difficulties. For example, Lloyd et al. (1996), Beamer and Brookes (2001) and Bigby (2004) all consider the deficits in communication skills by people with profound learning difficulties. These deficits cause problems in any environment requiring interaction to facilitate the communication process. For example, a lack of communication can cause problems in a healthcare environment, because information from the person is an essential factor for the professional to make an adequate diagnosis (Bradshaw 1998). In contrast, Keywood et al. (1999) suggest that people with learning difficulties need a third party who knows them well to explain, interpret and enable them to make decisions in their healthcare encounters.

### **3.3 Disputed knowledge and challenges**

Traditionally, case or medical knowledge concerning the person is seen as a more 'superior' type of knowledge, in contrast to other more subjective types of knowledge, because it is reliant on objective, observable facts and administered by a professionally trained and qualified individual (Stevenson 2002, Grant 2005). This type of knowledge is biomedical and enables the professional to make sense of the healthcare encounter and decisions concerning an individual's healthcare. Biomedical knowledge is exclusive to the practitioner and therefore excludes the layperson because he or she has not been educated in the same way, and does not possess the same type, or amount, of knowledge. Within this context, there is a mismatch of knowledge and worlds because the parties involved in the healthcare encounter will theoretically make sense of their worlds in differing ways. However, Liaschenko (1997), and Liaschenko and Fisher (1999) argue that there are many constructs to knowledge within the healthcare encounter and propose a classification of knowledge. This classification of knowledge includes case knowledge and Liaschenko and Fisher (1999) argue that case knowledge is necessary but insufficient in the healthcare encounter. Therefore, 'other' knowledge can assist the healthcare encounter when making decisions about, and with, the person as a 'whole' (Coyle and Williams 2001, WHO 2001, Mead & Bower 2000). This 'other' knowledge has been summarised by Grant (2005, p. 713) as follows:-

- *Patient knowledge.* This refers to how a person is supported and enabled to understand case knowledge existing in medical records and case files.
- *Communicative knowledge.* This refers to how an individual makes their preferences and choices known. Keywood et al (1999), Bradshaw (1998), and van der Gaag (1989, 1998), have already identified that many people with learning difficulties have

communication impairments, and therefore need a third party, or additional assistive communication technologies, to interpret and explain their choices and preferences.

- *Person knowledge*. This refers to individual social circumstances; how individuals relate to their physical and social environments. It also relates to individual capacity to initiate choices and decisions. Grant (2005, p. 713) emphasises that the dimensions of agency (*the individual's capacity to initiate meaningful action*), temporality (*how life patterns are shaped by developmental, social and cultural clocks*) and space (*how individuals relate to physical, social and political environments*) are of especial importance.

Patient, communicative, and person knowledge are areas in which people with learning difficulties, their paid carers and others have superior knowledge and insights compared to that of professionals. Policy is now emphasising partnerships between professionals, patients, paid carers and others (DOH 1998a, b, and d, 1999a and b, 2000a, 2001a and b, 2003a and b) and this seems, tacitly, to signal the importance of these complementary knowledge claims. Additionally, using case knowledge in isolation reinforces existing power structures (Lukes 1974), and fails to utilise other types of knowledge that may be used to include and empower people in their healthcare encounters. Valuing People (DOH 2001b) and Sanderson et al. (2002) emphasise that person-centredness means putting the person at the centre of any planning process. In order to put a person at the centre of any process, the guidance in Valuing People is to start from the experiences and aspirations of the individual and their wider social context whilst working 'in partnership'. Valuing People suggests that another key factor to working 'in partnership' is to address support, or use the knowledge of the individual, staff and family carers to make a healthcare encounter more person-centred. Action is a central part of the process to achieve more desirable outcomes for the individual. This means that the care management system will continue to be the formal mechanism for linking people with learning difficulties to services and therefore needs to be responsive to person-centred planning.

The care management system will need to '*link effectively with health action plans which are led by an identified health professional*' (DOH 2001b, p. 50). In short, Valuing People states that people with learning difficulties should be treated as equal partners in the healthcare encounter and knowledge from all parties involved needs to be considered thereby enabling a more person-centred approach.

Using different types of knowledge does not exclude the possibility of there being problems related to the different parties involved in making decisions. I have already aligned the individual model of disability with 'case' knowledge because it medicalises disability. I will now briefly describe the social model of disability and its suggested applications to the lives of people with learning difficulties.

### **3.4 The social model of disability**

The social model of disability arose as a reaction to the individual model of disability, where impairment is located within the mind and body of the individual (Oliver 1996). In contrast, Oliver (ibid.) argues that the social model of disability locates disability within society, in that individual limitations are not the problem, but rather the problem lies in society's failure to provide appropriate supports and ensure that the needs of people with disabilities are fully taken into account. For Oliver (ibid.), the social model of disability is not about '*personal experience and professional practice*' (p.41), it is about the barriers within society that serve to disable people with impairments. Stairs and doorways that are too narrow are examples of physical barriers that disable wheelchair users, preventing them from entering a building. However, barriers are not merely confined to the physical; there may be attitudinal barriers towards people with impairments, leading to discrimination and a loss of control over their lives (Morris 1996).

Some authors argue that the social model of disability does not adequately account for the experiences of all disabled people, particularly people with learning difficulties (Chappell 1998, Goodley 2000, 2001). The social model

in some cases may serve to relegate disabled people's experiences of impairment (Boxall 2002). For example, for people with learning difficulties, having superior knowledge to others regarding their healthcare may be dependent on their 'mental capacity', or their ability to communicate or convey that knowledge. This creates a tension within the social model because the barrier that serves to disable a person with profound learning difficulties is not necessarily within society. It could however be argued that the 'barrier' is located in our ability or inability to communicate effectively with people with learning difficulties. For example, Edge (2001, p. 12) suggests that we need to look at:

- how an individual communicates
- the extent to which someone understands the information
- the extent to which someone can remember the information
- different personal values and attitudes between individual and supporters
- a possible tendency to indicate 'yes' to questions asked
- lack of motivation to make choices
- limited opportunities to communicate
- people being labelled as 'challenging' and being ignored as a result

Edge gives examples of individuals who communicated by screaming and how the staff who knew these individuals the best observed, interpreted and recorded when individuals screamed, and examined nuances of the context in understanding and interpreting intent. The staff found that some individuals used screaming to send a variety of messages. The staff then responded consistently to the screams, depending upon the context. They also shared and discussed their approach within the team, checking out their interpretations for signs they had it right.

### **3.5 Capacity and the Law**

Before April 2005, it was difficult for some people to make decisions because there was little legal recourse if others made, or failed to make, decisions that were in their 'best interests'. To clarify and reform the legal situation, and to offer guidance, the Mental Capacity Act 2005 aims to improve the decision-making process for people who have difficulty making decisions. For example, in Part I, Section 2, a lack of capacity cannot be established merely by referring to an aspect of an individual's behaviour, or any condition they may possess, e.g., learning difficulties. This clearly outlines that a person with learning difficulties has the right, and where necessary, needs support, to make their own decisions, unless it can be demonstrated that they are incapable. Capacity is the central concept and aims at securing autonomy and individual choice.

However, Fulford (2005) argues that there are wide discrepancies between different legal definitions of decision-making capacity in current use. Furthermore, when it comes to saying what capacity is, the guidance is inconsistent. This is because the concept of capacity is complex and multi-faceted. For example, a person may exhibit fluctuating decision-making capacity, i.e., the ability to make decisions in one context, but not in another. Additionally, the descriptions of intellectual functions that outline capacity are complicated. For example, Section 3 of the Act outlines two functions as understanding the information, and using or weighing that information as part of the decision. However, Fulford (ibid.) argues that if the decision-making is complicated or highly emotive, as in some healthcare decisions, then other functions such as emotion, motivation, perception, volition, and values become important, and perhaps crucial to capacity, in healthcare decision-making. Section 4 (6) and (7) of the Act partially addresses Fulford's argument regarding values by involving a proxy decision-maker who has intimate knowledge of the beliefs, values and wishes of the individual. Additionally, in Section 35 are the proposed appointments of independent mental capacity advocates who may support an individual in making a decision.

Advice on supporting a person to make a decision, according to the Act; entails ascertaining what individual wishes, feelings and values would be if that person had capacity. Holland and Clare (2005) support this section of the Act and suggest that decision-making capacity is not about the decisions a person makes but about the belief system he or she draws upon, when making a decision. However, in the case of proxy decision-making, there is also the belief system and values of the proxy to take into consideration, and although advised by the Act to remain impartial, it can be questioned how far it is possible for an individual to completely ignore their own beliefs and value system. Another consideration for proxy decision-making is what happens when the values of the proxy and professional clash, and who makes the decision? Furthermore, when making serious and sometimes irrevocable decisions regarding healthcare, what weight should be placed on the values of family, paid carers, and others supporting the individual? I revisit these issues in Chapters 8 and 9 when considering constructions of competence and carer roles in the process of healthcare decision-making.

It appears that decision-making is about the process of making a decision rather than the outcomes. Holland and Clare (*ibid.*) suggest that many people with learning difficulties have had little or no opportunities and experiences of decision-making, and any existing experience has been restricted. Existing studies have examined contexts where people with learning difficulties have a tendency to acquiesce (Sigelman et al. 1981) and agree with care staff (Keywood et al. 1999). Booth and Booth (1998) suggest that the values of care staff can positively or negatively affect the decision-making process, promoting autonomy or acquiescence. Applebaum (2005) suggests that the weight given to values plays a critical role in the capacity assessment process and the resultant decisions. He suggests that a premium is placed on cognitive functioning as opposed to the emotional components of behaviour and choice, and that rationality becomes the model for making decisions. However, in Sections 2, 3 and 35, the Act appears to place a greater premium on the notion of autonomy, rather than rationality, by promoting the facilitation of choice in the decision-making process. I will

discuss how the decision-making process relates to service contexts in the next section.

### **3.6 Service Contexts**

Within the healthcare services, there are varying contexts where decision-making occurs. Primary and secondary care services divide these contexts (Rogers & Pilgrim 2003). Examples of primary care services are General Practitioners, or the local doctor, the local dentist, the optician, chiropodist, and complementary medicines (e.g., acupuncture, Reiki, osteopathy etc.). Any service directly accessed by the public is a primary service. Examples of secondary services are hospital consultants who receive referrals from the primary care services for more specialist interventions; for example, radiology, psychiatry, psychology, speech therapy, epilepsy services, physiotherapy, oral surgery and advanced prosthetic work, cardiology, endocrinology, gynaecology and obstetrics, etc. In addition to these services are specialist services; e.g., learning disability services, employing staff who are trained to work specifically with people with learning difficulties.

For some people with learning difficulties, their healthcare contexts may extend from the GP surgery and the hospital consultation to their home, leisure, or educational environment. These healthcare contexts have previously been in the form of individual service reviews, carried out in the person's home and although the intention was to focus on the disabled person, the family carer always had a strong voice (Williams & Robinson 2000). Furthermore, Carnaby (1997) has reported that people with profound learning difficulties who did not communicate with words suffered exclusion from the process of their IPP, and indeed from any form of decision-making.

Outside the home, some people with learning difficulties frequent day services that can structure leisure and educational pursuits. Other services are local colleges of education, which run courses for people with learning difficulties. Therefore, there are many contexts that a person with learning

difficulties may encounter, all of which may influence their opportunities to engage in decision-making.

The process of decision-making within a healthcare context has traditionally been the domain of the professional (Charles et al. 1997; 1999). With the advent of the Human Rights Act (1998), Signposts for Success (DOH 1998b), The Healthy Way (DOH 1998c), Valuing People (DOH 2001b), and the Mental Capacity Act (2005), there has been a shift towards enabling people with learning difficulties to maintain control over their lives through choice and shared decision-making. This involves the person with learning difficulties, their supporters (paid and unpaid), professionals, and anyone who assists in the healthcare decision-making process (Kirk & Glendenning 1998, Hogg 2001). This involvement has been extended with the growing emphasis on person-centred planning and the Health Action Plan (HAP) (Sanderson et al. 2002).

Person-centred planning is the process of putting the person at the centre of any decision-making process, and is an integral part of 'Valuing People'. The focus is on the relationships that a person with learning difficulties has with his or her supporters and people that are involved in the decision-making process (Sanderson et al *ibid.*). Support is a key factor. However, there are concerns as to the effectiveness and availability of person centred planning (Mansell & Beadle Brown 2004a, Emerson & Stancliffe 2004, Felce 2004, O'Brien 2004). I will describe PCP and discuss these concerns in detail in Chapter 6.

## **2.7 Care Management and Person-Centred Planning**

Valuing People (DOH 2001b) offers guidance on the process of care management in the shape of person-centred planning. However, it is important to recognise that there are many different professionals involved in the care management of people with learning difficulties. Policy guidance infers that the care management of people with learning difficulties involves

support that maximises their involvement. Duffy and Sanderson (2005, p.36) propose that there are two roles assigned to care managers;

1. *Support co-ordination role: helping people get the help they need by organising paid or unpaid support*
2. *Resource allocation role: allocating 'community care' resources to people who are deemed to need them*

They propose that these two roles are linked, but that in practice they can be separated from one another, as for example, organising an independent advocate whose role is to support the individual and use the resources allocated to them. The people sorting out the financial allocation for each person are therefore separate from the person co-ordinating the support. However, Duffy and Sanderson (ibid.) argue that, at present, the two functions are usually combined to some degree in a care manager's role.

In fulfilling the support co-ordination and resource allocation role, the care manager carries out an assessment of need. This assessment of need informs the type of support that the individual receives from the different services. Smale et al. (1993) outline five different types of assessment occurring in practice, summarised by Duffy & Sanderson (2005, pp 36-38)

1. Questioning model: Asking questions to determine what the individual needs. The questions reflect what the professional views as important according to their understanding of 'need'. It is entirely practitioner-centred and reliant on professional knowledge.
2. Procedural model: The care manager completes a variety of forms to judge the individual's eligibility for allocation of resources. The process is again reliant on professional knowledge employed to accurately complete the forms and inform action.

3. Exchange model: Personal knowledge, gained from the individual, and professional knowledge together helps create a shared understanding of the person, shaping the decision-making process.
4. PCP: An approach to planning and decision-making, supporting individuals in partnership with others to think through their needs, moving beyond professional assumptions of need. This encourages the individual to make choices and decisions about their lives.
5. Individualised funding: Assignment of funding to the individual so that they control how resources are used to provide support, as for example choosing what type of support they want in their daily lives in the form of a paid carer, transport requirement, or physical aids etc.

Using the questioning model and procedural model of care management is obviously undesirable in the current climate of creating ‘partnerships’ and working ‘collaboratively’ because it uses case knowledge alone. Therefore, non-medical knowledge needs to be acknowledged and employed within the healthcare encounter in order to put into practice policy directives and guidance stipulating working in ‘partnership’ and ‘collaboratively’. I will discuss and aim to deconstruct the terms ‘partnership’ and ‘collaboration’ in detail in Chapter 7, offering accounts of how people with learning difficulties as decision-making ‘partners’ can make sense of decision-making processes.

### **3.8 Enabling and Disabling Factors**

Booth and Booth (1994) suggest that there are enabling and disabling factors stemming from the different types of support that a person with learning difficulties may receive. The different types of support may promote or inhibit competence. Competence-promoting support allows the individual to feel in control, encouraging them to handle problems on their own, reinforcing their skills and sense of self-worth. In contrast, competence-inhibiting support is based on the assumption that

individuals are incapable of managing unaided, demotivating the individual, creating a crisis-oriented approach to management, which in turn is unresponsive to the individual's view of their needs. Booth and Booth (ibid.) argue that all of these factors have a direct bearing on the individual's actual level of competence, setting up a vicious circle, because this then affects how they are perceived by the support system.

Returning to the types of models in the context of decision-making (Duffy and Sanderson 2005, pp. 36-38) it would appear that the questioning model and the procedural model are both competence inhibiting because they are reliant on the knowledge and skills of the professional. Although this may critically hinge on how these professionals seek to explain the basis of such knowledge and allow it to be reflected on, questioned, rejected and so on. Therefore, possessing such knowledge is one thing, but **how** it is used is another. This prioritisation of professional knowledge can affect the individual's level of competence because it does not include the individual in decisions about their own healthcare.

One example is that given in a study by Hart (1998) where people with learning difficulties demonstrated varying degrees of fear about general hospitals. This fear was rooted in the lack of understanding about what was happening to them during medical procedures, enhanced by the fear of a strange environment. Furthermore, people with profound learning difficulties and impaired communication had a tendency to be ignored by medical staff because of a general lack of awareness concerning people with impaired communication. However, the study revolved around informing the individual rather than including and supporting them to make decisions concerning their own healthcare.

In another small-scale study, Browne (1999) suggests that it is important to involve family carers accompanying people with learning difficulties at all times because they could facilitate the communication process. Involving family carers alone still places little premium in soliciting

'patient', 'communicative' and 'personal' knowledge, to assist decision-making in the healthcare encounter. Williams and Robinson (2000) suggest that many family carers and care managers assume that they can speak for the individual and often considered themselves as advocates. However, their study found that independent advocates remained unused and people with learning difficulties were not defining their own needs. Additionally, carers appear to have many roles within the decision-making context, advocates, proxy decision-makers, and interpreters. I will return to these roles in Chapter 9.

In their study, Keywood et al. (1999) found that there were positive and negative aspects to involving staff and families in healthcare decision-making. The positive aspects were that people with learning difficulties acquired the confidence to explore options and make decisions. In addition, employing staff and families as proxies ensured that people were understood, and could understand information. On the negative side, professionals tended to look automatically to staff and family caregivers for decision-making, undermining any possible involvement by people with learning difficulties. One finding of their study was that people with learning difficulties felt that professionals, and sometimes staff or family carers, did not listen to them, excluding them from even very basic decisions such as choosing spectacle frames. Indeed, many parents and staff identified themselves as primary decision makers for adults with learning difficulties; and in addition their beliefs, values and attitudes influenced the opportunities for people with learning difficulties to make decisions for themselves. Another disabling factor was that people with learning difficulties had been given little information concerning their own healthcare and this limited their ability to make decisions. However, having information about the nature of treatment is one of the three elements of ethical criteria for informed consent. Decision-making appeared to be based on assumptions of incompetence, rather than competence, regardless of the context, thus creating a competence inhibiting environment.

Keywood et al. (1999) suggest that one of the reasons why people with learning difficulties are disabled by decision-making is the lack of access to information regarding their own healthcare. Another compounding factor is the inability of family and staff to give adequate support. Whilst they identify that a lack of access to information inhibited decision-making, there is no reference to inclusion in decision-making processes using the different constructs of knowledge that Liaschenko (1997), Liaschenko and Fischer (1999) and Mead and Bower (2000) propose. Furthermore, Keywood et al. (ibid.) do not identify whether examining the knowledge of family and paid carers to assess their ability to give adequate support will assist in the decision-making environment.

### 3.9 Summary

As this chapter has progressed, I have suggested that the creation of a decision-making environment that will enhance the competence of people with learning difficulties is reliant on more than case knowledge alone. 'Patient', 'communicative' and 'personal' knowledge are a necessity if the individual is to be included in decisions about their own healthcare, and if they are to be treated as a 'whole' (Liaschenko 1997, Liaschenko and Fischer 1999, Mead and Bower 2000). Additionally, using case knowledge alone reinforces existing power structures because it fails to utilise other knowledge that could both empower people with learning difficulties, and help professionals ensure that support is available to the individual during decision-making processes.

Another aid to decision-making lies in the use of family and paid carers and others who know the individual well, as facilitators and proxies in decision-making processes. However, according to Keywood et al. (1999) this can create both positive and negative outcomes. They found that positive outcomes ensured that the voice of the person with learning difficulties was heard, and that essential healthcare information was translated into an understandable format by the family or paid carer. Negative outcomes were the reliance by professionals on family and paid

carers to the exclusion of people with learning difficulties in the decision-making process. This hints at conflicting family and staff roles within the decision-making process. I will examine staff roles and the decision-making process in Chapter 9.

Decision-making appears to be concerned with the process of how a decision is reached, rather than the outcomes. This is directly related to the Mental Capacity Act 2005 where the individual is presumed competent to make a decision unless there is evidence to suggest they lack capacity. This is in direct contrast to Keywood et al.'s (1999) study where people with learning difficulties were excluded from the decision-making process because of assumptions of incompetence. This leads to attitudinal barriers concerning people with learning difficulties where they are viewed in terms of an arbitrary and deficient classification bound up in the taken-for-granted notions of handicap established within the individual model of disability.

The five types of assessment proposed by Smale et al. (1993); questioning, procedural, exchange, PCP, and individualised funding would all appear to play a role in the decision-making environment. For example, the type of decisions made by a person with learning difficulties might be directly applicable to the choice of support through individualised funding. The type of decisions made under PCP may be directly related to the ability of all concerned in the decision-making environment to work 'collaboratively' and in 'partnership'. I will discuss the different types of assessment used in practice, and their outcomes in Chapter 7, and how support for decisions is provided, in Chapter 9.

Person-centred planning is not without its problems, with recent publications challenging the ethos, implementation, and effectiveness of PCP (Felce 2004, Mansell and Beadle Brown 2004a&b, Emerson & Stancliffe 2004, O'Brien 2004, Cambridge & Carnaby 2005). I will explore the problems of PCP further in Chapter 6.

Chapters 2 and 3 have outlined the factors that can be involved in the decision-making process. I will discuss these factors further in Chapters 6, 7, 8, and 9, with examples from the experiences of people with learning difficulties, their carers and professionals. From the empirical evidence that I provide within my study, I argue that within the health care encounters of people with learning difficulties, we are still a long way from achieving the ambitions for person-centred planning.

## Chapter 4

### **Methodology: The case for an interpretive research approach**

#### **4.1 Scope**

This chapter seeks to establish the case for a qualitative research approach in studying the experiences of people who have limited verbal articulatory skills. I argue firstly that employing narrative methods (Booth and Booth 1996, Walmsley 1999, Walmsley and Johnson 2003) with people with limited or no verbal utterance can further contribute to existing life history research with people with learning difficulties (Atkinson and Williams 1990, Atkinson et al. 1997, Ramcharan et al. 1997, Atkinson 1998a, Booth and Booth 1996, 1998, Goodley 2000, Atkinson 2005). Secondly, narrative methods can assist in liberating the voices and stories of people who would ordinarily remain silent. Thirdly, they can facilitate understanding of the lives and worlds of people who have traditionally remained uninvolved in many aspects of their care and support, including their healthcare. This choice of qualitative methodology is inextricably linked to phenomenology, social constructionism, symbolic interactionism, and ethnographic perspectives, providing the framework for thinking about the experiences of people with learning difficulties in multiple but related ways. I propose that using narrative methods entails each researcher acting as their own methodologist. This means moving away from, but not totally discarding, the rigid structures that constitute traditional qualitative methods, such as interviewing, and using a more flexible inclusive approach. However, the flexible approach I propose does not mean that the rigour attached to how research is carried out is ignored; instead it means that the methods employed are more reliant on the skills and experience of the researcher. In Chapter 5, I provide examples of interviews where interviewer skills and experience enable a more flexible, inclusive approach for people with limited and no verbal utterance.

This chapter looks at the origins of life history research, narrative methods and their links with phenomenology, social constructionism, symbolic interactionism and ethnography. It then opens the qualitative ‘toolbox’, discussing the methods from which narratives are generated. From opening the toolbox, I then proceed to examine the ‘skills’ of the researcher, arguing that adapting the toolbox and the skills of the interviewer to elicit the views and perspectives of people traditionally deemed ‘non-verbal’ or ‘inarticulate’ influences the extraction and interpretation of narrative data.

#### **4.2 The foundations of life history research**

The life history approach is not a new phenomenon; it evolved from the field of Sociology in Chicago in the 1920s (Plummer 2001) with the story of the ‘Polish Peasant’, as an immigrant in America and Europe, and gathered momentum, continuing its evolution up to the present day. The original methodological position concerned firstly the relationship between the individual and social worlds of experience. Considering individual and social factors in social research links directly to the work of George Herbert Mead (1934), and looks at the interactions between the individual and their social world. Considering individual and social factors, explores the symbolic systems that structure, and give meaning and significance to social life for individuals. According to Mead, the most important symbolic system is language. He proposed that it is jointly through this symbolic system and social interaction that meanings are established and learned. Meaning is therefore employed, managed, reproduced and changed through social interaction. Mead (ibid.) called this process symbolic interactionism.

Using symbolic interactionism in social research, and examining individual interactions, assumes the need to examine the subjective experience of individuals in order to understand and describe their symbolic world, from their point of view. We are trying to understand a particular phenomenon. For instance, in my study I am trying to understand how people with learning difficulties experience healthcare. This approach is rooted in

phenomenology, which also provides the philosophical basis for interpretive research strategies (Robson 2002, p. 196).

According to Mischel (1993, p. 231), phenomenology is an approach that refers to an individual's experience as he or she perceives it.

Phenomenological approaches emphasise people's immediate experiences and current relationships, perceptions and encounters. The focus is on the *'individual's subjective experience, feelings, personal view of the world and self, and private concepts.'*

This focus on subjective experiences of a social world means using an interpretive approach to research. Interpretation of the social experiences of a particular cultural group originates from the field of anthropology; where the researcher became immersed in the social life of a cultural group (originally exotic cultures) to provide a rich 'thick' description (Geertz 1973). The Sociology department at Chicago University adopted this approach and looked at groups and communities in modern urban society (Bogdan & Bilken 1992). The approach became known as ethnography. However, central to the approach of how a researcher thinks about human social interaction is one more idea. This idea is that people construct knowledge of their social world, through their interpretations of it and additionally through the actions based upon those interpretations (Hammersley 1992, p. 44); this is social constructionism. Burr (2003, p.4) argues that a social constructionist would claim that knowledge of the world and our ways of understanding it are not derived from the nature of the world as it really is because people construct meaning between them. It is through social interactions that our shared versions of knowledge are constructed, and what we understand as 'truth', or our current ways of understanding the world, are not a product of objective observation, but a product of the social processes and interactions in which people are constantly engaged with each other. Burr argues that social interactions are subject to historical and cultural change. Therefore, how we understand the world is both historically and culturally specific.

However, Willig (2001) argues that social constructionism is not without its limitations. For instance, it does not explain individual differences in how people interact with their world and why they will sometimes place themselves in positions that are disadvantageous. Nor does it address why people claim or resist certain attributions in their narratives. Social constructionism does not account for the 'self', who that person is; their personality characteristics, attitudes, and behaviours; everything that makes a research 'subject' a human being. However, some qualitative research does not concern itself with the 'self', or individual differences, and how people interact with their world; instead it is more concerned with treating people as a homogenous group.

For example, Arscott et al. (2000) suggest that people with learning difficulties have poor knowledge about their medication, but fail to include details of the extent of learning difficulty for each individual, who was involved in the healthcare encounter, what the individual's beliefs and previous experience of medication was, and more crucially how those beliefs were acquired.

Cassidy et al. (2002) suggest that health checks were useful in detecting unmet health need for people with learning difficulties, but they failed to identify whether this applied to all people with learning difficulties, or just a particular group with specific medical needs. Furthermore, the opinions and attitudes of people with learning difficulties towards their own healthcare were not taken into account. Martin et al. (2001) suggest that women with learning difficulties have problems with the menopause and require support, but do not identify whether this applies to all women, or whether the individual beliefs and contexts of the women influence the study.

Talking of theories in isolation excludes the fact that research itself is a social process; it grows and flourishes or withers and dies, and is dependent upon the researcher to nurture its course. The researcher becomes a part of the process, guiding, interviewing, interpreting, and analysing the emergent data. The informant and the researcher are therefore actively engaged in

interpreting and constructing their social worlds. This questions how far objectivity is attainable. This is because we have two individuals (the informant and researcher), each with different perceptions of their social worlds. If we follow Kelly's (1955) construct theory, meanings and understandings for an individual are constructed and gained from their social world, and differ according to individual experiences. However, the main aim for Kelly was to identify and understand how an individual sees their world. Kelly was concerned with the suitability of people's constructs, rather than with 'truth'. He tried to understand the implications for the individual's life of construing it in a particular way.

Rogers (1980) argues that each person dwells in a subjective world, and each individual possesses a unique subjective experience of their world. Additionally, how that person sees and interprets events determines how they respond to them. The focus for Rogers is twofold; firstly how an individual perceives, grasps, and experiences their social world and secondly, trying to grasp that individual's point of view. Rogers argues that trying to achieve this perception of another's world means trying to look at the world through the individual's eyes and trying to stand in their shoes, aiming to experience a bit of what it is like to be that person. This is empathic awareness.

Conversely, Taylor (2002, p. 3) argues that the notion of objectivity suggests that a researcher is able to obtain knowledge of an external world because it exists independently of the research process. This appears to mean that the researcher is separate from their observations and the data. The research findings are therefore wholly derived from the data, not the interpretations of the researcher. We have captured an 'objective reality' that is value-free. If we accept this notion then we aim to reduce distortion and keep bias to a minimum. However, this approach is more strongly (although not exclusively) associated with rigid quantitative methods where researchers can accurately measure and manipulate numerical data, in contrast to the qualitative methods with which I am concerned.

Hammersley (1992, p50) would disagree with the view that the researcher is separate from their observations and data, calling this approach '*naïve realism*'. He proposes that the researcher is not independent of the phenomena being studied, but is instead a part of it. Additionally, Denzin (2001, p. 3) argues that a qualitative researcher '*is not an objective, politically neutral observer who stands outside and above the study of the social world.*' Denzin, like Hammersley, argues that the researcher is '*historically and locally situated*' within the processes being studied. This argument that the researcher is part of the phenomena being studied is central to arguments which challenge the objectivity of research.

To address the notion of objectivity and integrity of research, ethnographers developed reflexivity. Hammersley and Atkinson (1989) identify that this is where the researcher 'takes a step backwards' and examines their personal issues in undertaking a particular form of research. They establish that the researcher examines the taken-for-granted assumptions associated with personal value systems, gender, race, socio-economic status and political leanings. This process continues throughout the whole of the study, requiring introspection from the researcher in every situation encountered. Reflexivity then extends itself into how the account is written up, whether the evidence supports or refutes literature, and additionally, the question of whether particular aspects of the study, or particular informants are being over-emphasised, or whether a study exhibits representational integrity. The notion of reflexivity within the social sciences challenges objectivity because it draws attention to the researcher as a part of the world being studied, and the ways in which the research process represents, and is a part of, that study. Reflexivity considers the notion of power and the unequal relationship between the researcher and the researched. This notion of power is increasingly relevant in studies with people who have been subject to marginalisation (Illich et al. 1977, Goodley 2000, Walmsley and Johnson 2003).

What has evolved since the 1930s, has been the transformative position of the researcher from an objective onlooker outside the field of research to an

active participant within the field, who tries empathically to grasp, understand, interpret, and reflexively represent the perspectives and experiences of people whose voices have previously been unheard.

I will now look at narratives, and the skills employed in their extraction and construction.

#### **4.3 Life stories, skills and interviewing**

Interviews undeniably hold a prominent position in research methods for the social and behavioural sciences. Interviewing is a flexible and adaptable way of finding things out (Robson 2002). Taylor and Bogdan (1998, p. 88) describe qualitative interviewing as *'flexible'* and *'dynamic'* and modelled after a *'conversation between equals rather than a formal question and answer exchange.'* Furthermore, Kvale (1996, p. 125) proposes that the interview is an *'interpersonal situation, a conversation between two partners about a theme of mutual interest'*. This specific form of human interaction is one where knowledge evolves and is constructed, resulting from dialogue. Unlike Taylor and Bogdan (1998) however, Kvale does not visualise the research interview as a conversation between equals. Instead, he points to the power imbalance between interviewer and interviewee. This power imbalance occurs because the interviewer defines the situation, introduces the topics to be explored, and through questions 'steers' the course of the interview. This questions whether the conversation really is a theme of mutual interest because the interviewer, not the informant, has chosen it.

In addition to the practical aspects of the interviewer's function are the hidden power relationships between the status of the interviewer as the expert and the interviewee as informant. However, Czarniawska (2004) would disagree that there is a power imbalance during life story work, claiming that the informant is the expert on their life and therefore in the driving seat. Czarniawska argues that the informant being an expert addresses the perceived power imbalance with the interviewer as the expert. However, the interviewer does retain power in other domains, because accompanying the

interview are interviewer observations concerning the interviewee's facial expressions, tone of voice, and body language to give a richer access to interviewee meaning rather than a transcribed text. These observations are reliant on the researcher's empathic interpretation of the jointly constructed and negotiated meanings within the interview situation (Bruner 1991).

What is being described here is a process constituted of many layers. It is not simply the telling of a story that is recorded and retold. Hammersley (1992) argues that the interviewer is inextricably part of the process because their skills in extracting and interpreting a particular story are an important component of the interview process. Extracting a particular story for Plummer (2001, p.20) would mean differentiating between a long life story, which is gathered over a long period with gentle coaxing from the researcher, and the short life story. The short life story is gathered through *'in depth interviews with open-ended questionnaires, requiring gentle probes and lasting between half an hour and three hours'* (Plummer 2001, p.24). Short life stories can be woven together to create a wider account. The skills of the interviewer would vary in these different contexts; probing and coaxing are two skills developed through experience and exposure to differing interview situations. Probing usually repeats significant words from the informant's reply and reformulates the original answer, in order to gain further elaboration (Egan 1998). Coaxing can be a more coercive activity. An interviewer coaxes the story from an informant by listening empathically, gently guiding the direction of the story and eliciting details by 'feeling' their way through the interview. These skills are reliant on the personal interaction of the interviewer and informant; it is a unique interaction, placing strong demands on the interpersonal skills of the interviewer, his or her empathic awareness and knowledge of the field and their craft. The interviewer is therefore a tool for obtaining knowledge.

There appears to be a presumption in methodological resource texts that the interviewer automatically acquires the skills to be an effective communicator. The idea seems to be that one prepares and reads around what one wants to explore, devise a research question, enter the field,

interview and leave with the required information. There appears to be little guidance in the research literature regarding requisite skills of the interviewer. For example in Robson's (2002) comprehensive text, pages 270-291 are devoted to interviews. However, out of twenty-one pages, there is one 20 line paragraph concerning 'skills in interviewing', which merely glosses over 'skills', and instead encourages the interviewer to appear friendly. One line on page 274 concerns non-verbal communication '*vary your voice and facial expression*', but does not explain why this is necessary, what facial expression should be used and when, or how to look at the body language of the interviewee and moderate the interview accordingly.

Keats (2000) concerns herself with '*a practical guide to interviewing*' and out of 162 pages, devotes pages 21-27 to the relationship between the interviewer and interviewee, but with no examples to demonstrate differing relationships. Pages 59-61 discuss interpreting responses, again with no reference to examples that describe specific situations, to lead the reader away from a generalised idea of interpretation. Chapter 12 is devoted to interviewing people with disabilities, but locates the 'problem' within the disabled person, and generalises that '*a person with intellectual disability has difficulty in comprehending complex sentences*' (p.125). There is no indication of including a staff or family carer, who may understand the method of communication far better than the researcher. There is little in the way of examples, strategies, methods, and ideas for the researcher in the field, especially when dealing with individuals who are less articulate.

Where an informant is highly articulate, it may be possible to use Wengraf's (2001) Biographic Narrative Method to approach the informant and just ask one question, followed up by exploratory probes to clarify and deepen meaning. However, when an informant lacks the necessary articulation to answer in this way then the skills of the interviewer become increasingly important. This importance is twofold; on a practical note, to gain information, but another factor is to validate that informant as a valuable worthwhile human being; thereby building a trusting atmosphere through 'unconditional positive regard' (Rogers 1980).

Many of the interpersonal skills necessary in a more challenging research interview originate from counselling theory. Egan (1998) proposes that there are microskills that can assist in 'tuning in' to people. This means learning to use your body instinctively and being aware of your non-verbal communication so that you can enhance the interview relationship. Another way of 'tuning in' to a person is by active listening. Listening, for Egan (ibid, pp. 65-66), is being present, psychologically, socially and emotionally. For Egan, listening involves four things; firstly, listening and understanding verbal messages; secondly, observing and reading non-verbal behaviour e.g., tone of voice, posture, and facial expressions; thirdly, listening to the context or the whole person in the context of their social setting; and fourthly, listening to the '*sour notes*' or things that may require challenging.

Another skill is empathic listening. Empathic listening is an '*intellectual process that involves correctly understanding another person's emotional state and point of view*' (Egan 1998, p. 73). It also involves being aware of the inaccuracies in people's understandings of themselves and their worlds. Empathy becomes important in an interview situation because it is a '*tool of civility*' (ibid, p. 98) and plays an important part in building relationships. In an interview situation, another skill is shadow listening, where the interviewer has a 'shadow conversation' with themselves throughout the interview. For example, "My mind is wandering. I am wondering how to make sense of what is being said. I need to focus on what is being said now and I will make sense of it later".

However, there may be additional challenges involved when interviewing people with learning difficulties. Booth and Booth (1996, p. 56) highlight four in particular:

1. Inarticulateness
2. Unresponsiveness
3. Lacking a concrete frame of reference (unable to generalise from experience and think in abstract terms)

#### 4. Problems with time (ordering of events)

Using narrative methods may partially address the difficulties involved in Booth and Booth's four challenges. However, narrative methods alone are not necessarily the solution. Narrative methods would appear to be dependent on the skills of the researcher to construct a story that the reader can engage with, and enter the unique world of the individual represented in the text. I have given examples of using interviewer skills, coupled with the construction of narratives of people with reduced articulation in Chapter 5.

Referring to research interviews more generally, Plummer (2001, p. 145) encourages the practising of techniques in the interview situation such as 'funnelling'; having questions and linked probes that keep the interview going. There can be the standard funnel; with closed questions opening out into more in depth questioning. Alternatively, there is the inverted funnel; starting with five or six general questions and becoming more focused around specific areas. Plummer talks about being attentive and responsive and being familiar with the informant's linguistic turn, suggesting that this places many demands on the interviewer. Plummer's analysis of interviews does not however include interviews with people with learning difficulties.

Interviewing some people with learning difficulties involves more than just putting the person at their ease, or being attentive. It is sometimes not as easy as just listening and adapting accordingly. Occasionally, the informant's linguistic turn can be just one word. Conversely, the informant can sometimes possess no linguistic turn whatsoever. These difficulties in vocalising are a challenge for the interviewer and, I argue, should not be an eliminating factor when attempting to obtain the stories of informants. In these types of situations, the responsibility is placed on the shoulders of the interviewer. The interviewer becomes speaker, listener, and interpreter at the same time, for example, guessing and speaking aloud at what it is that the interviewer thinks the informant wants to convey, whilst simultaneously checking and re-checking the accuracy of the understandings and interpretations with the interviewee.

Pluralistic methods can entail employing an aide memoire, using pictures, drawings, diagrams, videos, employing tapes, and using the knowledge of people who know the interviewee well to find out how they communicate. This ascertains whether the interviewer can manage the interview situation unaided. Other interviewer skills include practising active listening and observation skills, examining your feelings throughout all daily interactions, and using any other form of additional documentation that may help build a picture of the individual. All of these skills may help transform a challenging interview situation into a successful interview situation for informant and interviewer. In the process, the aim is to provide a more inclusive experience for the informant.

In an interview situation, the interviewer is reliant on the interview of the informant as a means of gaining access to their experiences, and evaluative accounts. In this sense, the research interview is a '*specific form of conversation*' (Kvale *ibid.*, p.27 ), '*the purpose is to understand themes of the daily world from the subjects' own perspectives*'. To fulfil the requirements of a specific form of conversation the informant needs to be knowledgeable and eloquent (Spradley 1979), and have '*the capacity to provide full and sensitive descriptions of the experience under description*' (Polkinghorne 1988, p. 47), to be able to provide a coherent account, and stick to the interview topic (Kvale 1996), be fairly articulate, able to verbalise, and have a 'good story to tell' (Plummer 2001). However, few informants conform to this ideal, and some may be harder to interview.

One interpretation of the literature is that the researcher should judge people who fail to fulfil the criteria laid down by Spradley, Polkinghorne, Plummer, and Kvale, as inadequate in an interview situation, and condemn these unheard voices to a life of silence. Alternatively, if we contextualise research within a disability rights perspective, then excluding people who are unable to verbalise, are inarticulate, unable to provide a coherent account or stick to the interview topic, means that the researcher is reproducing the inequalities in a non-disabled world that denies opportunities to and

oppresses disabled people. One ethical argument against research studies that have people with learning difficulties as informants is that they are vulnerable individuals.

McCarthy (2001) argues that deciding not to research individuals because they are vulnerable could actually increase their vulnerability because people will remain in ignorance about their circumstances and treatment.

Furthermore, exclusion from research may also denude the knowledge base about marginalised groups concerning their health, education, welfare, and quality of life etc.

#### **4.4 Types of interview methods**

There are many types of qualitative research methods. Some examples are: telephone interviews, face-to-face interviews, participant and non-participant observation, analysis of documents and records (Robson 2002, Cohen et al. 2000). For my study, I chose interviewing as my main method of data collection, with an aide memoire and participant observation, some analysis of documents and records, and extensive field notes relating to context and feelings observed and experienced during the interview situation. I explain my justification for these methods in Chapter 5.

One frequently used method is the interview, but the degree of structure can vary from interview to interview, dependent upon the research aims. Robson (2002) defines three main types of interview method. There is the fully structured interview where the fixed wording of pre-determined questions is asked in a set order. There is little flexibility in this form of interview and it has strong parallels with the stimulus-response models of behaviourism (Mischler 1986). Additionally, the wording and order of the questions can lead a respondent to reply in a set fashion. There is also the presumption that every interviewee will understand the wording of the questions, leaving little room for clarification. Semi-structured interviews have pre-determined questions but the order can be modified, depending upon the interviewer's perceptions about what appears the most appropriate. Additionally, the

wording of the question can be changed, omitted, or supplemented. The interview is not standardised and this obviously raises questions as to the reliability of the data and the question of bias. Alternatively, there is the unstructured interview where the interviewer has a general area of interest, and lets the conversation develop in this area. Kvale (1996) calls this type of interview the open interview. To facilitate this interview, an aide memoire can be used to guide the interviewer through the topic to be explored. One further distinction is that by employing this style of method, the informant retains some control of the interview situation because it is non-directive. Non-directive means that the interviewer takes a 'back-seat' role, allowing the informant to direct the situation. The interviewer then asks probing questions to deepen the knowledge of the situation and experiences that the informant describes. The informant is at the centre of the interview. Life history interviewing typically employs this type of method. The lack of standardisation is a methodological problem, but the data this type of interview produces is usually far richer than that obtained from a standardised interview schedule. The main criteria for these types of interview are that we have an informant who can verbally articulate, and who can understand the questions that the interviewer asks.

Qualitative interviewing places an isolated informant at the centre of the picture. It also concentrates on the verbal aspects of interviewing and the resultant transcripts, ignoring the non-verbal communication and bodily expressions that accompany the situation. If we relate life story interviewing to qualitative research methods, what we have is the case history of one isolated person where that person is at the centre: their life story, their narrative and their evaluative account of their life and experiences (Bertaux and Delcroix 2000). Therefore, this type of life story interview also appears individualistic. However, the main difference with life story interviewing is that the individual describes and accounts for their experiences: why they interpret and interact with their world in a particular way; why they (sometimes with the help of the interviewer) link past events to present actions. This account is told to an interviewer and although this puts the person at the centre of the picture, it allows for interpretation of their story.

After negotiating the meaning with the informant, interpretation is carried out by the interviewer. To aid this interpretation, various literary devices are used. These devices can range from description of the informant's circumstances and surroundings (the setting), locating the narrative in time and place (Czarniawska 2004). Additionally, more rhetorical devices, such as metaphor, can be used to dramatise and enhance descriptions for the reader. These literary devices are used after the initial gaining of the story from the lone informant. However, Bertaux and Delcroix (2000) point out that few people live their lives in isolation and most people are connected to other individuals in some way, whether through dependence or moral solidarity. Connections to other individuals were important for Bertaux and Delcroix, because their study looked at family stories; they placed the bonds that connected families at the centre of the picture, allowing them to examine the interpersonal and socio-structural relationships. The result was that they provided a sociologically richer account of families than a life history.

Part of the research process for Bertaux and Delcroix concerned not only an interview situation, but also detailed observations concerning surroundings, and researcher interpretations of family relationships. Detailed observations are a useful tool that can give more breadth and depth, assisting understanding in certain situations. These approaches acknowledge that the world is complex and multi-faceted, and socially constructed. Using observational methods alongside interviewing attempts to explore, understand and interpret how others construct and experience their worlds. These methods can transform individual issues into societal or structural issues, but they initially develop from consideration of the individual story (Walmsley and Johnson 2003).

#### **4.5 The form of the interview**

Research methodology texts caution against asking certain types of questions in an interview. Cohen et al. (2000) give a comprehensive analysis of what to avoid. An interviewer is supposed not to ask leading questions, or

questions worded in a particular way, suggesting that there is only one acceptable answer. Additionally, they caution against closed questions, or questions that require a yes or no answer. Wengraf (2001) particularly advises against leading questions because, he argues, they contaminate the response. Instead, he recommends asking a number of indirect questions of the informant. In addition, he argues that closed questions inhibit the production of a narrative response. In contrast, Kvale (1996) agrees that the wording of a question can shape an answer but that leading questions are a necessary part of an interview situation. He argues that leading questions can be used by interviewers to obtain information that they suspect is being withheld, and for checking the reliability of informant responses. However, Sigelman et al. (1981) would disagree with the use of leading and closed questions for people with learning difficulties because of their tendency to acquiesce. Sigelman's research has been used as a basis for not including people with learning difficulties in research because this 'tendency to acquiesce' apparently makes them unreliable informants. For example, Lennox et al. (2001) concern themselves with the primary healthcare of people with learning difficulties and suggest that this is one area demonstrating significant shortcomings. They used a postal questionnaire to elicit medical information from the GP, but did not involve the opinions of people with learning difficulties as to how they experienced the primary healthcare encounter. There has however been a shift in this way of thinking, and today most inclusive research with people with learning difficulties is narrative research. Dismissing narrative style research would, in effect, exclude much learning disability research, and *'questioning the role of narrative research for people with learning difficulties would be to question the whole inclusive research enterprise for people with learning difficulties as it currently exists'* Walmsley (2001, p. 199).

The process of challenging the purpose of non-inclusive research means that people with learning difficulties have begun to be active participants in research that concerns them. For example, in their extensive studies with people with learning difficulties, Booth and Booth (1996) disagree with Sigelman. They argue that leading and closed questions can make an

interview more inclusive for people with learning difficulties who lack the articulation to formulate concrete replies. Furthermore, they argue in favour of interpretivist approaches (for example narrative methods) to expand the story, creating a narrative using literary devices. Their argument looks at the interview methods we employ as interviewers and researchers that are mainly for articulate and coherent informants who have a good story to tell.

Unconsciously, qualitative methods appear to follow the medical model of disability because sticking rigidly to the interviewing advice of Wengraf (2001), Siegelman (1981), Plummer (2001), Polkinghorne (1989), and Taylor and Bogdan (1998), means that we are defining the 'ideal' (or the norm) in terms of the interview informant. I provide examples in Chapter 5 where not following standard interviewing advice has yielded interesting data. Additionally, rigidly employing qualitative methods can create barriers for people with learning difficulties by framing them as 'stupid', or excluding them altogether. In turn, this reproduces inequalities and marginalizes the people whose voices we are trying to represent.

Researchers at the Norah Fry Research Centre (2004) have tried to address some of the problems that may arise when undertaking research with people with learning difficulties. Their website suggests methods and approaches aimed at making research more inclusive. These methods range from using pictorial aids; photographs, drawings and diagrams, tapes, videos, writing; simple words, signs and symbols, non-verbal communication; body language, eye gaze, facial expressions, pointing, and sounds. The message they try to convey is that no two people give and receive information identically, especially people with high individual communication needs. They argue that the key resources for facilitating communication for people with high individual communication needs are families and staff carers, but they caution against the use of one person in isolation (e.g., a family member or paid carer) as a resource, but instead to use these 'key resources' as intermediaries or proxies. I have explored the roles of people as intermediaries or proxies in detail in Chapter 9.

Different ways of eliciting information from people with high individual communication needs, during the course of research, produce their own problems. Aside from the fact that no two people give and receive information identically, there is the problem of creating an accessible research environment for every person in the study. The resources required to facilitate every form of communication need would be enormous. There is also the problem of knowing how an individual communicates, and tailor-making a resource for each individual to facilitate the interview situation. Most research studies are under time pressure; therefore a large proportion of the study would be spent learning how each individual communicated, designing and modifying the learning resource, and finally employing it. The alternative would be to carry out smaller studies with fewer informants, or concentrate on the most articulate informants, which again creates inequality by discounting the voices of those who are inarticulate and perhaps more vulnerable because their voices remain unheard. Research with people with learning difficulties as active participants is not without its own unique set of problems. However, another possibility would be to use narrative methods.

#### **4.6 Using narrative methods**

A narrative is a story told by an individual, or group of individuals (Plummer 2001). Barthes (1977) famously identifies that narrative takes many different forms; written and articulated language, moving pictures, photographs, and paintings. Barthes states that narrative is present in myths, legends, fables, tales, history, novella, tragedy, drama, comedy, mime, stained glass windows, comics, newspapers, and conversation. Narrative began with cave paintings, and later with oral accounts passed down from generation to generation. Narrative has claimed its place in humanities, the arts and literature, and has recently started to claim its place within the social sciences. Roberts (2002) discusses various differences between types of narrative; the oral history account - dependent upon a face-to-face interview, the autobiography - where the individual writes the account and provides letters or diaries, the biographical account - where the interviewer may not

have met the subject but is reliant on interviews with significant others and any other writings concerning the individual.

A biography is not reliant on an interactive collaborative encounter, but is reliant on researcher/writer representation. These representations can take a variety of forms from full life histories, to case studies, which can be employed for a purpose, giving a snapshot of a particular event, incident or moment. The snapshot can reveal the inner working life of an individual, and can be a source of knowledge concerning the wider cultural features of a family or individual. These wider cultural features can relate to many popular discourses. Some examples are health, crime, gender, class, and disability (Hammersley and Atkinson 1989, p. 31). Representations of these discourses involve the use of narrative methods (or writing as a form of representation of the discourses), and a wide range of sources (for example, journals, diaries, public documents, descriptions) can be used to enable an understanding of individuals and their social circumstances. Polkinghorne (1988, p. 5) would add that narrative is a type of *'discourse composition that draws together diverse events, happenings and actions of human lives into thematically unified goal directed processes'*.

Additionally, Clandinin and Connelly (1994) argue that narrative relates to both a method and a story. Method is the process by which a researcher would collect the story and translate it into a narrative, and a story refers to people telling stories of their lives, and lives of other people. The limitation here, for Reissman (1993, p. 18), is simply equating narrative and story, and she suggests that there are a number of narrative genres; for example topic-centred, (e.g., health) that are chosen by the tellers to *'persuade differently'*. The teller can refer to both the originators of the story and the process of 'telling' (or re-telling) the narrative, through the medium of text, to the audience (readers). Additionally, Schütz (1973) argues that it is impossible to understand human intentions while ignoring the settings in which they make sense. Therefore, the context within which narratives are formed are important in order to gain a fuller understanding.

#### **4.7 Conclusion**

Narrative analysis is not a new phenomenon. It has been used within the social sciences since the 1920s. More recently, what has evolved has been the transformative position of the researcher from an objective onlooker outside the field of research to an active participant within the field, who can grasp, understand, interpret, and reflexively represent the perspectives and experiences of people. However, there is an imbalance here because the methods used to produce narratives have remained virtually the same over the past ninety years. Society has changed over the past ninety years; developments in our communication methods have altered dramatically. We use text messaging, email, and mobile phones to communicate with one-another. The Norah Fry Research Centre has published guidelines with the aim of facilitating communication with people who are less articulate. Arguably, our research methods should have altered and adapted in line with our expanding ways of communicating with one another. Additionally, it appears that many (but not all) researchers are still using more traditional qualitative methods to collect data. These methods are fine if they 'fit' the purpose of the research, but they are mainly, although not exclusively, interviewing, aiming at capturing stories and experiences from people who are articulate, knowledgeable, and have the capacity to fully describe the subject under research. Traditional qualitative methods exclude a large proportion of people who are inarticulate or preverbal. Excluding people who are inarticulate, preverbal, or with profound learning difficulties, also excludes the stories that may give us important insights into ways of helping people to realise their hopes and dreams.

The skills and experience of the researcher become important during challenging interview situations. Being able to facilitate or represent the silent world of inarticulate individuals into a world of words means empathically capturing situations, feelings and experiences, transforming them into text. The audience then re-interprets this text. The use of the reflexive stance becomes important when using inclusive research methods because it examines what our motivations are, why and how we are using a

particular tool. It allows the audience to make an informed interpretation of a situation. It also addresses the problem of objectivity because it makes the research process more transparent. Employing alternative methods is not without its problems, but in using narrative methods, I propose that in moving away from more traditional qualitative methods and advice on interviewing protocol, we are attempting to include people with profound learning difficulties in the process of researching their lives and experiences.

## Chapter 5

### Methods

#### 5.1 Scope

This chapter follows the preceding chapter where I argued the case for an interpretive research approach using narrative methods. In this chapter, I describe how I represent the healthcare experiences of people with learning difficulties. I gain my material from spending time with people with learning difficulties, staff, learning disability nurses, families and voluntary helpers. I interpret and draw inferences from their directly reported information, and place this in the context of observations that I make in their environments.

Transparency is important in research (Robson, 2002, Cohen et al. 2000). It is for this very reason that I present a detailed discussion of how the research was carried out; from conception of the idea to birth of the thesis. I begin by explaining how I searched for and organised the relevant literature. I explain and justify the methods I used in the field, the problems I encountered, and how I sought to deal with them.

#### 5.2 Searching for relevant literature

Before instigating the literature search, I initiated a 'log book' to keep track of searches, terms used and papers/documents/books acquired. I then drew up a list of relevant sources of information. I separated the list into sections, these were:

- Journals.
- Computer databases.
- Search Engines.
- Books.
- Learning difficulty associations who published work.
- Libraries that could be accessed.

- Specialist bookshops.
- Dissertations and theses.
- Conferences.
- Government documents.

#### Journals accessed

- British Journal of Learning Disabilities.
- British Journal of Nursing.
- British Dental Journal
- British Medical Journal.
- American Journal on Mental Retardation
- Australian Psychiatry
- Canadian Medical Association Journal
- Disability and Society
- Journal of Applied Research in Intellectual Disabilities
- Journal of Learning Disabilities
- Journal of Intellectual Disability Research.
- Journal of Advanced Nursing
- Medical Journal of Australia
- Nursing Standard.
- Psychology and Health
- Social Science and Medicine

I accessed these journals systematically, either in the library or online through the library electronic journal service. The journals in the list appeared to be those used the most by researchers and academics writing about people with learning difficulties. I scanned articles to identify which appeared to be of use, and listed them with a brief description placed by the title, alongside the journal reference, title, author, page numbers and ISSN. Articles appearing to be of greatest use (sometimes this was retrospective because it was not always possible to identify useful articles immediately) were downloaded or ordered from the British Library.

## Computer databases

The following databases were accessed through the university library:

- MEDLINE through OVID.
- PSYCHLIT.
- CINAHL.
- ASSIA.

There were two slight problems when the first searches were initiated;

1. Search terms to use for 'learning difficulties'
2. How to go about searching for two topics; 'healthcare' and 'learning difficulties'

The term 'learning difficulties' is relatively new and there are many other terms that have been used previously, making searching more difficult. Coupled with this is the fact that the United States still uses 'mental retardation', whereas Australia and New Zealand use 'developmental difficulties' or 'developmental disabilities', and sometimes intellectual disability. Additionally, other countries use the term 'cognitive impairments', and the UK and other countries can use 'learning disabilities'. Similarly, 'health' is a term that yields a high volume of data.

A preliminary search for 'learning difficulties and health' gave over seven thousand 'hits'. Going through each 'hit' would have been an extremely difficult and time-consuming task. I made the decision to whittle down the search terms.

Initially, the search was limited to English only and 'learning difficulties and health' through MEDLINE; this produced seven hundred 'hits'. Each 'hit' title was scanned, looking for titles that appeared relevant, then marking, saving, and returning later. Scanning and identifying took three hours of intensive reading. The same terms were then used whilst searching the other

databases. There were similar results, followed by another five hours of scanning and reading.

The next approach was to try the term 'mental retardation' which yielded only thirty-eight 'hits' through MEDLINE, but only one reference initially appeared to be of any use. The same term was employed with the other databases, producing similar results. The terms 'developmental disability' and 'developmental difficulties' were then used.

The many different labels for 'learning difficulties' were noted, as far as possible, and each term was searched looking for health-related articles. The terms used were

- Learning difficulties
- Learning disabilities
- Developmental difficulties
- Developmental disability
- Mental retardation/mentally retarded
- Intellectual impairment
- Intellectual disability
- Cognitive impairment
- Cognitive disability
- Mental impairment/mental disability
- Mental subnormality
- EBD (emotional and behavioural difficulties).

Each term was then linked with health or healthcare or health encounters, and the exercise repeated.

The next step was to use the terms:

- 'women with learning difficulties and health'
- 'men with learning difficulties and health'
- 'cerebral palsy and health'
- 'Down syndrome and health'
- 'fragile X syndrome and health'

- 'osteoporosis and health'
- 'learning difficulties and dental health'
- 'cervical screening and learning difficulties'
- 'prostrate cancer and learning difficulties'
- 'mental health and learning difficulties'
- 'health screening'.

Finally, the search was extended to look for narratives, narrative methodology, and first person accounts and self-report, because I was looking at first person accounts for the study and wanted to see how people had approached this style of research previously.

The searches were time consuming, slow and tedious. I found that the actual number of relevant articles that were of some use to the study were very limited.

### Search Engines

By far the quickest and easiest search engine to use on the world-wide-web was GOOGLE. The term learning difficulties and health and the search engine produced ten 'hits', but in particular one large and valuable article that was relevant, and available to download. LYCOS was useful but did not appear to have the same flexibility as GOOGLE.

### Books

My own book collection of works on disability was quite extensive because of previous research. However, I accessed the main publishers; Sage, Blackwells, Routledge, Jessica Kingsley and Open University Press, and scoured their catalogues for works on learning difficulties, disability, health and disability, empowerment, decision-making and disability.

I then looked at methodology, accessing works on qualitative methods, narrative methods, interpretive methods, and stories. The sites are useful because each book has a brief abstract or summary as to what to expect.

### Learning difficulty associations

There are learning difficulty associations; for example Values into Action and BILD (British Institute of Learning Disabilities), who have their own publishing section. It was simple to contact them and ask for a list of publications. Each publication had a brief resume as to its contents. I purchased the relevant articles. Although the NDT (National Development Team), the Joseph Rowntree Foundation and the Nuffield Foundation are not learning difficulty associations, they do publish work and have undertaken studies with people with learning difficulties. I accessed their sites and ordered relevant publications.

### Libraries

The University library was the most obvious place to begin a search, but the British Library uses different search engines and throws up alternative information. I searched the British Library site using the same terms I had used with the other databases. Many articles were duplicated, but occasionally a new article or book appeared that I had not previously logged. I ordered and photocopied journal papers from the British Library for ease of access.

### Specialist bookshops

There are no specialist bookshops that would have aided my search. However, I used the main branches of Waterstones and Blackwells. It was easy to walk in, peruse the shelves in the relevant sections, and briefly 'scan' a book for its contents. Occasionally a book would appear that I may have previously disregarded due either to its title or/and a poor report. It also pushed me into going somewhere different and shifting my focus. This was

useful because it made me consider ideas I may have missed due to over focusing in the library or on the computer. One example was Carnwell and Carson (2004) that appeared to be meant as a guide for social workers. The book was extremely helpful when addressing 'collaboration' and 'co-operative' working because it discussed practice regarding 'collaborative' and 'co-operative' working.

### Dissertations and Theses

Searching through the University database for dissertations and theses on topics that were similar was a necessity. I also accessed the ESRC theses databases.

### Conferences

I made myself aware of any conferences that were forthcoming, or had already taken place. I did this with the intention of either listening to papers being presented, or finding papers that had been presented in previous years that were or may have been related to my study.

### Government documents

I ordered the relevant White Papers from HMSO and any previous documents from the Department Of Health or National Health Service that might have been useful. I also purchased the Law Commission documents on decision-making and consent. The Lord Chancellors Office was also accessed online for the latest directives on human rights, decision-making and choice for people with learning difficulties. The online facility allowed free downloads.

### Organising the literature

The job of comprehensively analysing the contents of the search was a major task. I read each article or book chapter and began to think about the themes

and the links between each theme. Whilst thinking and jotting notes down concerning the themes I began to think critically about how the piece of work came about and the assumptions that had been made therein. The process expanded my knowledge on the subject area whilst making me aware of other related issues that I had not previously encountered.

Identification of some issues led me to initiate another search with the following search terms:

- 'choice'
- 'decision-making'
- 'empowerment'
- 'Human Rights' and 'Rights'
- 'independence'
- 'inclusion'
- 'capacity'
- 'consent'
- 'person-centred planning'
- 'health education'

The challenges involved in weighing up the evidence were time consuming, and difficult because some papers were difficult to read because of their intellectual complexity. Additionally, I initially found it difficult to identify 'grey' literature, and assess its relevance for my study.

I then linked each listed term with each of the terms for learning difficulties. The literature gained was now extensive but themes had been identified running through the literature. Constructing a literature review from these themes was not easy and needed several rewrites before a product possessing some clarity, structure, and organisation emerged. After the literature review, the next task was to organise the fieldwork and access the informants.

### 5.3 Establishing contact

In the early stages of any piece of research, it is important to establish contact with informants as quickly as possible (Stringer 1999). My study already had the sanction of senior management in Brancaster Trust and had been approved for research governance purposes. It had also received REC approval, but I still had to win the 'hearts and minds' of senior staff and staff carers in order to access the residents.

My first approach was to contact the two separate heads of nursing, one with responsibility for the ten core units at St. Francis' Hospital and the other with responsibility for the registered care and supported living homes. I also contacted the community learning disability team who supported people living independently in the community. Within these homes and units were housed approximately one hundred and ninety to two hundred people, with mild to profound learning difficulties. The homes are located over an extremely wide geographic area, making a meeting of all residents difficult to arrange.

The research process and aims were explained to the relevant team heads at their monthly meetings. They agreed to filter the news down to the carers working in the homes; informing them they could expect a telephone call and a visit. Each nursing head provided a list of homes, with a named member of staff in charge and number of residents in the home. It was then up to me to contact them. The homes were contacted by telephone, to arrange a short visit, with the purpose of explaining the study, and enquiring who wished to take part. Some homes were not visited; because on the initial telephone call staff indicated residents at the homes had a mental age of two months, and would be unable to communicate in any way. The staff said that their main difficulty was understanding what each person, in this position, required on a daily basis, and it was very 'hit and miss' in many circumstances.

I tended to visit homes on the advice of staff, taking heed of their suggestions as to which residents would be willing and unthreatened in an informal interview situation. The implications of this were that the staff were choosing who I could and could not interview, which may have accounted for some stories being given priority. Most of the homes were accessible and friendly, but one or two were officious and declared I would have to be 'checked out' before I could have an appointment to visit. At all stages, the advice of the staff was sought first, because of the intimate knowledge they had of each resident. After each initial field visit, I made notes concerning the initial contact, first impressions of the residence, and people who agreed to be interviewed. It did not take long to build up a list of willing informants. The format followed was very similar to a continuous spiral of observing, writing notes, thinking, interpreting, and then following a planned course of action when in the field again.

To expand the study and explore whether experiences of people differed, perhaps those living independently in the community, the local SEC's (Social Education Centres) were contacted independently, alongside the local branch of People First, and the learning disability nursing team. The Assistant Head of Social Services was also contacted directly, initially by telephone, but he appeared suspicious as to the aims of the study, and eventually declined to participate due to 'data protection' and because the Head of Social Services made all decisions. I decided that I had enough avenues of entry and did not pursue the matter further.

For the places agreeing to help, a poster and fliers were printed (appendix i), asking for help with the study. Out of seventy-five fliers distributed, there were three replies; two females, one male. I felt that this avenue of enquiry was limited in its approach because only people who were highly articulate, and who could negotiate everyday life without the support of a staff or family carer, contacted me.

### Establishing a role

The traditional researcher carries with them an aura and status of the expert/scientist (Stringer 1999). My wish was to establish a stance that was legitimate but also non-threatening to both staff and residents alike. At the time that the research was in progress, the Trust was in a state of flux. Jobs were being redefined, employees were afraid of losing their prior service; and were being made to sign new contracts or else face resignation or redundancy. The two heads of nursing were integrated into one post with responsibility for the entire learning disability team under the community section. Housing was also being changed; with the Trust having to relinquish some homes whilst others were taken over by Housing Associations. Housing Associations brought their own rules, alongside the Community Care Act recommendations. This meant moving some residents to alternative accommodation, although in some cases, they may have lived in a particular home for over eighteen years. Residents were understandably feeling insecure and apprehensive because they had already been subject to a round of people asking questions. I followed on the tail end of this process, and was frequently met by anxious residents telling me that they were happy and did not want to move even before I had a chance to explain about the research.

Most of the homes visited allowed me to sit with the residents and take part in activities. In some of the hospital-based units, I was allowed to assist with making the tea and serve lunch and dinner. Some of the residents allowed me to attend medical appointments with them; others were happy just to chat and share their photograph albums of their lives. Action research and ethnographic approaches influenced me to attempt to 'fit in' by dressing down, visiting in casual wear, and using similar language to the residents. I did not want to be identified as a medical or other professional that they normally encountered. The benefit for me was that I felt more comfortable in casual clothes, the losses were that some staff carers and professionals treated me like a first year student, until I gently pointed out that I was in fact working.

### Instruments employed

Putting methodological and ethical principles into place when researching and interviewing people with learning difficulties has been described as a minefield (Swain et al. 1999, McCarthy 2001). The research tool I chose for my study was that of an open-ended in depth interview with an aide memoire to guide me through the process (appendix ii). The intention was to use the aide memoire for my benefit to help me keep my focus (Kvale 1996), when asking about healthcare. The reason for my choice was that I did not consider any other research method to be suitable. A structured questionnaire, with pre-set questions would have been too restrictive and would not have allowed me any flexibility or follow-up discussion. Reading around the literature by Booth and Booth (1994, 1996), McCarthy (2001), and Thomas and Woods (2003), I knew that a rigid structured approach would not work well with people with learning difficulties. The cognitive abilities and communication skills of each individual differed greatly and it would have been impossible to construct a set of questions to suit everyone. For example, making questions too simple would have been patronising to some people, but making questions too complex would have been an inhibiting and destructive process for others. I had already spent time in the homes chatting to the various residents. Some of them felt comfortable enough with me to consent to talking about their healthcare, whilst others gave me names of people with whom they thought I should talk.

With the more articulate people, my worries about an interview were unfounded because they knew what they wanted to describe. With the people who lacked the same level of articulation, questions were adapted, until the informant understood enough to reply. For people with little or no verbal articulation the aide memoire was next to useless, leading me to search for new ways of communication during the interview process. This entailed 'thinking on my feet' and utilising every communication skill I possessed, to gain the most out of the communication environment for both parties concerned. At the end of this chapter, I describe how I negotiated problematic encounters.

To aid communication, I used some of the techniques proposed by the Norah Fry Research Centre (2004); showing and discussing cards depicting 'dentist', 'doctor', 'nurse', and happy to sad smiling faces (appendix iii). In some situations, the booklet 'The Healthy Way' (DOH 1998c) was used and discussed with the people being interviewed. Using a story with cartoon pictures appealed to some people with learning difficulties and 'talking' through the story aided as a 'memory jogging' device for other people with learning difficulties. Multiple methods were essential because not everyone communicated in the same way. Some found pictures easier to bring thoughts forward, whilst others found discussing a 'story' easier, or being asked questions more comfortable. In many instances, I asked staff how a given individual with learning difficulties found it easiest to communicate. The challenge was to find how people with learning difficulties found it easiest to express themselves.

Once an understanding was reached then the next problem would be attempting to assess the veracity of what was being communicated, and making sure there were no hidden agendas behind the information collected. In many cases, the staff confirmed the stories, and volunteered information without any probing on my part. They instinctively gave me a 'run down' of situations encountered by the residents. The residents gave me a more personal account of what happened to them in healthcare situations.

I did not impose an overall limit on time spent with each informant. Some sessions were half an hour long, some lasted two hours, some informants were visited five or six times, others twice. Working in this way was time-consuming, but I felt that it was unethical to rush in, ask people about their health and rush off. Another factor was the length of time some people with learning difficulties needed to think about what I had asked, process the information and formulate a reply. I felt they needed to be given the time and opportunity to speak.

A potential disadvantage of my research is that it does rely almost entirely on first-hand accounts from those involved, and this raises issues of validity and reliability. However, issues of validity remain within the agenda of positivists and Guba and Lincoln (1989) argue for the need to replace positivist notions of validity in qualitative research with notions of authenticity. Mischler (1990) suggests that 'understanding' is a more suitable term than validity in qualitative research. Therefore, the meaning that is given to accounts and the inferences drawn from them are important. Blumfeld-Jones (1995) suggests that 'fidelity' replaces validity because it requires the researcher to be as honest as possible with the reporting on those they research. Connors and Stalker (2003) suggest checking out findings and analysis by returning with it to participants; a process referred to by social constructivists as 'member checking'.

After I had transcribed the tape, or written a narrative, I returned to each informant and gave a written summary to the informant, whilst at the same time giving a verbal summary. Some informants agreed with what I had inferred from the interview; others asked me to add to, or alter the narrative. Sometimes, the staff carers in the home inadvertently corroborated the story, or else residents in other homes would tell me a story about their friends, who had already told me the same story earlier. Admittedly, however, I returned within a week or two of transcribing the tapes, or producing the narrative; any longer and people would not remember what they had told me because that story was no longer prominent in their lives. This questions how useful reliability is as a construct in qualitative research, because typically if the same methods are used with the same sample then the results should be the same. The uniqueness and idiosyncrasy of the situations means that they cannot be replicated and this is a strength rather than a weakness. Denzin and Lincoln (1994) suggest addressing reliability in qualitative research in several ways; one way that appears to stand out is that of inter-rater reliability. Denzin and Lincoln (1994) suggest that another researcher working with the same theoretical framework would interpret the phenomena in the same way. However, because versions of the same reality co-exist then reality is multi-layered, and even though clarifying meanings

and checking stories with respondents partially addresses reliability, it also places exclusive store on respondents, placing them in a privileged position as sole commentators on their actions (Hammersley and Atkinson 1989).

Not all the information for my research came solely from people with learning difficulties. Information was also garnered from 12 paid carers, 13 learning disability nurses, 2 psychiatrists, 1 psychologist, 1 chiropodist, 3 dental surgeons, 2 GPs, 2 advocates and 2 family members. I feel it is important to point out that I was trying to influence people to tell me stories of healthcare encounters. However, I do not feel I was encouraging people to tell me things, positive or negative, that were exaggerated or untrue.

### Inclusion

The original thought behind the project was to include the voices of people with learning difficulties in the research. This was because most research has tended to emphasise the perspectives of researchers and professionals (Cameron & Bernades 1998, Keywood et al. 1999). There was, however, a large body of lay experiences to tap into and use as a measure against the experiences of people with learning difficulties (Calnan 1987). My aim was to include as many relevant individuals as possible, with differing communication abilities, rather than concentrating merely on people who were articulate.

I wanted to give people a choice of how and where they wished to be interviewed; with a member of staff present, in front of the television, alone in a setting of their choice, or in a group. I also wanted to include all the relevant issues related to the person's own healthcare, and not concentrate on narrow administrative and political agendas. One informant produced a retrospective diary of thoughts, feelings and related events in his life. This proved to be highly informative. His key worker unintentionally corroborated the story within the diary. Another informant was going to keep a diary of healthcare encounters, but ill health prevented him from doing so. A further informant decided to write his own story but the chance

of being moved to accommodation that was like a home, without the intrusions he had previously suffered, made writing the story take a back seat. I approached and solicited the views of staff and professionals from the Brancaster area. Most were happy to help me build a bigger picture. The staff and professionals were from the NHS, social services, the voluntary and the private sector.

### Tape recording

The tape recorder is a useful tool because it allows the researcher to accurately record detailed verbal information (Kvale 1996). However, situations arose that did not permit the use of a tape recorder:

- Interviewing in environments where background noise was too intrusive.
- Refusal by the informant
- Refusal by the informant to continue audio-taping part way through the interview
- Where use of a tape recorder was at risk of turning an informal interpersonal encounter into something more formal
- Length of interview; some interviews were over two hours in length, continually changing a tape over would interrupt the 'flow' of what was happening
- Type of interview; some residents and staff members could only be spoken to whilst 'on the move', making tape recording an impossibility
- Speech of the informant; some speech patterns were difficult to understand, tape recording would have served no useful purpose as we struggled together to gain mutual understanding
- The informant being unable to communicate by speech.
- Where non-verbal methods of communication, eye movements, hand actions and other gestures were dominant.

Where the tape recorder could not be used, journalistic methods were employed such as writing memory jogger notes throughout the interview (Denzin 2001). Additionally, my experiences as a counsellor meant that I used a counselling technique of active listening, and 'feeling' with the

informant (Rogers 1980), as much as possible, followed by methodically thinking and writing everything down on reaching my car.

Where I used a tape recorder, I transcribed the tape as soon as possible after the interview. This was to recapture the sense of the interview. Alongside the tape, and after every visit, was a separate methodical transcription of field notes, describing where the interview took place, the feelings invoked, and what my impressions were throughout the interview. An example of the field notes is in appendix iv. I then returned to the informant with the transcript and a staff carer, or trusted friend read it to them. I amended any inconsistencies at a later visit. In other circumstances, I talked people through the contents, discussing and amending any inconsistencies.

### Participant observation

Ethnographic principles influenced me to observe the setting in which people lived and worked helped me to gain a picture of the research context.

Recording all the observations in the form of field notes provided important elements related to each setting. Descriptions of the following were made as soon as possible after the visits/meetings:

- Places; homes, units and residential contexts, physical layout and the location of any activities or events.
- People; individuals, types of people, formal positions and roles.
- Objects; buildings, furniture, equipment.
- Acts; single actions made by people during the visit (holding staff meetings, reading reports, taking part in an event).
- Activities; series of related acts leading to perhaps an assessment or to a restructuring of leisure activities.
- Events; a conference.
- Purposes; what people were trying to accomplish on that day, at that time.
- Feelings; what my responses to people and events were, and what theirs appeared to be.

- Time; when the residence was visited, what day of the week, time of day.

I saw this level of description as a necessary and invaluable tool. When I came to do the analysis of the interviews it provided me with the context and situation at the time of the interview. It also gave me the ability to check the veracity of my observations by questioning others. It was not always comfortable 'hanging around'. To resolve these feelings in many places I tried to make myself useful. However, in some places I limited the time I spent there because I felt I was 'in the way'. Some staff carers made it obvious that I was disturbing their routine, whilst others welcomed and included me. Residents in some homes welcomed a new face to chat to whilst others regarded me with suspicion, demanding to know what I wanted. This difference in how people accepted (or did not accept) my presence undoubtedly affected the data collection.

In using the word observation I include the physical process of observing actions and writing them down, and the processes that I have learnt from my previous work in counselling. These processes are the transference of feelings from individuals that, with experience, I have learnt to interpret. The process involves a high degree of reflection to understand and separate emergent feelings, transferred during interactions with other people, from ones own feelings (Rogers 1980). I firmly believe that the process of transference is something that cannot be taught, rather it is an innate ability in some people that can be developed and nurtured. However, in interview situations it becomes a valuable tool, and used effectively can broaden the interview situation, allowing the interviewer to probe emergent feelings, questioning the respondent in the process.

As a participant observer there were occasions, not very many, when I spent more time observing than participating but it was more usual for me to be involved in activities or in 'getting to know you' sessions with service users when things happened in the environment that provided me with opportunities to observe situations at close hand (for example in chapter 6 the case study of Samantha). I was also conscious of maintaining an ethical

stance in my relations with service users, so for example I was keen to respect the fact that I was a visitor, albeit an invited one, at their homes or places of work and leisure where there was a premium on preserving personal space, privacy and above all else the dignity of each person. I therefore adapted a conservative approach to observation and used my negotiated role as a participant to guide the limits of my observational endeavours.

#### **5.4 Analysis: constructing stories about the stories**

Initially, analysis of my data fits with Moore's (2004) description of her adaptation of grounded theory (Glaser and Strauss, 1967; Glaser, 1998; Strauss and Corbin 1990, 1997) because my ideas and recommendations emerged from the data and were grounded in the experiences and words of people with learning difficulties, the staff and professionals involved in my study. In many interview situations, it was not possible to obtain taped transcriptions, or to make detailed notes. I wrote field notes and detailed descriptions, or spoke into a tape recorder immediately after each interview, usually in my car. In addition to these methods, I also used ethnographic methods of participant observation. However, like Moore (2004) I was using the social model of disability as a lens through which to view my data because the social model draws a distinction between impairment (physical, sensory or intellectual limitation) and disability, which refers to social, material and cultural barriers which exclude disabled people (Oliver 1990, Abberley 1987). The social model also has a far-reaching impact on the way disabled adults are seen and see themselves (Oliver 1990).

From my initial meetings with staff carers and people with learning difficulties, I was trying to make sense of what was happening to people with learning difficulties within a healthcare context, and to gain insight about the experiences and feelings of people with learning difficulties themselves concerning their healthcare encounters. However, my approach does not fully align itself with the grounded theory recommendations of Glaser and Strauss (1967) because a key feature is the constant comparative method of

analysis in which data collection and analysis is a simultaneous and interactive process. The process also involves constant comparison between words, sentences, paragraphs, codes and categories. In addition, my study does not strictly fit an ethnographic approach (Hammersley and Atkinson 1989) even though I participated in people's lives for an extended period, took extensive field notes, was aware of power relationships, and used my observations and field notes to assist with the analysis of my data. To some extent, I also used narrative analysis in my construction of the stories (Bruner 1991, Polkinghorne 1988, Reissman 1993, Czarniawska 2004, see previous chapter). The approach to analysis that I adopt within this thesis draws upon grounded theory (Glaser and Strauss 1967), ethnographic approaches (Hammersley and Atkinson 1989), and narrative analysis (Reissman 1993).

However, I also deviate from grounded theory and ethnographic approaches because my stance is essentially constructivist. A constructivist stance builds on the premise that the *'study of the social world requires an approach which allows access to people's interpretations of their world, because human beings can interpret and construct realities which are shaped and perceived by cultural and linguistic meanings'* (Galvin, 2005, p.232). A key assumption underpinning constructivist evaluation is that people construct their own reality, but constructivism is also premised on moving towards shared constructions with informants, especially about what sense they make of their personal and social worlds (Rodwell 1998, Charmaz 2000). Therefore, my interactions with the people concerned in my study also formed part of my analysis. The issues, concerns and claims of people with learning difficulties, staff and family carers, and professionals determined what information was needed and how it was collected. Within this chapter, I give examples and describe differing methods of interacting and collecting information from three people with learning difficulties.

One aspect of my stance was that I did not regard the perceptions of staff or family carers and professionals as being more 'right' or 'true' or 'real' than that of people with learning difficulties. Instead, I tried to understand the

multiple social constructions of meaning and knowledge within the healthcare encounter. Using research methods such as interviewing and observation helped me to acquire multiple perspectives in an effort to represent reality through the eyes of all the people participating in my study. In addition to interviewing and observation I clarified meaning throughout the process of each interview and then returned one or two weeks later with the story (built from the interview, my observations, and sometimes those of staff or family carers) to again re-clarify the meanings. Sometimes, as in the case of Callum (chapter 8), and Jack (chapter 9), my return heralded a different interpretation and the story was built over three or four visits rather than two. In these situations, narrative analysis was invaluable in helping to develop the stories.

Reissman (1993) views narrative analysis as using multiple methodologies in pursuit of its own aims, rather than a single method in its own right. This would appear to link with constructivism because the narratives themselves are a starting point, rather than the end-point of the analysis. I am not suggesting that a single narrative can fully grasp all the meanings ascribed to healthcare encounters because a constructivist approach argues that individuals construct different meanings at different times to explain different aspects of their experiences.

I nevertheless chose narratives because they depicted different healthcare experiences. I discarded some narratives either because there was no discussion of healthcare experiences or because some individuals refused to discuss anything related to their health.

I arrived at themes by viewing the narratives through the lens of the social model of disability. For example, thinking about the social model of disability in conjunction with the data focused initially on the word 'barriers', which then led to linked themes such as

- narratives of competence
- competence promotion
- competence inhibition

- articulation and the relationship between narratives of support and constructions of competence
- prioritisation of knowledge (medical over lay)
- decision-making
- consent.

Analysis of the narratives according to these social model linked themes enabled me to identify which of the narratives I would present within this thesis. I tried to present a balanced account of the positive and negative healthcare experiences of people with learning difficulties, within most of the themes and not just concentrate on the horror stories that arose.

However, where there were clearly more negatives than positives then this is reflected in the narratives that I present. For example, in Chapter 7, I identified that a large number of negative experiences for some people with learning difficulties originated within the dental healthcare encounter. Two themes which illustrated more negatives than positives were the prioritisation of knowledge where medical knowledge took precedence over lay knowledge, or intimate knowledge of the person (Chapter 7) and decision-making (Chapter 6) where people with learning difficulties were excluded from many decisions concerning their own healthcare.

#### 5.4.1 The limits to constructivist research

Murphy and Dingwall (2001) concur that qualitative research methodologies do have an important role in terms of exploring areas that are inaccessible to other methods. However, the problem with constructivism is subjectivity. In addition, the process of interpretation and defining a situation is itself a product of the circumstances that the researcher and those participating are placed. One important factor to consider is the power of other participants to impose their meaning of a situation on others. For example, a doctor's surgery is a location where inequalities in power are regularly imposed on unequal participants. If power inequalities remain unrecognised then we return to silencing the voices of those we try to empower by trying to interpret the world through their eyes. In addition, Habermas (1984, pp. 109-

10) argues that striving to understand and interpret the meanings of a social world through its actors is a *'double hermeneutic'* because people are already striving to interpret an interpreted world. To establish the trustworthiness of my data I triangulated my interpretations by clarifying meaning with people with learning difficulties, staff, supporters of people with learning difficulties and professionals, and through the use of my field notes.

### **5.5 Interviewing and its problems**

Booth and Booth (1996) have already summarised four problems of interviewing people with learning difficulties:

1. Inarticulateness
2. Unresponsiveness
3. Being unable to think and generalise in abstract terms
4. Problems ordering events (temporal sequence)

In the previous chapter, I argued that using standardised methods for interviewing could inhibit people with learning difficulties. For example, Polkinghorne (1988 p.164) proposes that interview questions should be as *'open ended as possible, drawing out responses to themes'*. This is accepted practice in the world of sociology and psychology when undertaking research with articulate groups. But, what happens when we encounter informants who do not possess the level of articulation that assumes a *'conversation between equals'*? The surfacing methodological problems agitate even more issues in their wake. Issues of validity, leading the informant, unreliable informants, and misleading or misunderstanding the data all roll together (Wengraf 2001, Plummer 2001, Sigelman et al. 1981, Kvale 1996). The challenge is to ride these waves, adapting and changing techniques. I suggest that this constant adaptation is a starting point to examine things differently. In examining things differently, I argue that perhaps employing contrasting methods enables us to contextualise and

perhaps look at situations from a more informed stance. Booth and Booth (1996) argue in favour of a narrative approach for expanding interviews, and employing various literary devices from the humanities.

For example, in texts such as 'The Mark on the Wall' (Woolf 1942) the opening dislodges our sense of temporal sequence because it begins *'Perhaps it was the middle of January in the present year'* (p.41). The suggestion here is that the story spans a couple of months, but on reading the text it appears that the story follows the wanderings of the narrator over a couple of minutes. Forster (1976) also recognises that the temporal ordering of events is not the whole story with secondary events showing how they are related to primary events. Therefore, the parts of a narrative serve as functions of the narrative structure as a whole. Construction of the whole appears difficult without reference to the various parts. Furthermore, the telling of the story and its comprehension as a story is dependent upon the capacity of the individual to process this knowledge in an interpretative way (Bruner 1991).

Interpretation is problematic in that the problems are related to context rather than the text. Bruner (1991) suggests that the first contextual problem is one of intention, or why the story is told. Interpretation of the story is dependent upon the different intentional stances of the reader/listener and teller. Bruner's second contextual problem is the question of background knowledge (of both the teller and the listener/reader), and how individuals interpret the background knowledge of each other. Therefore, transparency becomes an issue for researchers when writing narratives because, as Bruner suggests, the interpretation of any story is dependent upon the knowledge of the reader.

Even the simplest question about a text constructed using narrative methods runs into the problem of representation. The problem of representation is the problem of the relationship between the text and worlds (Bennett and Royle 1999). My aim is that the vignettes, and stories, are considered as performative in that they entice the reader to read on and to be drawn into

another world; seeing through the eyes of each represented individual. However, at the same time I am employing Derrida's (1976, p.163) point that *'Il n'y a pas de hors-texte'*, translated; there is no outside text, or nothing outside context. This means that there is no perception or experience that is not bound up with the effects of the text, or the language. Derrida aims at making us think that there is no way to imagine or perceive 'the world' without that world being contaminated by language. He suggests there is no access to 'the world', except through language. 'Language' need not merely be verbal but can include anything that works as a system of signs; for example, the language of eyes, gestures, touch, smells and so on. Some of these points may become clearer on reading three of the problematic interviews I encountered in my study.

The following vignettes highlight narrative methods and their contrasting uses whilst striving to achieve inclusion. I propose that the character is of great importance, because through identification the reader ceases to objectify the character. James (1986) suggests that the character and the story are equal and mutually defining, and that the novels and plays that people strongly respond to have intriguing or forceful characters in addition to the story. Perhaps using evocative descriptions of people becomes part of the process of constructing the narrative for the reader.

The first vignette is about Anne who does not speak and is partially sighted. Anne lives in a registered nursing home with five other women with learning difficulties. Her lack of speech means that she is not the 'ideal' informant; she is not articulate, cannot provide full and sensitive descriptions, and cannot provide a coherent account.

### Anne

Anne is religious; her life revolves around the church and the Saints. Anne has definite ideas about her life and how she wishes to lead it. She frequently visits

friends outside the home she resides in. Anne dislikes visiting the doctor because he does not talk to her and keeps her waiting in the waiting room. Anne's doctor makes her feel ignored. The doctor talks to Anne's carer in front of her, but she acknowledges that the good thing about going is giving her tablets for her heart as these stop the pain. Anne visits the doctor regularly and he listens to her chest with a stethoscope. He takes her blood pressure and the nurse takes her blood with a needle.

The dentist does not do the same because he looks at her mouth instead. Anne likes the dentist and the nurse. They talk to her and make her feel loved (accepted). They fixed her mouth when it was sore and gave her new teeth to eat with. Anne likes the man who comes to cut her toenails and do her feet. He is good looking and has a kind face; her feet feel good when he has been to see her. When Anne sees the optician she goes out in a car. She likes going out. The optician saw that one eye was not working and could not see but gave her stronger glasses to help the good eye. This helps because she likes looking at her photographs of friends and family.

There is nothing remarkable about this story; the language is simple because it had to be read back to Anne to confirm I had interpreted the story correctly. What is unusual is how the story came into being. To do this I must first tell you more about Anne. Anne has twinkling mischievous eyes. She is slim and the proud model for the archetypal blue rinse and perm. From my field notes I observed that Anne listens intently to the various conversations taking place in the main sitting room of the home where she

lives; she is a pensioner, partially blind and does not speak. Anne was sitting at a table whilst I was explaining the purpose of my research to staff carers; she was obviously listening to the conversation. Anne leaned towards me during the conversation, indicating she wanted to be included by pulling at my arm and pointing to herself. I interpreted her non-verbal communication as expressing an interest in what was going on. I thought it would be interesting to see how we communicated and if we could manage an 'interview' situation. Anne's staff told me that she could give her own consent for medical treatment; they encouraged me to 'chat' with her, saying she would enjoy the interaction. Anne consented to 'talk' to me about her medical treatment. I was sceptical of having any success, but intrigued as to how we would communicate.

At the outset, I followed other approaches indicated by Simons et al. (1989) and Whittaker et al. (1990) in utilising pictorial aids and simple vocabulary (Flynn and Hirst 1992). Although the use of visual aids dates back to Horowitz (1936) in his studies of racial awareness and attitudes in children, visual aids then developed further in the field of psychology, in assisting indirect or projective questioning. Thinking about the various psychological techniques using pictures, I decided to bring a small collection of pictures with me, to make my focus clearer. I carried small computer generated pictures of a doctor and a dentist alongside smiley, sad and angry faces; these were scrutinised by Anne, alongside my aide memoire. I could not expect to use open questions because Anne could not reply verbally. I had to quickly alter some of the questions to closed questions and expand others into a forced-choice format, whilst at the same time focusing on how I was going to approach Anne to get the most from the encounter. An hour later we had reached an agreement about who she liked/disliked and why.

Achieving this occurred without Anne using the medium of speech. I asked the questions and gave the answers, running through a number of responses. Sometimes the responses were wrong and Anne shook her head vigorously. Anne patted my arm when satisfied the answer was correct. She used various props, pointing at the clock then stretching her arms reminiscent of

the fisherman's tale, indicating that she had to wait a long time at the doctors. Anne pointed towards her staff carers and turned her back towards me when I asked about the doctor. This confused me initially because I knew she wanted to be included. When I brought this up she faced me. Asking about the doctor brought her back into view once more. It slowly dawned on me that she was intimating that this was how the doctor made her feel; ignored. Asking Anne about how she felt and using the word ignored brought vigorous arm patting and head nodding. Throughout our transactions, Anne's staff carers respectfully kept their distance, no doubt amused by my attempts to interview Anne. Afterwards and out of earshot, they confirmed that all she had told me was true.

Thinking about the various phrases attached to interviewing and to the qualities of respondents, I began to question the necessity of *'having a good story to tell, being 'able to verbalise' and being 'articulate'* (Plummer 2001, p.136). Additionally, Polkinghorne (1988) sees it as a requirement that informants have *'the capacity to provide full and sensitive descriptions of the experience under investigation'* (p.47). These texts suggest that the informant must possess a level of verbal fluency in order to tell a good story. My experience of interviewing Anne does not fit with these requirements. Throughout the interactions I had with Anne something more tangible had occurred; understanding how someone with no speech felt because others made little effort to understand. Anne had in effect taken over the interview situation and made me work harder to understand her. I could have chosen not to make the effort because she had no verbal capacity. In fact, I very nearly did, but curiosity and determination drove me forward. Asking questions is part of the role of an interviewer, but the actual use of questioning can have many functions. I used questioning in this context to:

- obtain information
- communicate to Anne that her involvement was valued
- encourage Anne to respond
- express an interest in her
- encourage maximum participation

- ascertain her feelings, attitudes and opinions

It was also useful to use closed questions to gain a yes/no response, and build on those responses. Closed questions were also useful for involving Anne in the interactions from the outset. It was easier for Anne to reply. Usually closed questions give the questioner control over the interview. In this case asking closed questions gave Anne some control over the interview because she felt included. I started using closed questions using an inverted funnel sequence (Khan and Cannell 1957); the questioning then opened out to much broader questions. I used this method initially to obtain information about Anne and to ascertain how to proceed with the interview. After the closed questions, I used forced-choice questions where Anne was presented with alternative responses; Anne chose the response with which she identified the most. To elicit a clearer and more concisely phrased answer to clarify her responses I used probes. For example; *'Are you saying that this is how you feel when you visit the doctor... ignored?'* Anne nods in agreement. I also used extension probing to expand upon her GP visits. *'I know you visit the doctor, can you tell me anything about the visit?'* This probe brought the fisherman's tale hand actions into play. I thought about the standard technique of tape recording interviews: myself as the interviewer, using open questions to gain responses, avoiding closed or 'leading' questions, whilst having an 'articulate respondent' replying. This standard technique would not have been possible for Anne because she did not fit the 'stereotypical respondent'. Using standard methods would have excluded her and rendered her experiences to be of little value. Interviewing therefore is not a simple skill, it is a complex procedure; but used effectively it can nurture participation and authentic responses.

Anne taught me a great deal about interviewing. Instead of striving to capture words on tape, I was battling to liberate words and to create her story in the process. My approach to collecting the data was neither orthodox nor accepted in the world of research. It was more of a counselling technique. I used advanced empathy (described in the previous chapter) to put myself in her shoes and adapted my line of questioning accordingly. I watched her

facial expressions and body language to give me clues as to how she felt. The whole process was intensive, requiring concentrated effort. This approach worked for Anne. Grele (1998 p.44) argues that an interview is more than seeking to obtain a complete interview on tape. Even if the interviewer only nods in response then there is still potentially a relationship or 'conversational narrative'. My conversational narrative with Anne may appear one-sided but Anne gave me the information in her 'language' and I verbally translated it, later capturing the words in written form.

Shula Wilson (2003) works as a therapist for people with learning difficulties and multiple impairments. She argues that '*when speech is impaired both client and therapist have to struggle to express and understand without the protective clothing of words.*' (p.82). Using words as protective clothing is an excellent analogy. I felt protected using speech and extremely naked and vulnerable without words. Anne was used to operating her world without the spoken word, but my world took speaking for granted. We needed to find a 'common ground' from which we could both understand each other. Obtaining Anne's story was a struggle for both of us; communication was difficult. Anne had no words; she 'spoke' through me, using my words to express her actions and thoughts. My words were the foundations of her story. Building Anne's wordless story utilises narrative methods; these narrative methods translate Anne's impressions into the spoken then written word. Without narrative methods, Anne would have remained ignored.

### **5.6 Leading and closed questions**

There is a history of understanding the pitfalls of leading questions and the tendency towards acquiescence in people with learning difficulties (Sigelman et al. 1981). As a result, researchers have proposed differing methods of eliciting biographical narrative from informants. For example, Wengraf (2001, p.113) proposes that the interview session should be limited to a '*single question (aimed at inducing narrative)*'. In the case of Anne, I started with general closed questions and funnelled out into broader issues.

Anne is one individual for whom this worked. The main problem is that what works methodologically for one person does not always work for another. When interviewing Anne I was striving to elicit a narrative. We could call the interview 'fictional' because she did not verbalise her thoughts and feelings. Polkinghorne (1988, p.13) proposes that narrative is a term used to distinguish prose from graphics, hinting at the possibility that something without words fails to qualify as a narrative. My view however, is that the use of narrative methods can help translate a wordless/virtually wordless encounter into a narrative. Translating the story therefore becomes as vital as its construction in the interview situation and this leads to challenges regarding authenticity, accuracy, and meaning. The use of metaphor can therefore become an invaluable tool of description. Most people can visualise 'the fisherman's tale', when talking about his catch, without further explanation. We can see the blue-rinsed pensioner, with no speech, stretching her arms wide to 'tell' her story. The only way to release Anne's voice from captivity, for that brief moment in time, was to commit it to a lifetime in text, using metaphor, representation, and characterisation, to ensure the sentence.

The following vignette concerns Lucy, and highlights different ways of employing narrative methods when gaining yes/no/single word responses.

### Lucy

Lucy is a young and attractive woman with an ear splitting smile. Lucy enjoys going to the pub with her friends, having a few drinks and socialising. The friends she has live in different areas but they all meet up at work. Lucy has a part-time clerical job and she is building up her proficiency with information technology. Lucy has learning difficulties, is severely physically impaired and needs a computer-aided speech box to communicate. Operating a motorised wheelchair ensures she has a certain level of autonomy. For all other physical functions,

Lucy is totally dependent on others. Lucy lives in sheltered accommodation. She has her own apartment and a key worker who helps her with her daily needs. I explained the study to Lucy. She agreed to participate and I arranged a date to return because of her hectic social life.

The beginning of the interview was, I felt, a disaster. I arrived with my list of questions. Lucy took me to her sitting-room, indicating to her staff carer that she preferred to be alone with me and refusing to have her computerised voice machine attached. I realised that Lucy could only answer 'yes' or 'no' without the computer and thought this would again ruin my idea of an 'interview'. How was I going to build a 'relationship' with someone who could not verbalise thoughts and feelings? Was it possible to 'capture the essence' of what was occurring if the interview did not flow freely?

I had read papers concerning problems interviewing people with learning difficulties; there was a lot to learn from previous research (Booth & Booth 1996, Rodgers 1999, McCarthy 2001, Goodley 2000, Ramcharan et al. 1997). I remembered Jackie Rodgers (1999, p.428) experiencing an imbalance when interviewing an informant with the staff carer present; the staff carer taking over and the informant's '*confidence decreasing*' as the interview progressed. I was determined not to involve a carer because Lucy had deliberately chosen not to have one present for the interview. Therefore, the first step towards building a relationship of trust with Lucy hinged on my resistance to the temptation to call for help. I realised that Lucy's autonomy was fragile and needed to be respected. Calling in a third party would have unbalanced the relationship.

I started out with the usual 'what' and 'how' line of questioning. This proved fruitless and Lucy appeared increasingly frustrated by my bumbling efforts. I remembered the interview with Anne and threw caution to the wind, deliberately changing tack, asking closed questions to gain a yes/no or one word response. This included Lucy in the interaction and slowly we

began to build confidence; Lucy's confidence in herself and her ability to answer, my confidence in the fact that at least we were achieving some level of interaction. This 'worked' for a while until we hit upon visiting her GP. The questioning changed and my approach became slower, the space between Lucy replying and my next question gradually increasing. Lucy's body language had changed subtly and I became aware that she wanted to tell me something; the air became charged with tension. The process was requiring more intensive thought on my part. In changing responses, Lucy had changed my approach.

Interviewer; "Do you like visiting your doctor?"

**Lucy;** "No"

Interviewer; "Is he rude?"

**Lucy;** "No".

Interviewer; "Does he talk to you?"

**Lucy;** "No"

Interviewer; "Do you want him to talk to you?"

**Lucy;** "Yes"

Interviewer; "Are you frightened of asking him to talk to you?"

**Lucy;** "Yes"

Interviewer; "Have you asked him to speak directly to you?"

**Lucy;** "No"

Interviewer; "Do you feel he will think you are stupid?"

**Lucy;** "No"

Interviewer; "Do you feel you are not capable of asking him?"

**Lucy;** "No"

Interviewer; "Do you feel you will not understand what he has to say?"

**Lucy;** "No"

At this point, I was beginning to struggle with finding the right words. The silence in the room felt oppressive. However, Lucy was using the silence to 'send' a message. She had become more attentive. Lucy kept looking at me, her eyes willing me forward. She wanted to continue, she had something to tell me... but what? Lucy could not tell me because she did not have the

words to say what she wanted to say. I was aware of how different we were. I had the facility of speech and could articulate my thoughts and feelings to clarify a situation and to assert myself. Lucy could not. I needed to think quickly to make a difference to this situation; I needed to think about Lucy, and how her life operated. In desperation, I looked around Lucy's room for inspiration. As I looked, it dawned on me that nothing was adapted for her use, despite her obvious multiple impairments. Even the toothbrush was for someone who was able-bodied. The room gave me an insight into how she operated on a daily level. A flash of inspiration made me decide to alter my line of questioning.

Interviewer; "Do you put your make-up on yourself?"  
**Lucy (smiling);** "No"  
Interviewer; "Brush your teeth?"  
**Lucy (nodding);** "No"  
Interviewer; "Does your carer do everything for you?"  
**Lucy (eyes widening);** "Yes"  
Interviewer; "Do you feel as though you rely a lot on your carer?"  
**Lucy;** "Yes"  
Interviewer; "When you visit the doctor does he talk to your carer about you and your illnesses instead of to you?"  
**Lucy;** "Yes"  
Interviewer; "Are you frightened of upsetting your carer if you ask the doctor to speak to you?"  
**Lucy;** "Yes"  
Interviewer; "Are you frightened your carer will stop doing as much for you if you offend or upset her?"  
**Lucy;** "Yes".

After replying Lucy smiled and closed her eyes, leaning her head backwards. Tears began to run down her face. I dried her eyes, concerned and anxious that I had upset her. Lucy affirmed she was merely relieved at being able to tell someone how she felt. She indicated to me that when she felt sad or wanted to talk there was usually nobody to talk things through with her in

this way. The computer took a lot of time and energy to use; it did not sound like her and it was like having someone else talk for her. She wanted to use her own voice. It struck me that Lucy was totally dependent on her staff carer for everything; the staff carer was her lifeline.

The methods used to gain this narrative challenged my confidence as a researcher but they turned out to be a confidence builder for Lucy. Lucy felt understood. We were both shattered after the hour and a half together. As an interviewer I realised that I was part of the barriers that Lucy regularly encountered and had to quickly relearn how to communicate effectively and build a narrative from someone with limited verbal articulation.

Without asking leading questions, Lucy would not have been able to indicate how dependent she was on her staff carer to the point that she felt she could not ask for the autonomy she wanted. Using observational methods were crucial, coupled with continually thinking about the person I was interviewing, placing myself in her position for a short period of time and asking myself why? How would I feel? What clues about her lifestyle were prompting this response? Being empathic but not sympathetic altered how I saw Lucy; it gave me some insight into being dependent on another. The growing insight, coupled with Lucy insistently staring at me, willing me to understand, pushed me into altering my line of questioning. Throughout the transaction, I was having a 'shadow' conversation with myself. My mind began to wander at one stage; I was worried about the quality of the interview and what use it was going to produce for subsequent analysis. I had to pull myself back on track, put the feelings of hopelessness concerning the analysis on one side, and live in the moment.

Where the interview had taken place had dramatically affected the amount and content of the data collected. Polkinghorne (1988, p.164) sees context as a main factor and points towards interviews being context dependent. Lucy's room had given me the clues as to why she negatively responded to questioning about her GP. Lucy also felt comfortable in the privacy of her own surroundings, deliberately choosing not to use her computer. Lucy was

in control of the interview situation. She made me work hard to understand, testing me, seeing if she could make me understand and how much of an effort I was prepared to make.

Strangely, using my words had given Lucy some autonomy, for it permitted part of her story to be retold. The yes/no answers inadvertently dredged up other aspects of research related to advocacy and person-centredness. It highlighted the impossible position of someone dependent on another for daily bodily functions that most people take for granted. The next question was how could a person-centred approach be used with someone who felt as dependent as Lucy?

Unlike Anne, Lucy could vocalise, (saying yes, no, me) but not enough for classification as a 'good informant'. Her story highlights the importance and potential of involving people with learning difficulties who appear to lack the necessary articulation to be 'good informants'. I did not deliberately seek out Lucy with the knowledge that her situation and experiences would be different. I chose to interview Lucy because I felt I should make the effort to include people with limited articulation. Lucy decided to make this more challenging and interesting by her refusal to use her computer voice. I was able to construct a story using her building blocks of yes/no replies utilising narrative methods. In this instance, employing narrative methods enables the researcher to access and thereby build stories, highlighting areas that require further research.

### Selling to Anthony

The following description relates to an interview I had with Anthony. Anthony lives in supported accommodation. He is a nervous, slightly built man who talks in disjointed sentences in a headlong rush like a runaway train. Trying to interview Anthony was amongst my most difficult and problematic challenges. Anthony talked about what he wanted to talk about, not what I wanted. His sentences were rapid, incoherent in parts, disjointed, and muddled. After ten minutes, I realised that the tape recording would be

useless because his speech was unintelligible in places, and I turned the tape off. I then fell back on my sales training from a previous job.

When a client went off the tracks, I as the sales person had to try to get them back on line, and get the person to commit to what I was selling. Another ploy was KISS (keep it simple stupid), using easily accessible language, and short sentences, which made the sales pitch more direct. I therefore 'sold' to Anthony. As Anthony continued in his headlong rush, I jotted words and phrases that appeared to have more meaning for him. When he paused for breath, I gently asked him to tell me more about the phrases he had previously said. He frequently mentioned his mother. I asked him to tell me more. A touching story emerged about the loss of his mother: the hope that he was wrong and she was not dead; the longing for her unconditional love; the rejection from his father; the disappointment regarding his inability to return home. This took place over an hour and a half. I constantly returned to the phrases he had used and doggedly kept asking for clarification. At one stage, my mind wandered with the sheer effort of remaining focused as he rambled onto another topic. I had to keep telling myself to stay alert and focused. I keenly felt Anthony's loss, his longing, and sense of helplessness. I felt anger concerning his rejection and I felt sadness that his one wish, to return home, remained unfulfilled. The interview left me feeling dazed from the effort and 'hollow' from the emotions I had experienced. The end result was surprising. I had a narrative that made sense, but my feelings of his circumstances coloured that narrative. However, when I read it back to Anthony, it appeared to make sense to him and he verbally agreed that it was his story.

### **5.7 Narrative methods to processes and inclusion**

We have now moved into the twenty-first century, and there are many new ways of understanding speech and language (Hall 1997). Looking around we are faced with a new generation of people exploring, utilising and adapting text messaging and computers as methods of communication.

Research methods are changing and adapting as we strive to become more inclusive in our approach (Booth and Booth 1996, Killick 2003). Using narrative methods aims at including people who cannot articulate to the extent that they are classified as 'poor informants'. The writer, poet and researcher, John Killick has spent the past nine years working with people with Alzheimer's. He is passionate about exploring pathways of expression, and is convinced that people are more aware of failing or deficient skills than we are prepared to admit (Killick 2003, p.49). His first impression of people with Alzheimer's in his study agreed with that of their care manager; *'you'll get nothing from that lot'* (p.49). My first impressions of people with learning difficulties had a similar echo, with advice from their care staff; *'they can't tell you that much'*. Eventually Killick noticed that far from not being able to communicate, people were saying things he thought were interesting and original. He learnt how to initiate a conversation, leaving the person with enough time to frame a response. He then transcribed words and thoughts, in the process discovering that some fell naturally into poetic form, thereby allowed him to shape them into poems. Killick uses narrative methods to gain his transcriptions and narrative processes to produce text for a wider audience. He firmly states that the secret is *'to listen as if your life depended on it. Never dismiss something as nonsense'* (p49). However, Killick's approach is more anthropological because of the length of time he has 'lived' in the field with people to gain an understanding of their world. I would be extremely naïve to report that I intimately knew the world of Anne, Lucy and Anthony through these short visits and interviews. Killick, however, knows his informants personally; he has worked alongside them for years and has learnt to interpret their communications.

Using narrative methods aims towards inclusion of people who are sometimes classified as non-people by virtue of their label. John Killick's informants, alongside Anne, Lucy, and Anthony, have no means of articulating fluently. The readers within the wider audience relive the experiences through the writer's words. These narratives are, however, co-constructions within a context because they involve both the interviewer and the informant; and their relation to outside factors. If we changed the

historical time of the interview, the place, the interviewer, and/or the informant the nature of the narrative would be vulnerable to change. The narrative is therefore only a by-product of the relationship between the interviewer and the informant. I have demonstrated that the non-verbal communications, facial movements, hand actions, and subtle altering of posture all lend shape to telling the story.

Recently narrative genres have been blurred and enlarged and altered to include poetry, drama, and conversations (Richardson 2000). Goodley et al. (2004) unpack and focus on the actual doing of narrative research because they feel that previous work *'fails explicitly to account for the relationship between different epistemologies, method/ologies and analyses'* (p. x). Killick is already experimenting with modes of writing that are not tied to mainstream and interpretive realist criteria of evaluation (Denzin 2001). In experimenting with different research methods, and writing genres, the possibilities for expanding interpretation of the worlds being researched are limitless. Narrative can be employed as a method of representing people whose voices would ordinarily remain silenced.

Conventional research methods could not have produced these stories and indeed would act as a barrier to their collection. The limitations are the result of methods that do not promote inclusion, not the limitations of the informant. It is easy to ignore informants who do not possess the criteria of being 'articulate', who neither have 'a good story to tell', nor 'the capacity to provide full and sensitive descriptions of the experience under investigation', as laid down by Bertaux, Bruner, Plummer, Polkinghorne, Taylor and Bogdan, and many others as the essentials for being a 'good informant'. This places responsibility for a 'good' interview firmly on the shoulders of the informant, resulting in the exclusion of many people. Narrative methods take the responsibility and share it allowing for greater inclusion, valuing people with diverse characteristics, giving them an equal opportunity to participate in a project that concerns them. Atkinson & Williams (1990), Atkinson et al. (1997), and Booth and Booth (1994, 1996, 1998) have used narrative methods to explore, whilst simultaneously building the narrative,

and seeking to understand the relationships from the past as they appear in the present. The resultant narratives are a facet of a relationship, produced in a space between the interviewer and informant, not as an artefact of the individual.

## 5.8 Ethics.

### Beneficence

A key ethical feature of research is that it must take into account the well-being of the people. Or, the researcher takes into account the impact of his/her activities on the lives of the people with whom they are engaged. The study had already been placed before a research ethics committee, and had received clearance. Point 7 on the research ethics application form addresses 'procedures that may cause discomfort or distress'. There was a potential for discomfort arising from the interviews, but the degree of risk was mitigated by the use of consent and opting out procedures. At each meeting, I reinforced the fact that the individual did not have to participate, and could stop at any time. Any issues that arose during the interview, that caused the informant distress, were handled at the time and, with the consent of the informant, a trusted carer was called in to assist. The option to terminate the interview was offered when signs of distress or tiredness arose. This only occurred with one informant, but their key worker emphasised that the situation I had encountered was a regular occurrence, and was more likely to do with the informant's background than the interview itself.

### Nonmaleficence and Autonomy

Nonmaleficence means that the researcher is obliged to do no harm (Thorne 1998). Autonomy means respecting the right of the person to take responsibility for themselves (McLeod 1994). Interviewing people under the promise of confidentiality and anonymity meant changing the names, and in some cases details of interviewees, to protect them and their families. Furthermore, it meant changing the area name, street names and residential

descriptions in order to protect the participants. To protect individuals, I altered some stories that contained intimate details that might be directly traceable. The content of these stories remains confidential, and not for public consumption. The right to privacy was observed and, following Kelly and Gluck (1979), and Guba and Lincoln (1989), in relation to the hermeneutic dialectical process, the effects of the research were evaluated in terms of:

- **Pride:** confirming people's self-worth.
- **Dignity:** observing people's autonomy, independence and competence, and refusing to treat individuals as subjects, or objects of study.
- **Control:** people's control over events, actions and decisions, allowing choice.
- **Place:** listening to people where they felt at ease, ensuring any participant observation did not interfere with routines and activities. This included visiting at times that were convenient for informants, and their staff carers, rather than myself. Many visits were carried out at weekends, because it was quieter. There were no day-care centres open, and the informants liked a change of face to break up the monotonous weekend.
- **Unity:** recognising that some people felt safe in a group, and because they had always operated in that way, leaving the group situation intact.
- **Data protection:** keeping all tapes and transcriptions in a secure place, destroying audio tapes after transcription, and not carrying details on interview schedules that would identify individuals.

### **Process factors**

#### **Consent**

It is generally accepted that informed consent for all subjects is important for research studies (Ryen 2004). McLeod (1994) details a description of informed consent and explains why it may be difficult, or impossible, to obtain consent from certain groups of people; for example children, people exhibiting emotional distress, or people with intellectual deficiencies.

However, I approached the issues of consent after considering the guidance from the Lord Chancellor's Office regarding capacity to make decisions. The Mental Capacity Act 2005 was passed on the basis of this guidance, and external reviews, and clearly states that a lack of capacity to make a decision cannot be established merely by reference to a person's behaviour or any condition they may possess (Part 1, section 2). I therefore worked from an assumption of capacity.

Consent was gained verbally at each meeting, mainly because most of the informants could not read or write. Before meeting to interview the informants, their main support worker discussed the matter with them first and then they were given as much time as they felt they needed to make a decision as to whether they would take part in the study. If they agreed to participate, I reinforced the aims of the study in very basic terms at each meeting, and gave them the option to opt out at any time, and for any reason. I restricted my study to people who were able to indicate, verbally or non-verbally, with or without assistance, their consent to take part.

### **5.9 Limits to participatory research**

Northway (2000) suggests that research is a process. She confirms the importance of this process during her participatory research project with people with learning difficulties. I argue that perhaps we can never move away from '*violating the experiences*' (Oliver 1992, p.106) of people with learning difficulties throughout the research process because in many cases the topic of research is chosen by the researcher. This leads me into an area that generates much academic discussion concerning user involvement in research; participatory and emancipatory styles of research. My study concerns contemporary policy context, and national policy now emphasises the rights of service users, and their supporters, to be involved in the planning, management and delivery of services, and additionally recognises the importance of user voice (DOH 1998b, DOH 2000a, DOH 2001b, DOH 2003a). Moore et al. (1998) argue that users have begun to challenge conventional forms of research because it objectifies participants viewing

them as passive and compliant with little or no say in the commissioning, planning, undertaking, writing, and dissemination of research. Danieli and Woodhams (2005) argue that there has been a great deal of methodological debate amongst researchers as to the purpose of disability research, what should be researched, who should do the research, and how it should be conducted. However, Chappell (2000) argues that current evidence of emancipatory research appears scarce, and I further question whether emancipatory research strategies are appropriate for *all* disability research because they can potentially exclude people with profound learning difficulties and those lacking in verbal articulacy.

Zarb (1992) suggests a broad set of criteria as a starting point for the critical evaluation of emancipatory research. These are:

- Who controls the research and how will it be done
- How far are disabled people involved in the research process
- What opportunities are there for disabled people to criticise the research
- What happens to the products of the research

Grant and Ramcharan (2006) provide a more detailed table of parameters for traditional, participatory and emancipatory approaches. I have provided a shortened table of the differences between emancipatory and participatory approaches from the original by Grant and Ramcharan (2006).

**Table 5.1 Parameters of participatory and emancipatory research**

<b>Parameter</b>	<b>Participatory</b>	<b>Emancipatory</b>
Research ownership	Joint/shared	Held by service users
Values	Shared/negotiated	Political, partisan, reflecting user interests
Accountability	Research group, host organisation, funding agency	Co-researchers (service users), host organisation, funding agency
Focus of Enterprise	Articulation of user voice, emphasis on dissemination and utilisation	Orientation towards changing or improving people's lives. Emphasis on research utilisation to bring about change in people's everyday lives.
Locus of control for change	Internal and external	Internal generated by service user research group
Concepts/methodology	Product of process, evolutionary	Product of process, evolutionary
Research dissemination	Written for multiplicity of audiences, found in academic or popular outlets	Written for user audiences, located in grey literature or user organisation websites
Costliness	Can be costly	Expensive
Sources of funding	Growing	Limited

I reconsidered my data using the parameters of Grant and Ramcharan (2006). I did ask three people to become researchers by writing their own stories. All three agreed. One person needed extra support to write a diary, but the staff carers were too busy to assist in the process. The first person

eventually moved house and the new staff carers were even less inclined to support any effort, and to have my extended presence in the home, so I abandoned the idea. The second person wanted to use a computer and I supplied floppy discs, paper, pencils and pens. I visited regularly and offered my support, but there were other more pressing issues in the person's life; a place to live, control over their own finances, control over their personal life, control over personal information, and building a social network. I did not feel my research aims warranted more priority than the issues in this particular individual's life, and I abandoned the idea of a co-researcher again. The third person agreed to write their own story concerning their healthcare, with the support of their key worker. The key worker left and was replaced by someone not as accommodating, the informant became demotivated, and the idea was abandoned again. I found that time constraints inhibited my ability to establish trusting relationships, where a person with learning difficulties would feel comfortable as a co-researcher. Another problem was the obvious lack of research skills of the group of people in my study. Other attempts at involving other people with learning difficulties as co-researchers were met with a lack of interest, and enthusiasm, from the people whose life the research concerned. I came to the conclusion that perhaps what was of interest to me was of minimal importance to the people themselves. My attempts at including people with learning difficulties as co-researchers had failed.

Another frustration of the study was the geographical distance between all the residents, and the difficulty in getting everyone together to discuss healthcare as a group. Coupled with this frustration was the time factor involved in gaining permission to approach people with learning difficulties living in the various homes. The whole idea of people giving me 'permission' to approach people with learning difficulties to see if they wished to participate is at odds with an emancipatory research paradigm.

In order to find a more diverse sample, I approached an advocacy service for people with learning difficulties, explained my study and asked for their involvement. The manager of the service declined without consulting the

people that the service represented. This was because ‘people already had enough topics to discuss, and they did not need to be overwhelmed’. I managed to gain approval to send fliers for people who wished to contact me to discuss their healthcare issues.

However, I identified the research problem and brought it to the attention of people with learning difficulties. Twelve months after the study, a self-advocacy group decided to discuss the issues associated with healthcare. The collective analysis of the research problem was in the form of healthcare stories from people with learning difficulties. I collected the data, wrote the stories and then returned to the individuals for verification that I had correctly interpreted the story. Some people deleted themes or added to the stories. Other people asked me to leave the story as it stood. However, I cannot truthfully put my hand on my heart and say I felt my research was emancipatory. It appeared to be positioned more towards participatory. The reasons for my feelings are as follows:

- Healthcare was my choice of research topic; it did not emerge from the service users
- People with profound learning difficulties, and some individuals lacking in verbal articulacy making it difficult for them to become co-researchers, leaving me to rely on advocates and proxies who knew people with learning difficulties well to articulate their views and experiences
- Ownership of the research was held by the University
- Accountability was mostly to the host organisation and funding agency, though I felt accountable to the people whose stories I represented
- The focus of the research was to increase knowledge in the area of healthcare and to articulate user voices in the process
- The concepts and methodology were a product of the research process and therefore evolutionary
- Research dissemination is being guided towards a multiplicity of audiences, not primarily those chosen by service users

- Although I did attempt to minimise power relations as much as possible and try not to portray myself as the ‘expert’, I still felt that there was an unavoidable hierarchy in the relationships between myself and service users

### 5.10 Summary

There was no escaping the fact that the people I interviewed, and came into contact with, were a vulnerable group. However, some of the stories I was told, and that I have retold in my thesis, convinced me that if these stories remained silent then the vulnerability of these individuals would increase because people would remain in ignorance. Ethically, I felt torn between the responsibility of carrying out the research, and desperately wanting to walk away because I felt that I was not including people with learning difficulties on the level that was essential for a participatory approach. The whole research enterprise left me feeling unfulfilled because I did not feel as though I had done enough for the people who had given me their stories. I felt like an intruder.

One satisfying part of the research was rising to the challenge of experimenting with different methods of researching with people with limited verbal articulacy. This experimentation allowed me to expand my researcher’s toolbox, in the process producing some unusual and informative narratives that may not have arisen had I stuck rigidly to traditional qualitative methods.

The stories told within this thesis, resulting from the methods I discuss, are a product of complicated research relationships. Presenting these stories does not mean that the experiences of people with learning difficulties have suddenly ‘stopped’ because these experiences continue on a daily basis. I have merely produced a snapshot of their experiences. My aim is that by raising awareness, future generations may seek to change negotiations within the healthcare encounter. My experience suggests that, even when someone like myself is driven by the ideals of including people as active agents in

research, it is very challenging to achieve complete participation. For those service users involved in my study emancipatory research was even more remote and was not part of their agenda.

## Chapter 6

### Person Centred Services

#### 6.1 Scope

Within this chapter, I examine how involved people with learning difficulties are in their healthcare encounters. An important thrust of the national strategy 'Valuing People' (DOH 2001b) concerns person-centred planning, or putting the person at the centre of the process of planning their lives and support services. An important aim of this chapter is therefore to critically examine what is meant by 'person-centred'. I shall examine the origins of person-centredness through the existing literature, and link it to patient-centredness within a healthcare context. I then examine person-centred planning through the current policy framework of *Valuing People* (DOH 2001b) before presenting data from my own study about the healthcare experiences of people with learning difficulties, their supporters and professionals.

I argue that the reported interactions between professionals and people with learning difficulties provide a contrast with the proposals for person-centred planning, and that there are many competing constructs of knowledge within decision-making contexts that can alter perceptions about what it means to be person-centred. These competing constructs of knowledge emerge from people with learning difficulties, their supporters, professionals, and paid carers. The chapter that follows this seeks to develop this discussion by examining the types of partnerships that underpin person-centred planning processes where there is a premium on including people in decision-making.

#### 6.2 Person Centred Services: From here to there and back again

PCP is not a new idea. Brewster and Ramcharan (2005) identify the origins of PCP as rooted in the past, within its predecessor Individual Programme Planning (IPP). They argue that Individual Programme Planning was innovative when first implemented because it sought to include people with

learning difficulties and their families in planning services that concerned them. The earlier IP work was founded on a strengths-needs model so it looked at people's experiences, expertise, gifts and capacities and how these could be built upon, in addition to meeting their needs (Humphreys 1987). Brewster and Ramcharan (2005) suggest that later studies imply that IPP was practitioner-centred, meaning that although individuals and their families were included in the planning process, the professional still 'knew best' and decided what was in the 'best interests' of the individual. The IPP, as implemented, appeared deficit-focused when planning the needs of individuals:- in other words, it planned from what an individual could *not* do, rather than starting with what the individual could do.

Mansell and Beadle-Brown (2004a) argue that there are studies of individualised planning that share some characteristics with Person-Centred Planning. They point out that Individual Planning appears to reach only a minority of service users. Similarly, Felce et al. (1998), reporting on the All-Wales Strategy, found that only 33% of service users had an Individual Plan (IP). Grant (1997, p. 128) commenting on the All-Wales Strategy, argues that the reasons for the low percentage of service users with an IP were:

- Overbearing demands on front line workers
- Underestimation of the amount of work involved in carrying out an IP
- Lack of integrated record systems
- Staff shortages
- Difficulties in the transition from crisis-led to more pro-active systems because of a backlog of work with people who had not been seen for a long time
- Resource shortfalls

Mansell and Beadle-Brown (2004a, p.4) suggest that '*where individual plans are created they are often a paper exercise*'. They point out that although many individuals had a plan in their case notes, that plan was not necessarily used, or translated into the daily lives of people. Additionally, they suggested

that IPs remained unconnected to the real lives of service users because of the severe deficiencies in the planning process. They claim that one of the main explanations for the planning deficiencies is that people with learning difficulties, their families, and advocates were frequently not present when goals were set, and long-term goals were often omitted. Additionally, there was no strategy or review date for reviewing and measuring the success of goals and objectives. Furthermore, the scale on which the IPs were originally implemented appeared to cause further problems because the larger the numbers, the greater the emergent problems with regard to coverage, quality and outcomes.

The lack of resources identified by Grant (1997) led to constraints on individually tailoring an IP, but these constraints were compounded by the standardised procedures for assessment. Whilst a standardised procedure makes it easy for a professional to assess a person, it does not necessarily take into consideration individual differences, and may omit something of importance that would make a difference to an individual's life. Additionally, Mansell and Beadle-Brown (2004a) claim that British IPs, unlike American IPs, were not legally mandated; therefore there was very little scope for redress should the plan remained unfulfilled. However, the wheels of justice move very slowly and litigation takes time and effort and it is possible that from voicing a complaint to resolution there could be a time span of up to five years (Symon 1997a, 1997b, Sakamoto et al. 2002). This is because expert opinions can take months to arrange. Some solicitors are inexperienced at medical litigation, case records can be difficult to identify and trace, record entries that are illegible or unsigned are inadmissible, and a lack of communication between both sides can increase time delays (Symon 1997a, 1997b). Furthermore, Sakamoto et al. (2002) found that using an expert medical witness in medico-legal cases in Japan actually increased the length of litigation by up to two years, even if the result was in favour of the patient, during which time the original individual plan would become obsolete.

Mansell and Beadle-Brown argue that even with a plan, delay in implementation, coupled with a restricted range of options within the health services, apparently serves to justify the rationing of resources. The emerging argument is that simply changing the style of planning, from the IP to PCP, is unlikely to make any difference unless the deficiencies with services and problems within Individual Planning have been addressed.

In contrast to Individual Planning, Sanderson et al. (2002, p.13) argue that Person Centred Planning is *'an empowering approach to helping people plan their future and organise supports and services they need. It seeks to mirror the ways in which 'ordinary people' make plans'*. Sanderson et al. propose that Person-Centred Planning means putting the person at the centre of the process. The British Institute of Learning Disabilities (BILD) describes PCP as a *'continual process of listening, learning and action and helps a person get what they want out of life'*. PCP reflects a person's capacities and defines the support they need. That person chooses, with support, what is important to them and then negotiates their needs. Support can mean family, friends, carers, but ideally, the individual chooses the support, and the supporters are full partners in the planning process. Support is a key factor and *'investing in long term relationships, ... walking with the person and staying with them'* (Sanderson et al. 2002 p. 169) is the goal of PCP. This centres on the relationships that a person with learning difficulties has with his or her supporters. These supporters form a circle around that person to assist in identifying need.

Circles of support are supposed to enable an individual to commission services that address his or her needs. This is in contrast to individuals having to 'fit' a standardised package. However, Sanderson et al. (2002) do note that PCP has not yet been used to any significant extent, but it has been used successfully by *'specialist teams involved in getting and keeping people out of long stay institutions'* (p.172). The main problem with this approach is that it appears reliant on a circle of support. To provide a consistent approach, each member of that circle would have to know an individual extremely well, and meet regularly to share their understandings of that

individual. This approach is time-consuming and places significant demands on the people involved. This links back to Grant's (1997) original evaluation of the reasons why the IP struggled to achieve its objectives. Additionally, that circle of support would have to be aware of the services available, in order to draw upon them, and demand improvement.

Brown and Scott (2005) raise a more disturbing issue about vulnerable categories of people and their circles of support when reported cases of abusive and neglectful supporters emerge. Brown and Scott (2005, p.215) argue that where *'people with learning disabilities are struggling with issues of exploitation, abuse or neglect. PCP also risks deflecting from the ongoing responsibility of social services to assure their personal safety and uphold their human rights'*. The main issue here is how far can ordinary safeguards and protection be incorporated into PCP as a strategy to prevent future abuse and neglect.

Mansell and Beadle-Brown (2004a) feel that local authorities are selectively ignoring aiming at responsive, high quality services because reliance on family, friends and people less aware of availability, means the creation of plans that do not rely on a service system. There does not appear to be any provision for educating supporters to facilitate choice and decision-making. Parley (2001) additionally argues that if PCP is to be successful then the implementation strategy should involve education, information and support for all concerned. Throughout the process of facilitating a decision, the individuals making up the circle of support would themselves need support to guide them through the process and clarify any uncertainties. If facilitating a decision is time-consuming and demands more supporters for larger groups of individuals with learning difficulties, then the existing staff shortages that Grant (1997), Appleby et al. (2003), and Felce et al. (1998) identify also need addressing. Failures to address staff shortages, coupled with lack of supporters, means that there will be a backlog of individuals requiring PCP, which immediately relates back to previously identified problems of Individual Planning and crisis-led interventions (Felce et al. 1998). Time is a necessity for people who do not have an existing circle of support both to

build a circle of support and for the individuals making up that circle to form relationships with each other and the individual they support.

Fitzgerald (1998), for example, found in her study with older people with learning difficulties that there was a marked lack of opportunity for people with learning difficulties to develop networks with other people of a similar age and with similar interests. This was because people with learning difficulties had not led independent lives, had only ever attended segregated day centres with structured activities, and had little or no opportunities to participate in non-segregated activities. These opportunities for social interaction decreased significantly with age and level of impairment because many people did not leave their homes. From this example, it appears that social interaction through non-segregated activities to expand social networks is a necessary precursor to relationship building, and that getting to know and understand an individual should be a prime objective.

O'Brien (2004) argues that using circles of support masks the social costs of insufficient public expenditure. However, there needs to be a circle of support in place in order to use it, and the individuals making up the circle of support need educating and supporting, in order to access the relevant services. It would therefore appear that only when there is a supported operational circle in existence can the challenges begin in terms of identifying insufficient public expenditure, in relation to specific individuals. This emphasises the need to link PCP processes at the individual level with strategic planning at the aggregate level and requires clear expectations about the design and use of information flows between these processes.

### **6.3 Patient-Centred Planning**

Within a healthcare environment, person-centred planning becomes patient-centred care (Stewart et al. 2003). Although the term '*patient*'-centred does in fact suggest a medicalisation of the process, patient-centred care is regarded as the optimum way of delivering healthcare since it seeks to value people as individuals (Winefield et al. 1996, Stewart et al. 2003). A team of

medical professionals from the Department of Family Medicine in Canada; Stewart et al. (2003, p.5), argue that the patient-centred model of care has transformed the existing professional-centred conventional clinical model of care (as described in Chapter 1). In order to promote and teach patient-centred care to practitioners, they defined six components of a model of patient-centred care:

1. **Exploring the disease and illness experience-** where the professional seeks to understand the patient's unique experience of being ill and their feelings about illness, how it affects their daily lives, and what they expect from the professional. This knowledge is then linked to professional knowledge of disease and this leads to:
  
2. **Understanding the whole person-** by linking the components above to provide an awareness of the patient's life and the multiple contexts in which they live. This leads to:
  
3. **Finding common ground-** in linking the components and providing an awareness three key areas appear; defining the problem, establishing the goals of treatment, and identifying the roles of the doctor and patient. This leads to:
  
4. **Incorporating prevention and health promotion-** in using the three key areas, a relationship is being built, upon which to establish further opportunities for health promotion and preventative strategies that are workable. This leads to:
  
5. **Enhancing the patient-professional relationship-** each encounter is used to progressively build on the professional-patient relationship, within the relationship, empathy and trust are developed, alongside shared responsibility for health. The professional and patient are starting to work in partnership. This leads to:

6. **Being realistic-** the professional is required to realise that building the relationship requires time; teamwork, teambuilding with other professionals requiring regular communication and input into healthcare delivery to positively influence outcomes. Another name for this type of teamwork is the multidisciplinary approach.

Since medical students and practitioners are being taught this model for use within the medical encounter, I suggest that it might be pertinent at this stage to consider the six components of the model in relation to people with learning difficulties.

The first component '*exploring the disease and illness experience*' assumes that the professional is dealing with an articulate individual who can adequately describe, understand, and account for their symptoms of illness, their perceptions of their own health, and how any alteration in their health status affects their daily existence. As I have already established in the preceding chapters, many people with learning difficulties have difficulty with verbal articulation. Additionally, many people with profound cognitive impairments may not be able to comprehend changes to their own health, merely that they feel unwell or are in pain. Furthermore, many people with learning difficulties are reliant on a third party, who knows and understands them, to explain their healthcare difficulties (Keywood et al. 1999).

Case knowledge alone will not necessarily lead to '*understanding the whole person*', in relation to people with learning difficulties because it upholds dominant medical discourses, silencing, objectifying, pathologising, and labelling an already oppressed group of people (Gillman et al. 1997).

I suggest that the initial stages of the patient-professional meeting are important because they affect the conditions that Stewart et al. (2003) propose. For example, '*finding common ground*' according to the conditions, can be achieved when the patient's experiences have been explored. One example of finding common ground is in the work of McWilliam et al.

(2000) with breast cancer survivors. They outline the importance of professionals and patients sharing information, and in the process building a relationship, whilst striving to reach common ground regarding the treatment of breast cancer.

Stewart et al. (2003) argue that medical jargon can intimidate patients, and this can limit their ability to express their ideas or concerns, and even prevent them from questioning their treatment. This can also apply to the supporters of people with learning difficulties in the healthcare environment, and can negatively affect the patient-professional encounter. An example of this is the work with people with learning difficulties and their supporters by Keywood et al. (1999, p. 26), who found that supporters were unwilling to question or challenge healthcare professionals because they saw themselves *'at risk of being negatively labelled'* or *'at risk of losing their jobs'*.

In addition to *'enhancing the patient-professional relationship'*, Barr et al. (2001) suggest that one of the requirements for effective partnership working is mutual trust. Fugelli (2001, p. 575) argues that trust becomes of pivotal importance when working with patients. Fugelli proposes that the sources of trust within a healthcare encounter include a *'just society'*, *'moral integrity'*, *'continuity of care'*, *'sharing power'*, *'compassion'*, *'authenticity'* and *'competence'*. Out of the seven sources he identifies, five are mentioned in Valuing People (DOH 2001b), they are; continuity of care, sharing power (working in partnership), compassion (empathy), authenticity (genuineness), and competence. Sanderson et al. (2002, p. 16) mention the *'just society'* in the phrase *"What is a decent way for our society and our services to treat someone of this person's age, gender and culture in terms of their living arrangements, security and autonomy?"* I have interpreted the term moral integrity to mean addressing the rights of people with learning difficulties so that they have the same rights, opportunities and choices as any other member of the community.

Fugelli (2001, p. 575) also argues that *'trust often implies a transference of power, to a person, or system, to act on one's behalf, in one's best interest'*.

A transfer of power within the patient-professional relationship means that the professional and the patient are working in partnership. Helplessness can also precipitate a transfer of power; one example is that of learned helplessness where an individual feels that they have little or no control of their life and faced with this knowledge they stop trying to exert control (Seligman 1975). Some people with learning difficulties have little control over even fundamental things, such as where to live, who to live with, and what to do during the day (Beamer and Brookes 2001). Arguably, a transfer of power in this context does not constitute working in partnership and the multidisciplinary approach achieved through '*being realistic*' will not necessarily occur. Working in partnership or a multidisciplinary approach involves complex relationships between and amongst all caregivers and with the surrounding environment that impacts on treatment outcomes (Kiser 2002). Whilst the patient-centred model of care promotes a '*whole person*' approach to care and does recognise the context in which people live and function, the model alone appears insufficient because it does not explicitly embrace the interdisciplinary and sociocultural nature of healthcare itself.

#### 6.4 Valuing People

In commenting on PCP, Mansell and Beadle-Brown (2004a) appear to have stirred up strong feelings. Following their critique, a flurry of articles appeared. Some articles partially agreed with their stance (Felce 2004, O'Brien 2004, Emerson & Stancliffe 2004). Initially though, the concerns appear to arise not from the aims of Valuing People, but instead from the definition of what it actually means to be person-centred. Sanderson et al. (2002, p.15) produce some definitions but they appear loosely worded:

- A powerful way to support positive change
- A different way of working together
- A better way to listen and respond to people
- Different for different people
- An invitation to personal commitment

- Working towards inclusive communities
- For anyone who wants it

I have some concerns with the last definition because it assumes that all people have the confidence and capacity to demand PCP.

However, Towell and Sanderson (2004) critique Mansell and Beadle-Brown through the Valuing People framework. Valuing People (DOH 2001) aims towards building a society whereby people with learning difficulties participate as equal citizens, *'leading full and independent lives as part of their local communities'* (p.2). Towell and Sanderson (p.18) point to Valuing People's fresh emphasis on:

- Starting from the experiences and aspirations of people with learning difficulties within their wider social context (putting the person at the centre of the process)
- Seeking to shift power in their direction (working in partnership)
- Addressing support to achieve greater inclusion (building circles of support)
- Understanding planning as a continuous process of *'creative problem solving'* and focusing on action in order to achieve more desirable outcomes (treating people as individuals and tailoring services to 'fit' the person rather than 'fitting' the person to a standardised service package)

They do not hide the fact that they have qualms about the implementation of the national strategy, because it is claiming to be available to all people with learning difficulties irrespective of the nature and severity of their impairment. Emerson and Stancliffe (2004) share their reservations and argue that an incremental introduction to PCP is advisable, especially in choosing a sufficient variety of people and situations and not just those with existing circles of support. Indeed, Felce (2004) argues that widespread implementation of PCP in the short to medium term appears to be an

unrealistic goal, and that it is more likely to be a long-term process that will go hand-in-hand with restructuring of service policies and practices. Additionally, Towell and Sanderson point to the difficulties of funding constraints and the likelihood that lack of funding will probably undermine effective action. However, they argue in favour of service modernisation and staff development as an integral part of PCP.

Valuing People recognises that there are problems; for example, exclusion and discrimination, and this recognition marks a change from previous policies. This admission of problems is the starting point for the policy, but Valuing People offers no analysis of the reasons for past difficulties in implementing IP; it merely offers a new model of planning as a central part of its reforms. Mansell and Beadle-Brown (2004b) argue that because action is a central part of the planning process, helping people with learning difficulties requires a *'sustained committed engagement with them as individuals'* (p. 33). They acknowledge that this process can be complex and difficult, and that it revolves around how others view people with learning difficulties, for example, employing a deficit or competence promotion approach (see Chapter 9 for further explanation of these terms). O'Brien (2004) notes that a restricted view of people's impairments can lead to an assumption that no change is required because that person is viewed from a deficit approach and is seen as already having as much inclusion, choice or independence as possible.

Despite the proposals for reform within the national strategy, there appears to be significant concerns about Person-Centred Planning. One such concern is that it is merely a new name for Individual-Programme Planning. The argument against this is that the old IP did not place the person at the centre of the planning process, and failed to consult the individual on what they wanted (Brewster and Ramcharan 2005). In contrast, PCP places the person at the centre of the process (Sanderson et al. 2002). Additionally, Sanderson et al. (ibid.) suggest that PCP uses circles of support, consisting of family and friends as full partners who assist in the planning process. These circles of

support act to empower people with learning difficulties when making choices and decisions.

The IP had problems regarding resources, staff shortages, difficulties in transitions from crisis-led interventions to more proactive responses, underestimation of the amount of work involved to implement an IP, overbearing demands on front line workers and a lack of integrated record systems (Grant 1997, Felce et al. 1998). Additionally, the sheer scale of implementation created an even greater backlog of people requiring a plan (Grant 1997). Furthermore, for those people with existing plans it could easily become a paper exercise, because many plans were not put into practice; in effect, people ignored what was written in the plan (Mansell and Beadle-Brown 2004a).

PCP is supposed to aim at more proactive ways of working with people, and using circles of support to complement existing processes. Building a circle of support as a resource is one immediate problem for some people who live an isolated existence. The main concerns appear to centre on the provision of resources required to implement an effective planning process that will genuinely empower people with learning difficulties and not merely pay lip service to their existence.

The next section presents evidence from my own research concerning person-centred planning. I will look at what works and what does not work for people with learning difficulties and their supporters, in their healthcare encounters.

## **6.5 Contexts for Person-Centred Planning**

There are many contexts where person-centred planning can take place. Sanderson et al. (2002) identify education, social encounters, housing, employment, relationships, leisure pursuits, self-care and healthcare. Person-centred planning in these contexts '*results in changes in people's lives rather than plans*' (Sanderson et al. 2002, p. 9). However, each category is very

broad and Sanderson et al. (ibid.) omit to mention that for many people with learning difficulties some of these contexts are subdivided and service dependent. For example primary and secondary care services divide healthcare services (Rogers and Pilgrim 2003), and because this thesis is primarily concerned with healthcare encounters I shall focus on the most prevalent healthcare contexts for person-centred planning.

Within my study these contexts are general hospital services (secondary), psychology services (secondary), psychiatry services (secondary), general dental services (primary), community dental services (primary and secondary), GP services (primary). I have also chosen to focus on women's health issues and men's health issues because there were gaps in these service areas that highlight where person-centred planning could have made a difference for the individuals concerned.

#### **6.5.1 Person-centred planning and Hospitals**

Studies have identified that people without learning difficulties can feel abandoned in hospitals (Irurita 1996, Coyle & Williams 2001). In these studies people were unable to locate staff to check monitors, request pain relief, request help with feeding or going to the toilet, to comfort them or just to check on them instead of leaving them alone for long periods.

Furthermore, many people did not like to 'bother' staff if they appeared busy, so staff appeared unavailable, even when they were physically present.

McLeod (1990, p.148) suggests that individual knowledge of people is important in how staff care for them within a healthcare context.

Furthermore, listening to families, and their knowledge of an individual, helped the staff to recognise subtle changes in people.

The following vignettes illustrate the 'person-centredness' of the healthcare encounters of some of the people with learning difficulties in my study. Out of the thirty-one people I spoke to, each individual experienced different levels of involvement in their healthcare encounters. For example, some individuals experienced some involvement with their dental practitioner,

whilst others experienced little or no involvement. Each practitioner had different ways of working and some adopted a more inclusive approach. It was difficult to choose the vignettes because I had so much data, and few people described total involvement in their own healthcare.

The first comment came from a learning disability nurse who was dissatisfied with the treatment experienced by individuals at the General Hospital in Brancaster. The individuals were all residents at the home where the nurse worked.

L.D. Nurse 1.: *“We have these fantastic little health booklets that our tenants carry with them. It contains all their important information, for example their likes and dislikes, how they communicate, what they are capable of doing unaided, what they require assistance with etc. Time and time again, when they are admitted, the booklets are ignored by the staff. They just don’t bother washing our tenants because they are just too busy to assist them. One of my tenants had sat all day in bed with nothing to eat. When I asked why, I was told that: ‘the food was put in front of her, but she did not eat it’. In her booklet, it states that she has no manual dexterity and cannot feed herself. She needs help. It’s the same with medication. You turn up to visit in the evening, and the day’s medicines are lined up in cups on the bedside. Just a few minutes to ensure the medication is taken, that’s all it needs. It’s as if they’re second class citizens because they have learning difficulties.”*

This nurse questioned the point of painstakingly writing everything down, and felt frustrated by the lack of continuity of care that the people within her home received when they accessed secondary services. Furthermore, she added that the booklets were originally used when people went on holiday, in case they needed medical services, and it was considered a good idea to use them all the time. She thought that they were especially useful for people

with little verbal articulation. Unfortunately, the outcomes were not always favourable for the vulnerable population that they were supposed to be assisting, because staff frequently did not bother to take the time to read the booklets.

Coyle and Williams (2001) suggest that the healthcare encounter could be more person-centred if the practitioner regularly assessed the person's desire for involvement. One example they give is a practitioner regularly seeking the person's views on treatment, how the treatment affects their lives, and encouraging them to ask questions. They also suggest that the practitioner interacts with another person or people who bring with them their own knowledge of the person. In my study, vital knowledge about an individual was supplied in the form of a healthcare booklet that nursing staff and medical practitioners did not take the time or trouble to read. This suggests that the interaction was far from person-centred for this particular individual.

The General Hospital in Brancaster was subject to criticism from everyone I encountered; staff carers, people with learning difficulties and their families. Problems were:

- Failure to involve the individual in their own healthcare
- Long waiting times
- Difficulty parking near to the hospital
- Poor staff attitude-treating people as cases and not individuals
- Lack of explanation by medical staff concerning procedures
- Lack of flexibility and continuity of care
- An unwillingness to get to know the patient as a person
- An unwillingness to listen to staff carers and families concerning the individual

In contrast, Capulet Hospital (a cottage hospital on the other side of Brancaster), was praised by people with learning difficulties, staff carers, and family for:

- Including individuals in decisions
- Ease of access
- Accommodating staff who listened
- No waiting
- Getting to know the individual as a person
- Medical staff who explained medical procedures simply

The next example is concerned with ‘what works’ in hospital. This is a case study about Dave, who is extremely articulate, but he still experienced difficulties in hospital. I constructed the narrative after two semi-structured interviews, which were not particularly difficult to obtain because of Dave’s high level of articulation and understanding. Dave was happy with the transcript of the interviews.

#### Case study: Dave

Dave is a relaxed and genial young man in his late thirties. He has lived in supported accommodation, in Tyke Street, for eight years. Dave has a friendly relationship with his carers, characterised by good-humoured bantering about the football team he supports. Dave’s carers have been with him for eight years and they have a detailed personal knowledge of his likes and dislikes, his family circumstances, and his personal history. Above all, I observed that they treated him with respect, exhibiting a genuine liking for him.

The relationship is also supportive and helps Dave when he is in unfamiliar situations with people who do not know him well. One example is the story he told me concerning his stay in hospital. He had cancer. His dad died of cancer, and I presumed that his fear stemmed from the fact his father had

died from the disease. When I explored further, I found I was very wrong. Dave was not frightened of cancer; Dave was frightened of being in hospital and having an operation. The hospital staff did little to allay his fears. However, his carers spent time exploring what his fears were; they explained in simple terms what would happen to him during the operation, and what part of his body would be affected. Dave's carers also told him how he might feel when he woke up after the operation, and what the risks were if he did not have the operation. Knowing what was going to happen, what part of his body was being operated on, and what to expect afterwards significantly reduced Dave's fears. Discussing the risks if he did not have the operation also reassured him that he was making the right decision to have the operation.

Dave expressed frustration at his lack of knowledge concerning the workings of his body and he expressed an interest to know more. He said that frequently he did not have the right words to question professionals about his body. One other factor was important; he trusted his carers. Dave said that in healthcare encounters he preferred his carers to be present because he trusted and had a good relationship with them. He did not trust the professionals because he had no relationship with them.

### **6.5.2 Person-centred planning and GP services**

The GP is usually the first port of call for most people wishing to access secondary services. One push of the national strategy is ensuring the registration of all people with learning difficulties with a GP. Holt and Huntly (1973), Howells (1986), Lakhani and Bates (1999), Aspray et al.

(1999) argue that people with learning difficulties will experience difficulties in having their healthcare needs met by GPs. This is because of the lack of training, specialist knowledge and related skills that make some GPs ill prepared to deal with the complex mix of psychiatric, physical and developmental problems that some people with learning difficulties possess.

I have enclosed two contrasting case studies of person-centred approaches by GPs in the Brancaster area. These studies were typical for nearly everyone I interviewed. Only five people out of thirty-one reported an accommodating and helpful GP. However, these five people all saw the same GP. The contrasting case study is typical of the other twenty-six people interviewed. The two case studies exhibit different types of assessment. John undergoes the questioning model (Smale et al. 1993) which is entirely practitioner-centred and reliant on professional or case knowledge. In contrast, Edward experiences PCP because the GP works in partnership with Edward, the staff, and the hospital, to achieve the best possible outcome.

#### Case study: John

John has always lived within institutionalised settings. He started out at St. Francis' Hospital, later transferring to a community home during the hospital closure. He is now nearly eighty and in a wheelchair because of ill health. John needs his GP to prescribe his medication. He feels ignored and angered because the GP in John's words: *"treats me like a pile of shit"*. The reason for John's anger is that the GP does not talk to him when he attends, preferring to talk over his head to a carer. John says that he knows he is in a wheelchair because his legs have failed but there is nothing wrong with his voice. He admits to being irritated because his GP's English is poor and he has to make a great deal of effort to understand him, but the GP

makes little effort to reciprocate and understand him. John is glad that not all healthcare professionals are like his GP because he needs their help to keep him alive.

#### Case study: Edward

Edward is a quietly spoken man. He was admitted to St. Francis' Hospital in his teens, and moved into the community when the hospital was closed. He has had varied healthcare experiences with different healthcare professionals but has recently found a GP whom he likes and with whom he feels comfortable. He reports that Dr. X is a good GP who asks him about his epilepsy and what it stops him doing. When the GP has difficulty with the medication, or feels Edward needs more help than he can offer, he refers him to the consultant at the hospital. With information gathered from the staff carers the GP has identified the trigger points for Edward's epilepsy. The success means that Edward has not needed hospitalisation for over a year. Edward is happy because he knows he has some control over his epilepsy and can avoid the severe fits he used to suffer.

#### **7.5.3 Person-centred planning and Psychology Services**

Liaschenko and Fisher (1999) argue that there are many constructs to knowledge within the healthcare encounter. They propose that a classification of knowledge, or knowledge of physiology, disease, and interventions, plays a necessary but insufficient role on its own. They argue in favour of other forms of knowledge, gleaned from a variety of sources, allowing for a more informed healthcare encounter when different forms of knowledge are used. These different forms of knowledge can originate from the practitioner, the individual, the individual's supporters, and the

environment surrounding the individual. Brancaster buys in psychology services from Farmsley, a neighbouring area. For urgent cases, the short-term solution involves employing a part-time psychologist. Unfortunately, Brancaster covers a large area, and one particular psychologist has retired a number of times. This psychologist is unusual in that she possesses the knowledge that Liaschenko and Fisher (1999) are suggesting. Demand calls this psychologist back in, as is illustrated in my third example:

L.D. Nurse 2: *“It would help if we had a psychologist to refer to more regularly, for the things we struggle with. Behaviour can sometimes be an issue, and we are not qualified to deal with everything. Sometimes you are too close to see what is really going on. Sometimes another person can say something that is so obvious you wonder why you did not think of it yourself. We have Jeanette (anonymised Senior Psychologist) who is really helpful. Mind you, she’s had more comebacks than Gary Glitter. Jeanette has known most of our residents since they were born; she also knows most of their families and their personal history. Jeanette usually knows when it is a medical problem, or when it is something that relates to their past-history. She also knows whether this sort of thing has happened before, and its previous causes. When she eventually goes for good, all that knowledge will be lost.”*

Thinking about the types of knowledge that Liaschenko and Fisher suggest also means that a relationship needs to be built with the person that allows for a more complete understanding as to why a person is exhibiting certain behaviours. Emerson (2001) provides examples from studies with people with severe intellectual disabilities and challenging behaviour. He offers strong evidence to support the proposition that processes of negative or positive reinforcement can maintain some examples of challenging behaviours. Emerson argues that staff carers are likely to habituate (get

used) to challenging behaviour over time and may only respond when an individual exhibits more intense or complex forms of challenging behaviour. He also suggests that behaviour can be complex and a careful analysis of the person and their environment is essential. Emerson argues that analysis can only occur when there is continuity of care by staff or family carers who have built up a trusting and supportive relationship.

Furthermore, it appears that a more informed relationship needs building with the carers and supporters of an individual in order to give that individual more choice concerning their healthcare. What the learning disability nurse appears to be saying is that knowledge of an individual, built over the years, can assist in understanding whether medical interventions are necessary, and with facilitating individual choice. For this to occur it appears that there has to be continuity of care and continuity of support for individuals to be valued as people.

#### **6.5.4 Person-Centered Planning and Psychiatry Services**

Rogers and Pilgrim (2003) argue that psychiatry services are by nature problematic. They suggest that this is because the nature and purpose of the services is *'framed only within the terms of psychiatric treatment and case management and does not address aspects of social need or social exclusion'* (p.232). This centres round practitioner knowledge and fails to place the person at the centre of the process. It also fails to take into consideration the wider social aspects of an individual's life and their previous history. Jacobson (2003) suggests that many people with learning difficulties have a higher incidence, than the general population, of mental disorders and associated severe behavioural problems and are therefore more likely to be under the care of a psychiatrist.

Weber (2003) discusses the problems of diagnosis and treatment with people who have communication problems. This is because many psychiatric interventions are reliant on self-report; usually there is no physical evidence of the problem like a cut or a lump. Diagnosis of behaviour usually employs

subjective terminology. One example of employing subjective terminology is the diagnosis of ADHD (Attention Deficit Hyperactive Disorder); the terms ‘hyperactive’, ‘distractive’, and ‘impulsive’ are used as key factors in diagnosis (Owens 2000). However, when self-report in a healthcare interaction dictates a diagnosis, the people who lack the necessary articulation of adequate self-report become a ‘difficulty’. If someone cannot describe their feelings, and symptoms, and their social situation is unknown then it becomes virtually impossible to explore other possibilities as an explanation for behaviour. Another related problem suggested by Laing (1969) is that people’s challenging behaviours and mental health problems are a product of people’s social constructions and so their existence will vary between cultures and societies.

The fourth vignette is one in which a consultant psychiatrist echoes this problem:

Consultant 1: *“I treat people with learning difficulties using a broad brush stroke because of the difficulties of diagnosis with people who are less articulate...in cases where a person has poor articulation, and poor self-report, it can be like walking in the dark...most of the time I’m reliant on the reports and observations of carers and staff and people who are in close contact with people with learning difficulties. Experience tells me which accounts I can trust.”*

A problem within the healthcare encounter for this consultant is people with learning difficulties who lack the necessary articulation to explain their feelings, thoughts and concerns. Without these necessary forms of interaction, the healthcare encounter can too easily become practitioner-centred or incomplete, resulting in the ‘questioning model’ of assessment (Smale et al. 1993, Duffy and Sanderson 2005). The consultant explains how partnerships have been formed with paid carers of people with learning difficulties. Using carers as proxies or surrogate informants and decision-

makers is, in itself, problematic because of the issues of confidentiality, capacity and consent to treatment. This is because a proxy must make any decision using substituted judgement, based on their understanding of what the person with learning difficulties would decide. In addition, Fisher et al. (2003) argue that proxy consent procedures are not ethically justifiable unless the person with learning difficulties agrees that proxy assistance is a desirable way of protecting his or her interests (further discussion in chapter 9). The same consultant points out the difficulties of working with people with learning difficulties:

Consultant 1: *“I feel like a particle in Brownian motion, bouncing off people and hoping that I am passing something on...It’s alright for the people in Whitehall, sat there, giving ideas; they’ve no idea what’s going on in practice. Policy looks great but nobody thinks about the difficulties when you work with people with learning difficulties. We are constantly fire-fighting. There aren’t the resources to go round...I don’t know how we are going to cope with the number of problems that will ensue from people being housed out all over Brancaster. It’s likely to get out of control and very quickly.”*

Calnan’s (1987) work on health and illness argued that the proposed eradication of healthcare inequalities for all was misguided when the NHS was set up. This was because there were not enough resources to meet need, and providing a more comprehensive service automatically created more need. The consultant in my study is clearly saying that time and lack of resources are a problem in daily practice. Furthermore, many psychiatric interventions in Brancaster appear crisis-led rather than needs-led. In addition to the existing problems there are the difficulties of reaching people with learning difficulties who have been re-housed within the community. There is now a huge geographical area to cover, and an apparent shortage of staff. The problems of implementing IPs identified within the literature (Grant 1997, Felce et al. 1998), staff shortages, overbearing demands on

front-line workers, and problems with the transition from crisis-led services to more pro-active work, are all present within the psychiatric services. It appears that, unless the structure of the services alters, and more staff are employed, then person-centred planning cannot thrive as the services currently stand and the prevalent types of assessment once again will fall back on the questioning and procedural models because of the reliance on case knowledge.

#### **6.5.5 Person-centred planning and general dental services**

The oral health status of individuals with learning difficulties has generally been reported to be poorer and dental treatment needs usually greater than that of the general population (Malstrom et al. 2002). Hinchcliffe et al. (1988) argue that in many cases this is due to institutionalisation and a higher consumption of sweets and fizzy sugar filled drinks, as a result of reward behaviour modification programmes and poor health monitoring. These programmes were, and still are in some situations, used by institutions; giving people points or tokens (token economies) that could be exchanged at the end of the week to obtain a reward. In many cases, the reward was sweets. Further explanations of the treatment needs of individuals with learning difficulties are difficulty in maintaining good oral hygiene, and tooth fractures due to epilepsy (fits and falls) and poor motor control (falls). Some medications, for example Epanutin (for epilepsy), cause adverse effects on the gums, promoting gum disease. Coupled with this is the lack of preventative care and paucity of visits to the dentist (Hinchcliffe et al. *ibid*). The predominant form of treatment for people with learning difficulties is extraction (Prasher & Janicki 2002). This can lead to later problems with dentures that are poorly fitting, or alternatively no denture provision and problems with speech, nutrition and appearance. One general dental practitioner gives other reasons for poor dental provision:

General Dental

Practitioner:

*“Well really the problems of treating people with learning difficulties are not only communication*

*difficulties but having the time to communicate. We are not paid a sessional fee, which would be better. The capitation fee works out at approximately ten pence per month and when you are trying to run a business then it is not feasible. If you have someone with learning difficulties in the chair, you just treat what appears to be the problem. There's no time for anything else...Most dentists see people with learning difficulties as a gesture of goodwill. They are not a practice builder...No-one wants someone rocking and dribbling in the corner, the private patients would just go away...*

A general dental practitioner is paid by piecework. Every piece of work completed has a fee attached. The fee is the same whether seven minutes or seven hours is spent with the patient. Communication problems, as with the example from psychiatry, also interfere with the dental encounter. The capitation, or continuing care payments, introduced by The Department of Health are per patient, not per visit. In comparison, Australia implements continuing care payments per visit, but the dental health of people with learning difficulties is still poor (Scott et al. 1998). Perhaps the clue lies in the last comment of this particular dental practitioner who says that '*people with learning difficulties are not a practice builder...*' Apart from being time-consuming, and the difficulties with communication, there appears to be a discriminatory attitude to people with learning difficulties, perhaps even a sense of fear. When I spoke to this particular dentist, I sensed irritation and frustration because he did treat people with learning difficulties. He was one of the few dentists in the area who did provide treatment for this group of people, but he found the constraints on his practice difficult to tolerate.

### 6.5.6 Person-centred planning and community dental services

The community dental services operate differently to general practice; they are paid a set salary and can spend more time with people with learning difficulties. A community dental surgeon that I spoke to made the following comments:

#### Community Dental

Surgeon: *“I think for dentists there is a big time issue so in general dental practice it is not worth their while....When I spoke to one GDP (general dental practitioner) on a course he said I’m willing but the trouble is we don’t understand them and they don’t understand us. They (GDPs) would say that time is the factor but when I’ve talked to them I would say lack of knowledge as well...lack of exposure; in the undergraduate training programme there isn’t exposure to people with learning difficulties and then in the real world it’s a lack of time to do the treatment. I think a lot of importance revolves around attitudes, when we did disability studies they try to focus away and look at the environment, other than attitudes. But with kids’ parents, a lot of them would say it was the attitude of the dentist that put us off. They don’t say anything else, it’s the way they were approached....I feel that if we can address attitudes then the other obstacles can be overcome; you can devise something specifically for that person. I mean, I would have someone back time and time again just to walk around the surgery if that is what they want, and if the people who know them best say that is what would help...”*

There is clearly a difference, not only between how the two services are structured, but also between the attitudes of the two dentists. The community dental surgeon has a child with learning difficulties and runs courses to raise awareness of surrounding learning difficulties in particular. She is aware of, and has experience of her own child's exclusion from treatment, raising her awareness in how she deals with people with learning difficulties. However, she does concur that time is an issue, but feels that lack of exposure to people with learning difficulties is also part of the problem. She aims at being person-centred by using all the resources possible; the carers are a main source of information as to what would make the dental encounter less problematic for an individual. In the next example, there is contrasting evidence for a person-centred approach within the community and general dental services.

#### **6.5.7 A contrast between community and general dental services**

The following composite narrative is from the narratives of Sandy and Seamus (see appendix vii), who live at Tyke Street. Both experienced the community dental services and are now experiencing the general dental services.

I like my new dentist, the old one did nothing for us. I mean he did not do any work in our mouths. He had not done anything for years. When I left the hospital and came to live in my new home the staff helped me find a new dentist. My mouth needed to be rebuilt. My mouth is fine now, and I go back to the same dentist every three months. When I go, he paints a gel on my teeth to stop them from going bad. The hygienist cleans my teeth and makes sure I am brushing them right.

What is interesting is that fluoride gel is being painted on the teeth every three months to inhibit dental decay. Additionally, the dental hygienist is seen at the same time to instruct and reinforce oral hygiene procedures. It was not possible to ascertain whether this was private treatment, or funded through the Dental Estimates Board. The dental practitioner that Seamus and Sandy attend is unusual for a mainstream practitioner, because he has spent the time getting to know their individual needs. What is disconcerting is that the community dental services neglected to maintain Seamus and Sandy's mouths.

#### **6.5.8 Person-centred services and women's health**

McCarthy (2001) has investigated health issues among women with learning difficulties. Her research has shown that women with learning difficulties are less likely to have had a cervical smear because of assumptions that the woman is not sexually active and therefore at lower risk of developing cancer of the cervix. They are also less likely to have had routine breast screening. One example in my own study illustrates how these difficulties are compounded when the person has complex and profound disabilities.

This particular informant is a learning disability nurse who has worked with the people she cares for eighteen years. She also says that their doctor is more likely to speak to them if they say they are a nurse rather than a carer because he feels they understand more. She talked about one person, Sonja (anonymised), who had profound learning difficulties:

L.D.Nurse 3: *"I've known Sonja for eighteen years. I knew her four sisters. Each one died of breast cancer; she is the last surviving sister. The doctor will not put her on a regular programme for screening, so we check her here (in the home) regularly. It's not an ideal situation, but with the family history I feel we ought to take more care."*

Another learning disability nurse talked about the difficulties of accessing some of the primary care services, with the doctor acting as a gatekeeper for the services.

L.D.Nurse 4: *“Yes there’s a well woman clinic, but our GP does not refer our residents there because he says they don’t need to attend. Some of our residents are elderly and have never been sexually active. But the younger ones have had partners.”*

This general medical service is similar to the general dental service, in that the doctor appears to have a fixed perception of people with learning difficulties. They are asexual beings. The doctor has also failed to access the knowledge of the paid carers who could inform him of the risk status of his patients. If this doctor is employing a person-centred approach and working in partnership, then how is this achieved without accessing the knowledge of the people that know his patients the best?

#### **6.5.9 Person-centred services and men’s health**

Very little is written about the health needs of men with learning difficulties. One condition that is ignored in relation to men is osteoporosis. Osteoporosis is better known as ‘brittle bone disease’. It is usually associated with post-menopausal women. However, bone density relies on many factors; normal growth and development, normal timing of puberty, maintenance of adult sex hormone concentrations, normal activity and nutrition and the absence of other diseases (Prasher and Janicki 2002, p. 172-173). Center et al. (1998) argue that the best indicators of low bone mineral density are age and body size.

The next case study is that of Paul. The study highlights the importance of the importance of different types of knowledge in addition to case knowledge that may increase awareness of male health.

Medical professionals have ignored Paul's individual medical history and adopted a crisis-management approach. This has affected his quality of life. There appears to be little evidence of person-centred planning concerning Paul. I interviewed Paul in two different homes. Each interview lasted approximately one hour. The first interview had Paul's key worker present who assisted me with Paul's method of communication. The interviews were semi-structured. No tape recorder was used because his speech is impaired and he requires a great deal of concentration and feedback in order to understand what he is saying. Once you get used to his speech then it becomes easier to communicate. I built part of the background narrative from the observations of Paul's paid carers, in order to improve my understanding the context of Paul's experiences. I read the narrative aloud to Paul and he agreed with the story.

#### Case study: Paul

Paul is of slim build and short of stature. He looks at least twenty-years older than his biological age of fifty-eight. He likes his home and the people he lives with because they can all walk up the road to have a chat with the shopkeepers. He can buy his daily paper and tobacco for his friend who does not like going out. This daily routine has now changed.

Whilst he was on holiday he broke his arm; he was run over by a bicycle but admits it was his fault because he was not looking where he was going. On his return, he tripped over the doorstep and broke his leg. He had just had the plaster removed when he fell again and broke his other leg. This time it was a compound fracture and there was difficulty with healing. After the third break the consultant at the hospital decided to send him for a bone density scan. The diagnosis was osteoporosis.

Not being sixty years of age meant that Paul was denied admission to a rehabilitation unit for people with osteoporosis and fracture injuries. At the time he was fifty-five. There was no consideration of his medical history or of his individual needs. Paul's subsequent legacy is a Zimmer frame, which he detests, because he cannot support his weight adequately to get around. He lost his mobility. Unwillingly, he had to move house because his home could not be adapted to accommodate his reduced mobility. He lost his friends. The paid carers staffing the home are different. The home he now lives in is about two miles from the nearest shop, which delivers the papers. He lost his social contact. He now spends most of his time alone in his room listening to music.

There has been little in the way of choice for Paul, his move to a home miles away from the nearest shops is in direct opposition to the recommendations in *Valuing People* (2001b) where people with learning difficulties should have access to amenities without having to be dependent on others.

#### 6.5.10 Being Person-Centred

The next narrative has been included because it illustrates the importance of personal history when encountering a new person. The material for building the narrative originated from my observations and brief discussions with various staff members. The notes for the story are in appendix ix.

#### Case study: Samantha

Samantha is a young woman in her twenties. She lives in a hospital-based unit at St. Francis'. What started out as a routine visit turned into a frightening spectacle for me. The bungalow, on entry, stank of urine. The staff were all busy with a resident.

The residents all had profound learning difficulties and some had severe behavioural problems.

The senior nurse was sitting with some of the residents in the day room. Samantha was sitting next to her, having her feet rubbed. Another resident became irritated at the amount of attention Samantha was receiving and aimed a blow at her. Samantha reacted by screaming and running round the room, knocking cups and tables flying. Two of the residents made a hasty exit. One sat on the floor in the hallway, rocking backwards and forwards. The other went into the garden. Samantha ran towards me with wild staring eyes, like a frightened rabbit, and hugged me. I hugged her back, hoping that I was doing the right thing. Then, as a male nurse intervened, she ran away, ripping her clothes and sinking her teeth into her arm, tearing at her flesh. The front of her dress was now torn and bloodied. The senior nurse quietly asked the male nurse to leave and Samantha began to sob and beg that she did not want to be hurt. The senior nurse calmly handled the situation, without touching Samantha or invading her body space. She treated Samantha with dignity and respect, speaking to her gently but firmly, treating her like an adult.

A month later, I saw Samantha and she was an altered individual, calm and chatty, minus those wild eyes. Intrigued, I chatted with the senior nurse and asked about the change. It turned out that Samantha had been in a home, prescribed medication to 'modify her behaviour', and forcibly held down by male carers if she started to protest. The senior nurse knew part of Samantha's history when she arrived. She was also aware of the home by its reputation. This particular nurse keenly

observes the people for whom she has a duty of care. With the aid of the psychiatrist, she reduced Samantha's medication and a more lucid Samantha filled in the gaps. However, without the initial knowledge surrounding Samantha's history, coupled with the insight of the senior nurse, the outcome that day might have been very different.

## **6.6 Summary and Conclusions**

In the current climate of 'partnerships' and working 'collaboratively' I expected to find more examples of interdisciplinary teamwork. What I found was an absence of consistent evidence of interdisciplinary teamwork.

Admittedly, some professionals appeared more person-centred and strove to include the person, their carers and other professionals in healthcare decisions, whilst other professionals relied on the questioning and procedural models (Smale et al. 1993) and exhibited little awareness of the complexity of the carer/cared for relationship. Indeed, some professionals appeared to underestimate the importance of carer knowledge or expertise about the best ways of managing health. The complexity of the carer/cared for relationship is explained in detail in the next chapter.

Additionally there were gaps in women's and men's health issues. Medical criteria were used to assess ageing-related diseases, and if the individual had an ageing-related disease but had not reached the medically defined age of onset then treatment was withheld. Furthermore, some GPs appeared to regard many people with learning difficulties as asexual beings, omitting to monitor their health status, and failing to access personal history details that indicated the need for healthcare monitoring.

Questioning, procedural, and crisis intervention approaches appeared to be employed when there were staff shortages, a lack of time and resources, poor health monitoring, and a lack of awareness on the part of the professional concerning person-centred approaches. This relates back to previously

identified problems of Individual Planning and crisis interventions (Grant 1997, Felce et al. 1998, Appelby et al. 2003).

A further difficulty in the healthcare environment related to people with complex and profound disabilities who needed a proxy to facilitate choice and decision-making. Using a proxy to facilitate choice and decision-making, and circles of support to enhance the decision-making process, may entail difficulties for vulnerable people who suffer abuse and neglect (Brown & Scott 2005). The issue is how far can ordinary safeguards and protection be incorporated into the process of PCP to protect the individual against further abuse and neglect. Furthermore, where do the circles of support come from for people suffering abuse and neglect?

The main aim of person-centred planning is to '*put the person at the centre of the process*' (Sanderson et al. 2002, p13). This means finding out and fulfilling that person's hopes, wishes, and needs and in the process adopting a teamwork approach, constantly referring back to the individual and to one another. My examples find inconsistent supporting evidence for a teamwork approach. Furthermore, professionals may not appreciate carer knowledge and expertise about fluctuations in a person's state of health. This lack of awareness may act as a barrier to 'collaborative' approaches and working 'in partnership'. Additionally, this may have a negative impact on involvement in decision-making in healthcare encounters for people with learning difficulties. In chapter 7, I examine the teamwork approach and deconstruct working 'collaboratively' and 'in partnership'.

In some situations, the evidence is that medical knowledge takes precedence over other types of knowledge that would assist in the decision-making process. Healthcare matters appear to have varying importance for individuals, so perhaps a full blooded commitment to interdisciplinary, interagency practice is perhaps not needed all the time. However, what importance should be placed on healthcare decision-making not requiring commitment to interdisciplinary, interagency practice, and who decides when

**this should be so? Additionally, what are the contextual and personal factors involved and how do they affect the healthcare decision-making process?**

## Chapter 7

### 'Partnerships' and 'Collaboration': the prioritisation of knowledge

#### 7.1 Introduction and Scope

In this chapter, I explore policy proposals that people with learning difficulties need to be 'partners' in their healthcare experiences (DOH 2001b). Therefore, I aim to deconstruct the terms 'partnership' and 'collaboration', because they appear to take different forms. Firstly, I intend to critically evaluate the debates surrounding 'partnership' and 'collaboration'. Then I intend to offer accounts of how people with learning difficulties, as 'partners', make sense of decision-making, and relate these experiences contextually to a variety of healthcare situations. In the next chapter, the definitions of 'partnership' lead into how constructions of 'competence', within the healthcare services, affect choice and decision-making.

In their study on public and patient participation in Primary Care Groups, Callaghan and Wistow (2002) suggested that there were three possible explanations for different forms of involvement in decision-making. The first explanation was that structural forces created an environment that constrained people's actions and defined outcomes. This means that the entrenched beliefs and opinions of professionals, coupled with existing organisational frameworks, and the history of those structures for decision-making within a healthcare environment are important. In the second explanation, significant people with personal or institutional power may move a healthcare agenda in a particular direction. The third explanation was a lack of a clear definition or direction for participation, making room for the use of different approaches. From these three explanations, Callaghan and Wistow (2002) produced three models of evaluation:

- Top down. Where professional knowledge is the most valuable information and therefore individual participation will never be anything more than peripheral.
- Bottom up. Begins from the unique perspectives of the recipients of healthcare services. However, Callaghan and Wistow (2002) caution that these perspectives alone will not improve the focus of healthcare because there needs to be a framework of communication between professionals and service users.
- Integrating bottom up and top down models. Shifting the balance of power towards service users. Central to this shift is the importance of institutional redesign as an instrument for achieving positive interaction over the long term.

I argue that if people with learning difficulties are to be included in their healthcare encounters then Callaghan and Wistow's (2002) integration of top down and bottom up approach is important. This means that non-medical knowledge needs to be acknowledged and used in order to put into practice policy directives and guidance stipulating that practitioners and their employing agencies should work 'in partnership' with people with learning difficulties, their carers and each other. However, the main problem here, again, is the vagueness of the term 'partnership'. The White Paper Valuing People (DOH 2001b, p.51, para. 4.27) states that: *'it is no longer acceptable for organisations to view people with learning disabilities as passive recipients of services; they must instead be seen as active partners'*. Furthermore, it identifies that: *'Carers should be treated as full partners by all agencies involved'* (p.57, para. 5.16). Valuing People also suggests interagency working with a focus on the *'whole person'* that demonstrates that agencies are *'listening carefully to the views and experiences of people with learning disabilities'* (p.68). This suggests that professionals, supporters, people with learning difficulties, and indeed anyone in the healthcare encounter, need to work collaboratively and in co-operation with one another to provide a service that takes 'the whole person' into account.

Partnership, according to Valuing People, therefore appears to be a term applied to any kind of relationship between different agencies or individuals.

This lack of clarity about what actually constitutes working 'collaboratively', in 'co-operation', or in 'partnership', can cause ambiguities and contradictions in the healthcare process. For example, it is unclear when the 'partnership' starts, how it is to proceed, whether it ends, and indeed how it is understood by the parties involved. Does the term 'partnership' define work done together after a partnership is agreed (negotiation of treatment) or is it work done with partners before any agreement (form of treatment) is reached (i.e., developing a relationship with carers/cared for)? On the other hand, is it work done whilst the agreement is under way, and when the agreement is close to completion? Vague definitions of 'partnership' encapsulate rather than resolve practice dilemmas (Cooper 2000). It may be helpful at this stage, to look at a few definitions of 'partnership'.

Tennyson (1998, p.7) defines partnership as '*...a cross-sector alliance in which individuals, groups, or organisations agree to: work together...; share the risks as well as the benefits; and review the relationship regularly, revising their agreement as necessary*'. The attempt is to capture the essence of partnership in this statement, but I suggest that no definition can totally encompass what is involved in the complexities of building partnerships. Hutchinson and Campbell (1998, p.8) argue that '*having a partnership and working in partnership are very different, but the language can disguise this fact*'. They appear to be proposing that the term partnership can describe the form of the relationship, and a method of working that is sometimes called collaboration. From their proposal, it appears that there is no agreed definition of the terms 'partnership' and 'collaboration' and that they are used interchangeably. Nevertheless, my main aim is not to produce a comprehensive definition of partnership, or collaboration, merely to illustrate what might be involved, and how ambiguities and contradictions can occur.

## 7.2 Vital elements for Partnership

Carnwell and Carson (2005, p.8) argue that there are six vital elements for a partnership:

1. Trust in partners
2. Respect for partners
3. Joint working
4. Teamwork
5. Eliminating boundaries
6. Being an ally

They suggest that these six elements illustrate the '*shared commitment that constitutes partnership*' (p.8) and amount to partners having a shared identity. If all partners have a shared identity, then having trust in partners should work in all directions. However, there is no definition of the factors constituting the word 'trust'. Similarly, having respect for the partners: how do we define respect? What constitutes 'joint working' and 'teamwork'? How much involvement is necessary to apply the terms 'joint working' and 'teamwork'? What constitutes a boundary and how is a boundary broken down? What are the conditions for being an 'ally'? Many of the above nebulous and subjective terms appear to be influenced contextually. For example, what constitutes trust, respect, joint and team working, being an ally and eliminating boundaries, in one situation, will logically differ in another. Therefore, are these six elements vital to partnership, and do they all need to be present at the same time to constitute partnership working? Alternatively, are some aspects (items 3, 4, and 5) examples of collaboration (the method of working) as identified by Hutchinson and Campbell (1998), and other items (1, 2, and 6) examples of partnerships (the form of the relationship)?

Hudson et al. (1998) argue that a key characteristic of partnership is integration, with partners sharing an identity and no longer seeing their separate identities as significant. On the face of things, this sounds robust,

but it is uni-dimensional, and pays little attention to the power structures that are present in all relationships (Lukes 1974). Thompson (2001, p. 837) argues that *'at a cultural level, power operates in terms of discourses, many of them competing; professional (nurse v doctor v social worker); academic (biomedical v psychological v sociological); epistemological stance (positivist v phenomenological v realist)'*. What Thompson is saying is that different disciplines rely on different discourses and therefore the potential for conflict will always be there. This is because power and meaning operate differently between and within groups, including how service users are dealt with by practitioners within the healthcare relationship. In any relationship, Lukes (1974) argues that one 'partner' is always more 'equal', and one partner does not always recognise that their own interests are at risk.

Kinsman (1990, p.223) suggests that the word partnership has a *'nice neutral ring to it...Partnership sounds consensual, it implies that everyone is being given an equal voice, that all partners are equal...'*. Kinsman is arguing that the word partnership is used to label a relationship, but that the word has little meaning; it suggests a participatory approach when really one does not exist. Partnership according to Kinsman is more of a goal than a reality. Scott and Thurston's (2004) explanation for Kinsman's argument is to suggest that professional groups are directly linked to formalised health systems that are embedded within social institutions, which, in turn, are based on patriarchal and bureaucratic practices. They argue that these patriarchal and bureaucratic practices often do not support the relational work required for the development of partnership building. This implies that professionals are 'locked into' a system with little hope of improving health care delivery by including the patient in treatment decisions, and working collaboratively.

Ashwell (2003) provides an alternative view, arguing that working together is frequently problematic because of difficulties relating to clashes of professional culture, objectives and ways of dealing with the various client groups. This can also be linked to four main styles of doctor-patient interaction that have been identified by Charles et al. (1999). These are:

- The paternalistic model. Where the doctor takes prime responsibility for healthcare decisions.
- The professional-as-agent model. Where the doctor possesses superior knowledge regarding treatment, risks and benefits and the patient has superior knowledge about their health, beliefs and lifestyle. The patient then communicates their preference to the doctor and the doctor makes the final decision.
- The informed decision-making model. Where the emphasis is on the process of how a choice is made.
- The shared decision-making model. Where an emphasis is placed on the partnership and collaboration between doctor and patient.

The shared decision-making model emphasises partnership and collaboration, but it also acknowledges that there may be more people involved in the decision-making process than just the doctor and the patient (Georgiou & Robinson 1999). However, Georgiou and Robinson (1999, p.25) caution that some people have a distinct preference not to be involved in medical decisions, and suggest that requiring people to *'take responsibility when they already feel vulnerable may simply increase the burden'*. Therefore, they recommend that healthcare staff need to identify when and how best to engage people in making decisions, understand how people absorb and make sense of information in order to make decisions, develop measures to assess improved decision-making, identify under what circumstances it is useful to employ formal decision-making aids, and explore the socio-legal implications of shared decision-making. Georgiou and Robinson (1999) put these recommendations forward to the NHS to improve patient involvement in healthcare decisions. Furthermore, Primary Care Groups and Trusts were encouraged to consider the recommendations as part of their development programme.

In previous chapters, I have already argued that in order to understand how people with learning difficulties absorb and make sense of information, and which communication aids would be most helpful, then a dialogue of communication needs to be opened between healthcare professionals and those who know best how individual people with learning difficulties communicate. Furthermore, Beamer and Brookes (2001) argue that many people who have high support needs depend on others to recognise when they are making a choice.

MacKean et al. (1999) suggest that professional groups need to work in partnership and communicate with one another, in order to understand individual input into care and treatment. They give an example of how one young woman with learning difficulties spends a high proportion of her time moving between five medical specialists and having to repeat her medical history to each person in turn. Her carer questions why the specialists cannot have a meeting and collaboratively discuss her medical needs as a whole, and appoint one person to direct her treatment. This very scenario was one of the motivations for individual planning and care management, where collaborative development and partnerships with service users promoted PCP and person-centred action (Cambridge and Carnaby 2005).

Dalley (1993) suggests that professional collaboration may never be fully achieved, due to poor communication between professional groups, because of a lack of respect and trust for one another, and questions the nature and existence of partnerships within an inter-professional framework.

There appear to be many contradictions and questions as to whether partnerships can be achieved within the healthcare framework. Furthermore, if we take collaboration to mean a method of working then this too appears to be under question. Within the healthcare encounter, shared decision-making emphasises collaborative working and partnership building.

I now intend to look at what happens in practice. The next section will therefore examine how people with learning difficulties, and their carers, offer accounts of and make sense of decision-making. Out of thirty-one people interviewed in my study, four people gave 'positive' accounts that appeared to exhibit favourable outcomes. I chose examples from a variety of contexts. I deliberately chose the examples to avoid repetition with the other chapters. Some examples exhibit a worst case scenario. I chose the worst case scenarios because I felt that when something went wrong, it went spectacularly wrong, and spiralled out of control, until a major crisis occurred, which in itself challenged fundamentally any notions of 'partnership' and 'collaboration'.

### **7.3 Hospital partnerships and collaboration**

This is an account of Rosemary's original story, as told by the manager of the home where she had lived, retold by the interviewer (myself). I chose the story because it is a worst-case scenario, where lack of 'partnership' and 'collaboration' meant that basic care and treatment were overlooked. I have analysed this healthcare situation in relation to Carnwell and Carson's (2005) six vital elements for partnership:

- Trust in partners
- Respect for partners
- Joint working
- Teamwork
- Eliminating boundaries
- Being an ally

I have also examined Scott and Thurston's (2004) claim that professionals are 'locked' into a system of bureaucratic practices that prevents partnership building.

## Rosemary

Rosemary has severe communication difficulties and cannot verbally discuss her difficulties. However, she can indicate when she is in pain, what she likes and dislikes and communicate adequately with the people who have known and cared for her for the past ten years. Rosemary is extremely vulnerable. Rosemary is a middle-aged woman, with no living relatives. In addition to her learning difficulty, she has mental health problems, coupled with communication difficulties, but the care staff in her home had known her for ten years and could interpret her requests and behaviour fairly accurately. They had managed to stabilise her mental health problems by the careful monitoring of her behaviour against the dosage of medication. The care staff observed and monitored Rosemary, discovered what she liked and did not like, what she could do for herself, what upset her and whose company she enjoyed. As a result, Rosemary had become easier to interact with, and more expressive. Rosemary had a support system that respected her and that could ascertain her needs.

One particular weekend the care staff became concerned about her state of health and knew instinctively that there was a problem. They took her to Brancaster Infirmary where a doctor examined her. The care staff explained that they were concerned about her and knew she was in pain because of her behaviour, but because of her lack of articulation they could not identify the source of the pain. After a cursory examination, the doctor could not find anything wrong and they were sent back home. Twenty-four hours later, the care staff were increasingly concerned as Rosemary was in obvious distress. They therefore returned to the hospital. The same doctor saw them, became exasperated, told the

care staff that they were imagining things, and sent them home again. The doctor warned them that they would not be seen if they returned.

By Monday, Rosemary's situation had deteriorated further. The manager of the home (**the person who told me this story**) decided to take her to hospital and insist on an admission. She managed to get Rosemary admitted to a bed in a side ward. On Tuesday evening, the ward nurse told the home manager that the medical team could find nothing wrong with Rosemary and she would be discharged the next day. The home manager decided to give Rosemary a bed bath to 'freshen her up' because the nursing staff and auxiliaries did not have time to help Rosemary with her self-care. When the home manager rolled back the sheets, she discovered one leg was badly swollen and nearly black. The diagnosis was a suspected thrombosis. After alerting the doctor, the decision to perform emergency surgery took Rosemary into the operating theatre. That night, Rosemary had her leg amputated.

From this point onwards, the story becomes fraught with difficulties. Rosemary did not understand where her leg had gone. A prosthetic replacement was not possible. Altering her medication dosage for the operation destabilised her mental health, and the hospital staff would not listen to the home manager regarding altering the dosage. Rosemary regressed. Her home was no longer suitable for someone with a physical disability, and could not be adapted. She lost her home. Overnight, the people who had cared for her, understood her, and supported her, over the past ten years, were no longer available. She lost her support system. The hospital staff, finding themselves

unable to communicate with her to ascertain her needs, labelled her as 'difficult'. She lost the respect and unconditional positive regard that the care staff had provided.

Two weeks later, after many fruitless discussions concerning Rosemary's mental health, the home manager called on her daily visit, to find no Rosemary. Rosemary had been moved, in her nightclothes, at 10pm the previous night to another hospital forty-five miles away. The staff, and the home manager, were neither consulted, nor informed about her move. They could no longer visit her because of the distance involved. Rosemary regressed into a catatonic state.

Rosemary had received continuity of care from the learning disability team, and her immediate carers, over the ten years they had been in contact with her. There had been a useful bank of knowledge developed over the years concerning her medical history, behaviour, likes and dislikes, abilities, and style of communication. They admitted that they did not always get things right, but were constantly learning about Rosemary.

Two very distinct professional groups were therefore involved in Rosemary's 'care' and 'treatment', each with their own way of working. Each group used different discourses to inform their daily practice. The hospital group appeared to use one type of knowledge, case knowledge, informed by medical discourses, to inform its daily practice. The learning disability team and carers used three types of knowledge; case knowledge, informed by medical discourse, coupled with an in depth knowledge of working with people with learning difficulties, and a unique, more intimate, knowledge of the person gained exclusively from daily interactions with Rosemary herself, and built over time. When a larger group became involved with the established group, collaborative work in partnership faltered. This was partly because case knowledge and the discourse of medicine, took precedence over knowledge of people with learning difficulties, and unique knowledge of

Rosemary as a person, on her admission to hospital. The prevailing dominance of case knowledge was in direct conflict with knowledge of Rosemary as a person. It appears that areas that do not require medical knowledge, in some situations, are of less concern and therefore on the periphery of the management of vulnerable individuals than at the centre of their care.

#### **7.4 Dental services, partnership and collaboration.**

I built the following narrative from two one-hour interviews with Seamus. The interviews were not particularly difficult because Seamus is extremely articulate. However, he has had negative experiences in previous residential homes, which affect how he interacts with people. For example, previous care staff actively discouraged him from asking questions in his healthcare encounters, demanding that he left it to the carers to talk for him. His present home actively encourages him to ask questions, and to challenge situations that cause him discomfort. The transcript for the interviews is in appendix iv. I chose to represent his experiences because he had very little healthcare intervention, apart from routine visits to the doctor and dentist. There is nothing remarkable about the narrative, but it does highlight the variation in his interactions with different healthcare professionals. I feel that at this stage, I need to point out that the greatest number of problems appeared to originate from people's experiences with the dental services. Perhaps there are more stories from this area, because it is one that most people encounter regularly, and therefore springs to mind more readily. Another contributory factor could be my own previous experience and insight gained from working in this environment, with people with learning difficulties, and people with physical impairments.

#### **Seamus**

Seamus is a timid young man, in his thirties, who has lived in many homes in the Brancaster area. He moved

from St. Francis' when the closure took place. He has a mother, father and brothers, whom he misses, and who visit him infrequently. He says that he wants to visit his parents but they discourage him because of what the neighbours may think. His healthcare encounters have mostly been routine with no major operations, or healthcare interventions. His latest home had supported him in finding a new dentist because the community dental service had left his teeth to crumble and decay.

Previously, the community dental service had seen him at six monthly intervals. Seamus did not believe his old dentist wanted to help, and he did not have a choice about whether to receive treatment. He moved, with the support of his carers, to the general dental service. His carers recommended whom he should go and see, because they had experienced favourable outcomes from a particular general dental practitioner in the area. Seamus sees a difference with the new dentist, because he is treated as an individual. The dentist listens to him, explains what is needed, gives him a choice, and involves him in the treatment process. He has undergone almost total mouth reconstruction and now knows how to care for his mouth.

One of the issues of working in partnership with people is the ethical obligation on professionals to maintain competence in their area of expertise (Allison 2005). Allison argues that this is part of the patient-professional relationship, and should a professional lack expertise they should refer to the appropriate person.

A community dental surgeon made the following statement:

*“...really we are required to do everything, but we’ve each got our individual niche and I’m very deskilled at Prosthetics (provision of crown and bridgework and dentures) because its ages since I’ve done it...”*

However, a general dental practitioner had a different view:

*“The community dental services are ideally set up to attend to the needs of people with learning difficulties, but unfortunately many have allowed themselves to become deskilled because of their self-imposed restrictions in treatment planning. For example, only choosing what they feel happy doing and avoiding crown and bridgework, so they are in a catch 22 situation.”*

People with learning difficulties recognise there are restrictions on their choices, but are unsure as to how to progress. They are unaware they could insist on alternative treatment options from other areas. My own previous experiences in the dental field may help shed some light here. Whilst working as a dental nurse in community, general practice, general and dental hospitals, I have encountered three forms of action on the part of dentists. One is to do nothing and ‘sit’ on the patient until the problem becomes unmanageable and crisis intervention is needed. A second option is by means of a referral to a specialist who carries out the treatment. Thirdly, a specialist provides a treatment plan and refers the patient back to their own practitioner for supervised treatment. The last two are examples of partnership and collaborative working within the dental services.

However, out of thirty-one people with learning difficulties that I interviewed, twenty expressed negative dental experiences. These negative experiences mainly focused around dental surgeons failing to work collaboratively and access specialist help when they were deskilled. Additionally, many people were not consulted about their treatment.

### Austin

Austin was used to attending six-monthly, having fillings and extractions but never offered alternatives, or knowing why he was having treatment. There appeared to be a lack of communication skills, or an absence of explanation about treatment.

### Kieran

One example of the community dental surgeon failing to act collaboratively and in partnership comes from Kieran, a young man in his thirties with one-half of his upper dentition missing. This is from the front incisor (1) on one side, to the first molar (6) which is present. The following number line may give a better idea: \* indicates missing, / indicates the midline between the front teeth: \*\*6\*\*\*\* / 1234567\*. Kieran wanted false teeth because of the big gap at the front of his mouth. He felt embarrassed because people called him names and the gap was obvious when he laughed. He went to see the community dentist about filling the gap. He was told that it might not be possible to make a denture but no reason was given as to why. He attends every six months and has had the gap for two years. To date, nothing has been done to fill the gap.

Sam, Haydn, Callum, Paul, Irene, Susan, Liam, Roger, Derek, Gordon and Arthur have all had similar experiences to Kieran, and have missing teeth. Some people are edentulous (toothless, and with no dentures), which makes their speech difficult to understand. Perhaps coincidentally they all use the community dental services.

### Haydn

Haydn wears a denture but has missing teeth at the front of his mouth, which he tries to cover up by talking down to his feet. Haydn also takes a little while to process information, and there can be up to a five-minute delay in his reply to a question. In a situation requiring interaction through conversation and facial expressions, it is easy to presume he is either not interested or not capable of responding. The solution to his habit of talking to his feet to hide the gap would be to add the missing front teeth to his existing denture, coupled with encouragement to maintain facial contact when conversing. Haydn has simply never had the choice.

### Paul

Paul had all his teeth removed as a twenty-first birthday present, and dentures fitted. He has not been offered new dentures, and is now in his sixties, cannot wear the original dentures, lisps terribly and is difficult to understand. His facial muscles have shrunk and he is over-closed, resembling someone at a 'gurning' competition. With these complications, denture provision is extremely difficult, if not impossible.

### Gordon

Gordon's dentures do not fit and 'skate' freely around his mouth as he tries to talk. He has had to alter his diet to accommodate his inability to chew. He is in his late sixties, at a stage when nutrition becomes even more important, but his diet is deficient because there are some foods he cannot chew.

Elisabeth, Mary, Austin, Bernice, William, Sandy, and Nigel have all experienced treatment with the community dental services and general dental practitioners, but each person gives examples of a lack of partnership and choice.

### Elisabeth

Elisabeth wanted a tooth removing because she was in pain. The general dentist sent her to the hygienist to have her teeth cleaned first. She never returned and went to someone who carried out her wishes.

### Mary

Mary wears a full upper denture. She had all her upper teeth removed in her early twenties and is now in her fifties. She is still wearing the same poorly fitting denture. She attends the community dental services.

### William

William attends the general dentist regularly. He is told what treatment is required, and appointments are made for him to attend. Like Austin, he does not know why he needs the treatment, nor is he given a choice as to whether he wants the treatment.

### Bernice

Bernice's (general) dentist has failed to build any kind of relationship with her, preferring to communicate with the staff. This is despite the fact that Bernice can talk and make herself

understood. After seeing the same dentist for three years, Bernice is still terrified of attending. She is physically impaired and admits that she feels vulnerable when lying down. One solution would be to treat her sitting up, giving her more control over her environment. The dentist has paid little attention to the causes of her anxiety.

All these people have access to care, but having access to care is obviously not the same thing as having access to high quality care.

### **7.5 Epilepsy services: collaboration and partnership**

I chose the next story about Sam because he lived alone in the community with no carer to support him. Sam is highly articulate, easy to interview, but we met in a café. This precluded taping the three interviews. Because of the noise levels and because I did not wish to draw too much attention to Sam whilst he told me his story, I merely jotted notes down as he spoke and clarified that I had understood. Sam read the transcript through with a trusted friend, and called me to alter parts that he felt needed more emphasis.

#### **Sam**

Sam experiences frequent difficulties with his epilepsy. It is uncontrolled and his medication is inadequate. Sam makes regular visits to the Accident and Emergency Department when he has seizures because they frighten him. One particular staff nurse terrifies him, and he has asked for another nurse to be present whilst he was being seen. His request was refused, because he was told nobody else was available. Sam would like more information regarding his epilepsy. He tried to speak to the nurses at the hospital but said; *"You don't get much chance to talk to people at the hospital, everyone is so busy"*. The epilepsy information

he sent for did not arrive and other information has been difficult to understand. He tried to talk to his doctor, but his doctor does not listen, and shouts at him whenever he attends. Shouting upsets Sam and it impairs his ability to think and put a coherent sentence together. He feels paralysed when he visits his doctor. His doctor has not referred him to the epilepsy liaison services. Sam does not know why.

Sam thinks that people with learning difficulties are treated as if they do not exist, and that services for people with epilepsy and learning difficulties, especially people with communication difficulties, could do with being more user-friendly. He thinks that, in many cases, pictures and diagrams would help as these could be used when the practitioner was talking to the person. Instead, he says that people with learning difficulties have to ask other people to explain things to them, when really he feels that it is up to the person performing the treatment to explain what they are doing properly.

Within Brancaster Trust, there is a health education programme for people with learning difficulties, but it is mainly for people who live in the Trust homes. I discuss the service and its problems in a little more depth in the next chapter. The programme educates people about health issues such as epilepsy, but many of the people who attend have carers who assist with health needs. For someone like Sam, isolation, fear, and frustration becomes part of his daily existence. He has little choice and support in how he lives on a daily basis. Where does collaboration and partnership appear for Sam?

I discussed Sam's case (without using his name), with a consultant psychiatrist, who was of the opinion that GPs do not refer out to epilepsy liaison and psychiatry services because they are inadequately trained and do not have the experience of dealing with people with learning difficulties.

The deeper issue here is that if medical practitioners are inadequately trained and lacking experience in treating people with learning difficulties but still not gaining specialist help, then they obviously are not recognising their limitations. An alternative explanation is that their reluctance to concede personal lack of competence prevents them from accessing specialist help. Allison (2005, p.47) argues that recognising one's limitations is an essential part of a professional developing self-awareness and of determining their own level of competence. Furthermore, she suggests that recognising limitations is the mechanism for developing sufficient confidence to recognise when specialist intervention is required. The consequences of developing this type of confidence means that it makes it more possible to work more closely in inter-professional groups without feeling insecure and 'losing face'.

#### **7.6 Physiotherapy, Collaboration and Partnership**

In Brancaster, physiotherapy, especially for people with learning difficulties, is an area that struggles with staffing levels. Edward is an example of someone who needed more physiotherapy, but his carers appeared to be 'gate keeping' his access. I interviewed Edward in his home on four separate occasions, two without his carers present. Edward preferred that I took notes as he was talking; he did not want his voice taped. He gave a very definite account of the physiotherapy services.

#### **Edward**

Edward is a highly articulate gentleman. He possesses immaculate dress sense, has a keen sense of humour, and loves music. He was admitted to a long stay hospital in his late teens, because he had epilepsy and mild cerebral palsy. His mother fell ill at the same time and was unable to care for him at home. However, he did go home for weekends. His mother subsequently died and his father remarried. His home visits were stopped.

Later, his father died and he lost contact with his siblings. This contact was partly re-established when he reluctantly moved homes, because of his hip operations and reduced mobility.

Edward was upset to move home because he liked the people he lived with and had a good relationship with the staff. The staff supported him in making choices and decisions. I was present in his new home, when he asked one of his carers for a physiotherapist to help him with his mobility. There was a disinterested and preoccupied reply from the carer; a précis of the reply was *'oh...we'll have to look into that'*. Months later, the physiotherapist had not been contacted, and Edward had given up asking.

This method of dealing with Edward's request was not an outright rejection, it simply disregarded what he felt was important. Moreover, there was no further discussion about the matter. The nursing and care staff obviously did not feel that his hip was a priority, but did not take the trouble to explain why.

However, discussions with the nursing and care staff in other homes gave me a different insight. The discussions revealed that many members of staff were confused as to how to access some specialist services, and there appeared to be different procedures for accessing services, depending on the type of funding each home received. Physiotherapy was one service directly accessed, by means of a telephone call, for some homes, whilst for other homes referral was through the GP, or through social services. Edward's new home needed a referral for him through the GP. Perhaps this was another reason for staff reluctance to pursue Edward's request.

## **7.7 Audiology: collaboration and partnership**

Arthur's story is similar to Edward's story. However, instead of his hip, his hearing is under question. I interviewed Arthur on two different occasions, and read back his story to him. Arthur agreed with his story. I have included it because he lives in the same home as Edward, and I gained further insight into the attitude of care staff towards the people who lived under their care.

### **Arthur**

Arthur has lived in community homes since his thirties, when his parents died. He is now seventy. He has had progressively deteriorating hearing for a number of years, and complained to care staff on many occasions about being unable to hear the television. He found this upsetting. Eventually, a change of staff brought a learning disability nurse who listened, and arranged for Arthur to visit the GP for a referral to the audiology department at the local hospital. When I first visited Arthur, he was excitedly waiting for his hearing aid to be made and fitted. A month later, he had his hearing aid fitted and was becoming accustomed to wearing it. He then moved to another home. By chance, I visited the home and met Arthur. He remembered me, but I noticed that he was not wearing his hearing aid. I asked a staff member why. They replied that it was a nuisance and Arthur kept trying to take it out.

Prasher and Janicki (2002) draw attention to the difficulties of people with learning difficulties wearing hearing aids. They propose that care staff need special training to support and encourage a person with learning difficulties who has had a hearing aid fitted. However, they argue that training alone is insufficient, and that other carer qualities need to be present for a successful outcome. These carer qualities are patience, a belief in the process of

encouraging and supporting the person to wear the hearing aid, and an appreciation that the end-results can help a person with learning difficulties achieve a better quality of life. Arthur had chosen to wear a hearing aid because he could not hear the television. The carers at his new home had decided that it was a nuisance, but had not ascertained why he kept taking the hearing aid out. The new carers had little knowledge of how to assist Arthur. Little support, or encouragement, was given to Arthur to persevere with wearing his hearing aid. In response, Arthur gave up.

### **7.8 Summary and conclusion**

The empirical evidence in this chapter indicates that there are some positive and creative examples of involving people with learning difficulties in their healthcare decision-making. However, these examples appear to be isolated and the majority of people interviewed experienced a top down approach (Callaghan and Wistow 2002) to healthcare. Professional knowledge was regarded as the most valuable information and involvement in decision-making was, in many cases, non-existent. This is in contrast to Charles et al.'s (1999) proposed models of informed or shared decision-making that emphasises partnership and collaboration. Instead, what prevailed was mostly the paternalistic model, reliant very much on case knowledge. The elements for partnership that Carnwell and Carson (2005) argue as vital: trust in partners, respect for partners, joint working, teamwork, eliminating boundaries, and being an ally appear to be difficult, if not impossible, to achieve. Just because partnerships are formed does not necessarily mean that they are working effectively. Forming effective partnerships with people with learning difficulties would appear to take a great deal of vision, strength and persistence in order to develop the partnerships to their fullest, and in the process, overcome the many obstacles on the way.

The partnerships within this chapter do not involve the service users; there is little evidence of any service user's active participation on an equal basis. This lack of involvement is apparent in the cases of Rosemary, Austin, Kieran, Haydn, Paul, Gordon, Elisabeth, Mary, William, Bernice, Sam,

Arthur and Edward. Furthermore, there appears to be a lack of partnership between staff working in specialist learning difficulty and generic services, which may be more to do with interagency rather than interdisciplinary working. This lack of partnership leaves carers unsupported when attempting to support people with learning difficulties with the healthcare process.

What my study adds is that some care staff can also exclude people with learning difficulties from involvement in their healthcare because of structural influences and a lack of awareness about what is important to the people for whom they have a duty of care. For example, access to some services appears to create procedures that do not directly address the need of the person. Additionally, for some care staff, there appears to be a lack of awareness of the need for specialist help and a lack of knowledge of how to assist in supporting people with the healthcare process. This is in contrast to the suggested guidance in *Valuing People* (DOH 2001b, p. 68) for interagency working with a focus on the '*whole person*' demonstrating that agencies are '*listening carefully to the views and experiences of people with learning disabilities*'. Listening carefully is however not enough. Knowing how to act on the views and experiences of people with learning difficulties, and supporting them appears to be a complex process. Support and training appears necessary for professionals, care staff, family members, and others involved in the decision-making process in order to support people with learning difficulties with their healthcare.

Another worrying factor is that some medical practitioners fail to access specialist help and intervention, thereby failing to work in partnership with one another, the care staff, and the person at the centre of the treatment. On the surface, groups appear to be working collaboratively, fulfilling their legal and ethical requirements, but not actually operating in partnership. This benefits the services, but not the service users.

Within this chapter, I have identified that for some people with learning difficulties the support and involvement of staff carers is essential. Therefore, in chapter 8, I propose to compare the views of carers and

professionals with the experiences of people with learning difficulties in the healthcare decision-making process. These views and experiences centre on the construction of competence, or how people with learning difficulties are supported to acquire competence-promoting behaviour in relation to their own healthcare.

## Chapter 8

### Narratives of Competence: Support, Choices, and Decision-making

#### 8.1 Scope

In the previous chapter, I argued that decision-making was a process and part of working ‘collaboratively’ and ‘in partnership’. My empirical evidence suggested that some professionals and carers lacked the support and training to facilitate the decision-making process. Consequently, there was little evidence of working ‘collaboratively’ and ‘in partnership’ with people with learning difficulties. Therefore, the first aim of this chapter is to extend the examination of the decision-making process and explore whether there is a difference between specialist learning disability services and mainstream health services as contexts for decision-making. Firstly, I intend to look at the social model of disability, and its assumptions relating to disability, and question whether we can use these assumptions for people with learning difficulties when making healthcare decisions.

In order to examine the social model of disability in relation to decision-making, I intend to represent the experiences of people with learning difficulties within the healthcare encounter. Decision-making does not occur in a vacuum and people with profound learning difficulties are often reliant on a third party to make their views known (Keywood et al. 1999). However, Keywood (2003) forces a different issue in relation to staff carers in that they can experience overlapping and conflicting roles, which place a burden on the carer. I consider staff conflicting roles more carefully in the next chapter. In this chapter, I argue that there is significance attached to issues concerning roles, and additionally how constructions of competence within healthcare services affect choice and decision-making.

## 8.2 The social model of disability

***“A key principle of the law is that every adult has the right to make their own decisions and is assumed to have the capacity to do so unless it is proved otherwise. Some people may need help or support to be able to understand the decision...to make a choice or to be able to communicate...the need for help or support does not remove their right to make their own decisions” (DCA 2003a, p.2)***

This statement from the Department of Constitutional Affairs follows the social model of disability. The perspective that the social model of disability advocates is that society creates disablement and reproduces pathological understandings of disability. Therefore, social barriers rather than individual impairment create disability.

For example, it is well documented that people with learning difficulties have some form of communication disorder (Beange 1996, Lennox & Kerr 1997, van der Gaag 1998, Mansell et al. 2002, Bigby 2004). Furthermore, there is evidence to suggest that people with learning difficulties underutilise their communication skills if the context does not provide adequate and appropriate opportunities for communicating (Bradshaw 1998, van der Gaag 1989; 1998). If we apply this to people with learning difficulties in relation to decision-making, we could argue that decision-making would be difficult to achieve because of their poor communication skills or because of lack of opportunities for decision-making (Lloyd et al 1996, Bigby 2004).

Alternatively, borrowing from the social model of disability, we could suggest that it is civil society that displays incompetence in lacking the requisite communication skills to interact meaningfully with people with learning difficulties. Within a healthcare situation, this translates in two ways:

1. Healthcare service staff display incompetence in lacking the requisite communication skills to meaningfully interact with people with

learning difficulties, thereby reducing their opportunities for decision-making.

2. Healthcare service staff display competence and possess or employ the requisite communication skills to ensure meaningful interaction with people with learning difficulties, thereby enhancing their opportunities for decision-making.

The Department for Constitutional Affairs suggests that some people with learning difficulties may need support with their choices and decisions. Needing support with choices and decisions may mean an explanation about the consequences or outcomes of a particular choice or decision. Support may mean increasing the existing knowledge of a person to facilitate a choice or decision, thereby enabling that person to function in context. However, types of support can vary from individual to individual, and with patient professional partnerships in the ascendancy, then the focus is on how people are supported in making choices and decisions.

Supporting people with learning difficulties to make choices and decisions, because of their lack of 'capacity' to function in context, or those unable to clearly articulate their needs and preferences, suggests competence is axiomatic because the presumption of competence is not extended, and people must strive to be seen as competent (Jenkins 1998, p.1).

### 8.3 Markers of competence

#### 8.3.1 Jargon and competence

Herb Lovett (1996, p.47) argues that the '*use of language and labels has a powerful effect on people's lives.*' He suggests that professionals have a tendency to use jargon because it expresses professional needs and concerns. Jargon assumes that the person you are addressing has the same knowledge background. '*It is easiest to communicate with people most like ourselves*' (Hogg, 1999, p.24). This use of jargon sets a particular group of people

apart; it renders them different from others unable to access the meaning system, creating a hierarchy of knowledge. This hierarchy of knowledge allows people to understand reality in different ways. Each person understands reality differently because of the function of language in its social structure; the language each person has access to '*depends on their position in the social system*' (Fairclough 1995 p 26).

Lovett finds it useful to leave the jargon of his work as a psychologist behind and is often surprised as to how much he can learn about a person by using plain English, and asking what particular jargonised terms mean to others in context. Jargon appears to draw people deeper into the very system they may be resisting, whereas using plain English can lead back to the person.

The following comment came from a community dental surgeon (CDS) who was running a disability awareness course for general dental practitioners (GDP).

CDS: *"One GDP said I am willing (to do treatment) but the difficulty is we don't understand them (people with learning difficulties) and they don't understand us...emm, our literature, the way we use jargon, none of it is geared up towards someone with a learning difficulty. We do use a lot of jargon within our general practice and the idea that you would have to constantly repeat or explain something in a way that the person would understand..."*

There are assumptions made relating to a person's deficits. The main barrier here appears to be the attitude of the professional towards people with learning difficulties. The dentist acknowledges the continuing use of jargon in everyday practice, coupled with what sounds like irritation at having to constantly repeat or explain an aspect of treatment to a person with learning difficulties. However, the dentist makes a symbolic comment that I have underlined, but I would also argue how many people *without* a learning difficulty could understand dental terminology? This question is reinforced

by comments made by four different staff concerning treatment with hospital consultants and dental practitioners.

Staff member 1: *“Sometimes we don’t understand what the consultant has said and he leaves us to explain treatment to the residents”.*

Staff member 2: *“The dentist presumes that because we have a general nursing qualification we will automatically understand dental procedures and terminology”.*

Staff member 3: *“Sometimes we just don’t have the knowledge to assist people with making the right decision”.*

Staff member 4: *“It takes a while for us to understand the consultant, and sometimes we end up asking someone else to explain before we can explain to our residents”.*

Leaving staff to explain is one way of ensuring a person understands, but it assumes that staff are competent and understands the medical terminology employed. In many circumstances, this lack of competence and understanding may become a barrier to treatment. Furthermore, in the first comment, the staff member appears to be unwilling to question or clarify what the consultant has said. The next two comments came from people with learning difficulties who expressed problems with understanding professionals in the healthcare decision-making process.

Edward: *“It would help if they had pictures, a video, or just see more to explain what they are talking about...but they are so busy”.* (At the hospital)

Sam: *“There are no pictures or diagrams that explain at the doctor’s, dentist, or hospital. People with learning difficulties have to ask other people to explain...communication is a problem...People with learning difficulties are treated as if they do not exist. We could do with services for people with epilepsy and learning difficulties, and especially for those with communication difficulties being more user friendly...”*

Sam suggests that the health services are not ‘user friendly’; they are constructed to treat people, but not to be used by them. Sam explained that when people with learning difficulties attend for treatment they are told what treatment to expect and are rarely involved in the decisions. Sam thought that if a service was to be used then the person using the service should be included in the process of decision-making that concerned their lives. One of the consultant psychiatrists suggested a problem that may account for the lack of involvement for some people with learning difficulties.

Consultant Psychiatrist 2: *“People with learning disabilities cannot understand the reasoning as to why they need to take the medication”.*

This consultant is employing a deficit model for people with learning difficulties. Morris (1996, p.177) suggests that doctors have a tendency to focus on functional impairment, making assumptions about competence with little reference to environmental and other barriers that may be important. However, this particular consultant specialises in treating people with learning difficulties, and ascertains that the biggest problem is communicating effectively, and reaching understanding with many people with learning difficulties. I returned to my data from professionals and carers and found a statement from the community dental surgeon and a contrasting statement from a learning disability nurse who had worked with people with learning difficulties for over twenty years.

CDS: *“...things are being produced, various CDS produce things locally, there is a booklet about going to the dentist produced for people with learning difficulties. There is a Makaton book about people with learning difficulties with Makaton signs for dentistry...It’s all very ad hoc...nothing specific...in our own service a lot of leaflets are not accessible for people with learning difficulties, they’re not pictorial, we’ve looked at making videos...we are looking at some of the language we use on the information we give out...”*

L.D.Nurse 3: *“It’s alright using drawn pictures to explain, but a lot of my residents wouldn’t recognise a drawn picture of... let’s say a car, but they would recognise a photograph of a car. I’ve told them this when we go for eye tests, but they just do not listen. Sometimes it’s how the information is presented that causes the communication difficulty. Then they think the person doesn’t understand, or lacks competence. We tend to think a picture means the same thing to everyone, but it doesn’t.”*

There is contrasting information regarding medical jargon. The dental services are aware they have a communication problem and that their use of jargon is fuelling the problem. However, they appear to be at a loss as to how to proceed. The Norah Fry Research Centre (2004) has just issued guidance for researchers and anyone seeking to elicit and provide information from and for people with learning difficulties. The aim of the guidance is to enable them to make their information easier for people with learning difficulties to understand. Nevertheless, they propose that *‘there is no one accessible way of giving and receiving information that will suit everyone. This is particularly true for people who have high individual communication needs’* (Norah Fry Research Centre 2004, p.4). Furthermore, they point to the fact that people with high individual communication needs

do not necessarily share a common system of communication, and are therefore reliant on people who know them well to interpret their wants and needs.

This returns to getting to know the patient as a person, sometimes with the help of the people who know them the best. It also means that there has to be a greater diversity in the way information is presented to facilitate any encounter. Logically, it follows that there also needs to be greater resources to enable services to provide, and individually tailor, information.

During one of my visits to the homes, it became clear that services were making sweeping assumptions about how people with learning disabilities communicate. To take one example: I asked Edward about the latest newssheet from an advocacy group run by Brancaster Trust because it was written in Makaton, a language with which I have no expertise. He replied that he did not know about it because he did not understand Makaton. Nobody he lived with understood it either. When I asked how he obtained his information, he told me it was by word of mouth from the self-advocacy groups he attended.

In contrast, one home consisted of people who used Makaton exclusively, and the nursing staff had devised a labelling system for household substances so that the residents could use them safely. The system was well thought out and promoted inclusion for the residents for this particular home. There was also a proposal to use the labelling system throughout the Trust homes, but I wondered how this would benefit Edward and his colleagues. It appeared that employing standardised packages in all homes heralded returning to treating people as a category, not treating people as individuals, and concentrating on deficits rather than abilities.

In this study, both people with learning difficulties and their carers displayed dissatisfaction with the way that medical knowledge is communicated to them. One learning disability nurse highlighted that there can be problems with assumptions concerning pictorial representations. Again, within the

Norah Fry website there is guidance on signs, symbols, pictures and photographs. The guidance highlights that some people will not recognise a symbol, others will not recognise a drawing, some people will recognise a photograph, and some people will respond to black and white. There is also a section indicating that people will interpret a sign, symbol, picture, or photograph differently. This can be because of previous experiences, socialisation, or ways of relating to their environment. This links back to knowing the patient as a person and understanding their preferred medium of communication.

The diverse approach that the Norah Fry Research Centre advocates appears to work well for making information more accessible, but how this approach works in translating ideas is yet to be explored (Walmsley 2001, p.202). For example, if we think about the symbols used in hieroglyphics, these symbols do not make a language, they are merely ideas. Working with symbols is merely working with ideas, not language. Hieroglyphics is therefore the silent representation of ideas, open to interpretation by people who do not have access to their original meaning.

### 9.3.2 Articulation and competence

Edgerton (1967) noted that the physical appearance of most people with learning difficulties in his study was not distinctive, and that they were able to move through most public places without '*revealing any tell-tale signs of their stigma*' (p.215). He argues that this situation alters radically when they encounter others in a face-to-face interaction. The person without the learning difficulty then apparently alters their interactions, reducing them down to a less complex level, to the extent that cessation virtually occurs. Verbal skill deficits for Edgerton mark the absence of intellectual proficiency. Furthermore, it appears that intellectual proficiency and social proficiency are linked inextricably.

Williams (1992, p.182) asserts that for language to have any meaning one must be able to relate to it. Williams is autistic and, for her, when the

directness of relating is too great, erecting a barrier is a coping mechanism. Her impairment means that Williams has to find a way of coping with her environment. This places the barrier not outside in society but within the person, but additionally her impairment is actually a product of 'agency-environment' fit. This is important when looking at how people with learning difficulties 'fit' their environment.

The next two comments came from an advocacy worker and learning disability nurse supporting two people, Sam and Elisabeth.

Advocacy worker: *“People think he is more competent than he is because he is so articulate. People tend to think being articulate and having competence is the same thing. They don't think he is vulnerable and needs support with doing everyday things that we take for granted.”*

L.D. Nurse 5: *“People make the mistake of thinking she is more competent than she is because of her level of articulation. In reality, she needs a lot of support.”*

Sam was experiencing profound difficulties with his social worker at the time of my first interview with him. He lives independently in the community. I sent him the narrative I had written and he contacted me to alter some parts of it. He had also discussed the narrative with an advocacy worker who became concerned by his story. It appeared that committing his story to paper had allowed him to discuss matters that had been troubling him, and with which he was uncertain how to proceed.

The advocacy worker supported him at his next meeting with his social worker, ensuring that he had a voice in the meeting, and prioritising his needs. The outcome was a proposed change of residence to somewhere he was more independent, where he had his own front door key. Another

change was an agreement not to allow other people into the meetings, and not to discuss his medical history, without Sam's prior consent and involvement. One final change was the release of money his parents had left him, with independent support on how to manage the money. Sam now wants one more thing, help with understanding and taking control of his general health. He wishes there was a worker at the hospital he attends who could facilitate his interactions with the medical staff.

Elisabeth has had two children removed from her care. The first child was removed because Elisabeth was in hospital, struggling with a difficult second pregnancy and stroke. Her husband has learning difficulties and mental health problems. The social workers considered neither parent competent enough to look after the children; the house was unclean and standards of hygiene were poor. There was little practical support available to enable Elisabeth to keep her children. The courts saw adoption as the answer. Booth and Booth (1994) identify that much professional practice is guided

*'by the implicit belief that some minimum level of intellectual functioning is necessary for adequate parenting. As a result, children are removed from families not because they have received inadequate care but because their parents have learning difficulties' (p. 52).*

Furthermore, Booth and Booth argue that these same practitioners are usually specialists in child protection work, but have little or no experience in the learning disability field. Ten years after the research by Booth and Booth, and five years after policy guidance in the NHS Executive (DOH 1998, p. 11), there are still situations where people with learning difficulties are receiving inadequate support to effectively look after their children.

Elisabeth is very distressed about losing her children in this manner and is at pains to reinforce the fact that she did not sign the adoption papers. Elisabeth insists that the judge signed the papers because she was told she was not a 'good enough parent'. She expressed her thoughts that her solicitor was 'next to useless' because he did not defend her properly to help

her keep her children. Elisabeth questioned what they meant by 'good enough'. The whole process had caused her enormous distress, confusion and alienation. Being allowed to contact her children once a year causes even more distress. The adoptive family have changed the original name she chose for one of her children, which she cannot understand. Elisabeth says that even though her children are being brought up by other people nobody can say she is not their 'mammy'.

The consultant psychiatrist disapproved of her husband because he treated Elisabeth badly. He said the temptation was always there to have the marriage declared null and void because of her limited level of comprehension concerning what marriage involved, but questioned what good that would do her.

In writing policy and practice guidelines for Scotland on relationships when working with people with learning difficulties, Littlejohn et al. (2004) clearly state that people with learning disabilities have the same rights in law as anyone else to marry and live together. The only criteria are that the person is over 16 and has a general understanding of what it means to get married.

Women with learning difficulties share many life experiences with other women, a normal adult sexual relationship and perhaps marriage falls within most female expectations (McNamara and Hall 2004). Elisabeth had lived alone in a flat, since she was nineteen, paying the bills, the rent and feeding herself. When she was twenty-five, she met her present husband. He moved in with her and manipulated her financially. She became pregnant with her first child, and decided to get married '*because people call children bastards if their parents aren't wed*'. This statement shows a level of understanding concerning societal expectations and relationships.

Elisabeth is competent to live alone, pay the bills, and care for herself, competent to marry, competent to have children, but evidently not competent to look after them. Coupled with this is her high level of articulation, which apparently exceeds her levels of understanding, causing a '*cloak of*

*competence*' (Edgerton 1967) to mask her (in)competence. Articulation, or lack of it, appeared to promote a difference in the approaches of members of staff in the community homes towards people with learning difficulties. On contacting one home in the study area, I recorded the team leader's response:

***"Oh, you won't get much out of this lot, most of them cannot speak."***

Contrastingly, in another home, one resident, Anne, could not speak. Staff told me:

***"Anne cannot speak but she can understand and give her consent to treatment. Have a chat with her, she'd enjoy the interaction".***

I did have a 'chat' with Anne; it was difficult because I lacked the knowledge of how she communicated (I have described our interactions in detail in chapter 5). However, after a short period I began to feel more comfortable with staff initially assisting with interpreting what she was telling me. As I relaxed, the interaction became more fluid and it became easier to understand Anne. I interpreted what she was saying by going through a list of what I thought she meant. When I was right, Anne responded by vigorous arm patting and head nodding. The process was time consuming and tiring, requiring a great deal of concentration on my part, and a lot of encouragement from Anne, who must have felt frustrated by my initial attempts to understand her. Anne's healthcare interactions took place through staff who interpreted what Anne was saying for the medical practitioners she encountered. I thought about the differing approaches the staff used in the two homes; one advocated knowing the person, the other advocated treating people as a category.

It appears that the level of articulation is not the only predisposing factor in interactions with people with learning difficulties. One factor appears to be the perception of people without learning difficulties employing a deficit model of competence towards people with learning difficulties. We could argue that employing this deficit model of competence can restrict access to

information for people with learning difficulties. However, verbal articulation is not always a condition for levels of understanding, nor is it an indication of individual abilities.

This is demonstrated by Boazman (1999) who became aphasic (where linguistic, cognitive, and communication skills are lost in varying degrees) after a brain haemorrhage. Boazman documents her struggle to communicate, alongside fellow aphasia sufferers. The main outcome was the identification of the fixed ideas that some professionals demonstrate regarding disability and impairment. Killick and Allan (2001) provide further examples of fixed professional ideas regarding disability and impairment in their work on dementia where people possessed a greater understanding of their condition than previously thought.

In my study, some staff appear to be saying that it is misleading to presume that because a person possesses a high level of verbal articulation their levels of understanding and abilities are necessarily of equal status. One case, Nigel, contradicts this view. I constructed the following vignette from information that Nigel and staff gave me on four different visits to his home:

Nigel regularly visited the dentist and optician for routine appointments. He did not wear his prescription glasses because he felt he could manage without. He was convinced he did not need glasses. When he moved to a different home, he spoke to a staff member with whom he had built a trusting relationship. He explained that he felt he did not need glasses and could not understand why the optician kept prescribing new glasses for him. The staff member listened, then checked the other people, whom she knew had visited the same optician. Alarm bells rang when every person at the home, when checked, had the same eye prescription. A second opinion was sought; as it turned out, Nigel did not need glasses. The

optician had over prescribed for all people with learning difficulties attending.

This approach by the optician leaves us with two scenarios:

Scenario 1: the optician used a deficit model of competence, which in turn created a barrier that prevented him from getting to know the patient as a person. The person is merely a category. The outcome is to 'guess' and prescribe the same glasses prescription in relation to the category. In effect, what is being offered is a standardised service.

Scenario 2: the optician recognises that people with learning difficulties are a devalued and vulnerable group; he therefore deliberately over-prescribes. The person goes away with glasses, and because they are exempt from treatment charges, the optician charges the NHS, thereby recovering the money. If questioned he merely states that communication was difficult and he acted in the 'best interests' of the patient.

I propose scenario 2 because of my previous work experiences as a dental nurse involved in the assessment of legal cases where dental surgeons have over-prescribed treatment. The matter has only surfaced when the patient has requested a second opinion, or when the treatment has failed and the patient has 'lost faith' in the practitioner and sought help elsewhere. When a patient is vulnerable, believing the medical practitioner has specialised knowledge can be one condition for increased vulnerability. Under these circumstances most people would unquestioningly accept that the practitioner is acting in their best interests.

However, after interviewing Nigel, staff told me that:

***“He appears more competent than he is because he is so articulate, there’s a lot he cannot do.”***

Nigel had brought the attention of the staff to the fact that the optician was over-prescribing. Nigel does his own shopping, washing, ironing and cooking. He attends his medical appointments alone and negotiates treatment, although, regarding the optician, Nigel needed support and assistance to challenge his treatment. He has a full and varied social life, with many interests, especially sport. He travels alone on public transport to many sporting venues. However, staff perception aligned with a deficit model of competence towards Nigel.

In contrast, some staff with less specialised medical knowledge exhibit tacit compliance; they are almost deferential in their interactions with professionals. This mirrors the study by Keywood et al. (1999), where professional caregivers believed they were in danger of losing their job if they challenged specialist opinion. Alternatively, they were afraid of being negatively labelled as a trouble causer, or difficult, and consequently failed to challenge attitudes, or practices with which they were unhappy.

L.D.Nurse 3: ***‘I often wonder how the optician knows whether Sue, Tom, and Mikey need glasses. None of them are proficient communicators, none of them can read an eye chart, but when I’ve asked I’m told he has a special machine that can tell if they need glasses or not.’***

L.D. Nurse 6: ***‘We tend not to make a fuss if the consultant psychiatrist cannot make the appointment he has with us. We find if you don’t make a fuss you are viewed more favourably.’***

## **8.4 The relationship between support and constructions of competence**

In their study of parenting by people with learning difficulties, Booth and Booth (1994, chapter 5) highlight types of support that lead to assumptions of competence, namely competence promotion or competence inhibition.

Competence-promoting support allows the person with learning difficulties to remain in control, whilst simultaneously developing skills that enable them to cope in similar situations. These could be skills that are simple and taken for granted by the general population, for example making dental or doctors' appointment or, alternatively, asking questions concerning treatment, or describing symptoms, entering the treatment room alone in private and undertaking any treatment necessary, or developing healthcare behaviours that would aid individual wellbeing.

In contrast, Booth and Booth describe competence-inhibiting support as based on assumptions that the person with learning difficulties is incapable of managing on their own, making decisions and choices, and that intervention is necessary and in their 'best interests'. They propose that the second type of support is unresponsive to the needs of people with learning difficulties, and is demotivating and crisis-orientated. Furthermore, competence-inhibiting support undermines a person's self-worth and denies any opportunity to overcome problems alone, and make a choice or decision regarding healthcare and lifestyle. Using these two types of support as a guide to compare and view the data, a clear pattern emerged.

## **8.5 Competence inhibition**

### **8.5.1 A trip to the dentist**

The following narrative came from Callum and the field notes I made when I accompanied him to the dentist.

I was fortunate to accompany Callum on a trip to the dentist. Callum had lost his front teeth in a fight when he was younger. For many years, he had a chrome cobalt (metal) denture with the two missing teeth attached. He had broken this denture and attended the dentist to have it replaced (repair is impossible due to the tensile strength of the metal; any join weakens the structure).

Callum described the agony of having impressions, feeling as if he was going to choke, and his resulting embarrassment from vomiting over the dentist. The dental staff failed to reassure him and ease his embarrassment. He had a plastic replacement until the chrome was ready. The plastic denture was slightly too big and he found it bulky as he spoke, giving him a lisp.

When we arrived at the dentist Callum, his support worker and I sat and waited. We were called into the surgery as a group. I asked Callum and the dentist if they minded if I watched. Both seemed surprised to be asked, but both concurred with my request.

The dental nurse sat with her back to Callum, ignoring the whole procedure, making little effort to acknowledge his presence. There were no social niceties that I have come to expect when I attend the dentist - simple words like 'how are you', 'what have you done since I last saw you', 'has everything been alright in your mouth'? The dental surgeon merely removed Callum's plastic denture and tried the metal

framework in Callum's mouth. He muttered *that's why the other probably broke'*, telling Callum he would have to stick with the plastic one because a metal one would break again. The dentist turned towards me and told me that the treatment was now finished. Initially, I was bemused because I had not introduced my background (ex dental), or my relationship to Callum; merely asking if I could watch. I then decided to ask about other options. Apparently, there were no other options. I doggedly asked about bridgework, a spring cantilever, or a different design for the denture. There was no reply, merely a defence concerning what had already taken place (even though it was unsuccessful). I left with Callum and his carer, feeling a strong sense of dissatisfaction on Callum's behalf.

I knew the denture he had in was unsatisfactory, because originally it was meant as a temporary measure. Furthermore, I knew that there were other treatment options. Callum now had the temporary denture as a permanent measure. I asked how he felt. He said 'fine' because he did not have the gap at the front. However, a week later, he had time to think and he expressed dissatisfaction with his treatment. He told me the dentist was rubbish and did not know his job. Callum decided that he would just visit the dentist who had made him his first metal denture because he knew what he was doing.

Callum sat quite happily in the chair, not challenging the interactions taking place around him. I surmised that for Callum this was a typical experience.

An appointment in a week may have given Callum the chance to think and challenge the dental surgeon as to the suitability of the denture, and to explain that it fitted poorly. Instead, he had an inferior, poorly fitting piece of work in his mouth, causing him to lisp. His support worker had no dental knowledge and could not assist him in challenging or making any further decision than the one offered to him on the day.

### **8.5.2 Mainstream health service experiences**

The following case studies are from the experiences of people with learning difficulties when they encounter mainstream health services. I constructed the narratives from interviews and observations.

#### **Gordon in hospital**

Gordon has asthma. He is in his sixties and enjoys the occasional game of football. However, during his last game he fell over with a tight feeling in his chest and was very short of breath. An ambulance was called and he was taken to Brancaster Royal Infirmary, and admitted to accident and emergency with a suspected heart attack. Gordon is unaware of why he felt ill. His explanation is that it was probably his asthma. Whilst in A&E a nurse put a 'thing' on his arm and chest. There was no explanation that he was having his blood pressure taken nor that he was being wired up to a heart monitor. Furthermore, there was no explanation as to the possible causes of his pain. Gordon was objectified, he became a case to be diagnosed through the use of tests.

### Bernice at Accident and Emergency

Bernice lives in a community home. She too suffers from asthma but otherwise is in good health. Bernice hates Brancaster Royal Infirmary; she dislikes the waiting involved whenever she attends. Bernice told me about falling and cutting her arm at eight o'clock on a Saturday evening. The learning disability nurses took her to the hospital because the wound required stitches, and she needed a tetanus injection. Bernice said she had to wait four hours before she was seen, and there was a great deal of blood. The waiting made her more agitated because of the amount of blood and she thought she might not stop bleeding and die. The learning disability nurses explained what was happening and helped her by putting her mind at ease. Bernice eventually arrived back at her home at two o'clock on Sunday morning.

### Austin at the dentist

Austin is a 'gentle giant' who has attended mainstream health services for most of his life. However, his mother freely admits that different professionals treat him in different ways; some are kinder and more patient-centred. At the local dental practice, the dentist tells Austin what needs doing and then proceeds to carry out the treatment. There is no explanation. There was no explanation or intervention when he complained that he felt faint after a local anaesthetic. The receptionist merely told him to sit down. Austin never questions things because this is what he expects when he encounters health professionals.

### Sam and counselling services

Sam has undergone sessions with many counsellors. Some have helped, and some have made no impression on his life or his problems. Sam discussed one counsellor in a college who identified that he wanted to work and managed to give him a contact. He gained a few months part-time employment, and felt better about himself as a result. He credits the counsellor for listening and identifying what he was trying to express, mainly about his feelings of uselessness and isolation.

The next section contrasts mainstream and specialist learning disability services in relation to sexual health and contraception. It compares the narratives of Samantha and Elisabeth; Samantha is supported by the learning disability services and lives in a community home; Elisabeth has no support and lives independently in the community.

### **8.5.3 Mainstream and specialist learning disability services**

#### Family Planning Clinics/Sexual Health Education

In her work on women's health and sexuality, McCarthy (2001, pp. 221-222) notes that women with learning difficulties are usually offered three types of contraception; the Pill, Depo-Provera, and Intra-Uterine devices and it is no coincidence that the three methods commonly used require little or no active user participation. McCarthy argues that no/low maintenance methods of contraception assume that women with learning difficulties are *'incapable and unreliable when it comes to managing their own fertility.'* Furthermore, *'women with learning difficulties... are not given sufficient or appropriate information and support to make the choices themselves.'*

Samantha and Elisabeth were two of the women in this study; both were prescribed the contraceptive pill, and had little knowledge of its action, or

side-effects. Elisabeth attended mainstream health services, Samantha the learning disability services. At the initial consultation, for both women, other forms of contraception remained undiscussed. Samantha was not in a relationship that demanded frequent sexual contact. Samantha received support from her mother and the learning disability nurses to reach a decision regarding having a child as the result of a sexual relationship. Samantha decided she did not wish to have a child but wanted a sexual relationship.

In contrast, Elisabeth had no support. When she left home at the age of nineteen, her doctor, with no explanation as to why, placed her on the pill. After experiencing severe headaches, she stopped taking the pill and became pregnant. Elisabeth went on to suffer a stroke, later having an Intra-Uterine device fitted. She had no understanding of the mechanisms of implanting the device, reporting the pain, shock and humiliation of the procedure, possessed no knowledge of how the device worked, where it was situated in her body, how often it needed changing, and what to do if there was any change in her bodily functions.

In both cases, the partner of the woman was not included in the decisions regarding contraception. There was no information given on sexual pleasure, no sex education on the importance of mutuality and feelings, coupled with the ability to assert when they did not wish treating as a sexual object. In unquestioningly prescribing the contraceptive pill, the assumption is that the male partner shoulders no responsibility for the act. The difference in the two women's experiences is that Samantha received support in reaching her decision, although no choice in type of contraception, whereas Elisabeth was initially prescribed the pill by her doctor, with no understanding of why she needed to take it.

The next section looks at the services offered by specialist learning disability services and employs the experiences of people with learning difficulties, presented as case studies. This is supplemented by reports from professionals employed in the health services.

#### **8.5.4 Specialist learning disability services**

##### **At the counsellors**

Counselling services for people with learning difficulties are thinly structured (Wilson 2003, p.125). Wilson advocates that a counsellor for someone with learning difficulties should be neutral. Neutral means that the counsellor has no prior knowledge of the person and that there are no blurred boundaries. Blurred boundaries mean that the person has no knowledge of the counsellor in a previous role, for example in a nursing or managerial capacity. Furthermore, Wilson stresses that counsellors are trained to address the internal world of the individual, not the institutions and social system that surrounds them. This places a counsellor in an unusual position because they have to analyse the situation from more than one perspective; the counsellor's professional perspective and theoretical stance, the client's needs, and the system's support or resistance towards the client. Different types of knowledge again need to be synthesised before the counsellor can form a complete picture of the person:

##### **Anthony and counselling**

Anthony identified that his counsellor did not help him. He said the counsellor did not want to talk about his mother, but insisted he talk about things he did not want to discuss. He preferred his advocate who talked about his mother and took him to put flowers on her grave. He also preferred his GP who made time for him and reassured him that his mother's death was not Anthony's fault. Later discussions unearthed the fact that the counsellor was a nurse who had worked in the same home he lived in, employed by the Trust.

### Gordon at the chiropodist

Gordon, and many other people within the community health services, are visited by the community chiropodist. However, many people can cut their toenails unaided but feel they have to be visited by the chiropodist because that is just the way things are done when they live in a community home.

### Mary and the continence services

The continence services are not learning disability specialist services but Mary accessed these services through the learning disability nurses. Mary received support from the learning disability nurse regarding her urinary incontinence and a referral to the necessary services. Mary will not go to her doctor because he is a man. Accessing the services through the learning disability team was easier for Mary. After attending the continence clinics, the learning disability nurse would explain and reinforce what Mary had been told, and help her with the exercises. Mary's incontinence is now cured.

### **8.5.5 Specialist Psychiatry Services**

In this study, consultant psychiatrists report that treating people with learning difficulties is something that they appear to 'pick up' along the way. One consultant takes responsibility for the majority of people with learning difficulties, alongside the mainstream population list (approximately 350 people), and another consultant is encouraged to 'help out'. Both the psychiatry and psychology services are limited by the poor staffing levels and one of the consultants says they are not making any progress; they are merely 'fire-fighting'. This means that a large percentage of treatment is crisis-oriented.

Further problems emerge when people with severe cognitive impairments are referred for suspected mental health problems. The consultants are reliant on the report of trusted learning disability service staff when trying to effect diagnosis. They dread the time when people with mental health problems live independently without the support of the learning disability nurses, and any medical intervention is technically classed as an assault. Furthermore, if any period of hospitalisation is required for a mental health problem then the psychiatric resources are limited for people with learning difficulties if they need a longer time for observation, diagnosis and rehabilitation.

The mental health services identify problems with general practitioners who have limited exposure to people with learning difficulties and who struggle to identify treatment needs. Additional problems are the lack of specialist forensic services for people with learning difficulties who require a more specialised approach than the mainstream population. People with learning difficulties with mental health problems appear to be an even more vulnerable group.

From these accounts, support that inhibited or skirted competence enhancement seemed to include:

- Using a practitioner-centred approach, instead of a person-centred approach
- Not listening
- Failing to explain treatment, and treating the person as a medical object, case (objectification), or 'other'
- Making decisions for the person (medical paternalism)
- Not speaking to the person directly and speaking over the head of the person to the carer (exclusion)
- Employing a deficit model of competence towards the person concerned

- Failing to ascertain the support worker's/family carer's level of healthcare knowledge whilst presuming they will explain the treatment
- Failing to allow a person time to think about the treatment offered
- Lack of experience regarding encounters with people with learning difficulties
- Lack of specialist services

The lack of awareness demonstrated can be explained, in some cases, by limited exposure to people with learning difficulties and interaction on the part of the professional. This lack of training and exposure is frequently documented (Dovey and Webb 2000, Hassiotis et al. 2000, Cumella and Martin 2004), even as far back as 1973 when Holt and Huntley argued that more training was needed for doctors when encountering people with learning difficulties. Additionally, there are low staffing levels and resources available, restricting the accessibility of a patient centred service.

At the start of this section (8.1-8.5), I argued that most people with learning difficulties were reliant on a third party to make their views known (Keywood et al. 1999). However, I found that some medical professionals routinely used jargonised language to communicate with people with learning difficulties and staff carers. For some staff, not understanding the medical professional increased the difficulty of explaining treatment to people with learning difficulties and inhibited the decision-making process. A second factor to the inhibition of the healthcare decision-making process was the unwillingness of some staff to challenge medical professionals or clarify treatment. In these situations, the healthcare encounter became paternalistic and reliant on medical knowledge.

Some medical professionals and staff appeared to assume that all people with learning difficulties shared a common system of communication. This led to little diversity in how information was presented. In addition, a second assumption was that increased or decreased verbal articulation

appeared to indicate that levels of understanding and abilities were of equal status. In some cases, these assumptions led to over or under prescription of medical treatment, and crucially exclusion from the healthcare decision-making process.

## **8.6 Competence promotion**

### **8.6.1 The Client Health Education Programme**

There is a health education programme run on a Saturday morning at the Ariel Centre for people who live in community homes. The aim is to provide healthcare information for people with learning difficulties, whilst providing a supportive atmosphere where people can examine issues relating to their own health. The programme explores issues like epilepsy, how to stay safe inside and outside the home, the basic principles behind a healthy lifestyle and the need for regular screening, stress rest and relaxation, and making friends. The learning disability team run the courses and they are approximately four and a half hours in length. The course organisers highlight the problems of producing accessible information for people with varying cognitive abilities. There are also issues for some people with the timing of medication, finding support staff to accompany people, transport, funding for lunches, and keeping the groupings small enough to allow for different learning styles to be taken into consideration but large enough to be cost effective.

### **8.6.2 Supportive environments**

One of the homes, Tyke Street, works towards a competence promotion model of support. The learning disability team works together trying to provide a better quality of life for their residents. Residents attend a College of Further Education; they do not use the day centre at St. Francis' Hospital, the special education centres, community dental services, or any other facilities specifically for people with learning difficulties.

LD Nurse 7: *“We use community facilities where possible. What’s the use of using hospital facilities like the day care when people no longer live like that. If we are looking at the whole person we need to be looking to the community and see what the resources are, what can it provide, what can it do for us? The more people get used to people with learning difficulties being permanently in the community, the more they will accept them. They are here to stay, you can’t just shut people away because they have learning difficulties, they have a right to a life.”*

This ‘right to a life’ translates into people’s health encounters. People with learning difficulties are actively encouraged by staff in this home to challenge their original health status and regain some control.

Other people with learning difficulties living in the community gave different examples of how support promoted competence. Case studies follow, constructed from interviews and observations, and field notes, to highlight different types of support that people with learning difficulties feel promotes competence.

#### Case study: Edward

Edward lives in a community home. He has lived in community homes from the age of seventeen; he is now a pensioner. He admits to being a bit forgetful when he has changes of medication and cannot always remember the names. When he attends the dentist, optician or chiropodist it helps him feel more confident if someone else is there who can remember the names of his medication.

### Case study: Joe

Joe is a sprightly eighty-year old who was hospitalised at the age of seven for a chest infection. He never left the hospital. When St. Francis' Hospital closed, he moved to a community home. Joe was now in his fifties. One of the support workers at his new home noticed he was Catholic and had come from the immediate area. She decided to contact the local priest to find if he had any remaining family. Two of his sisters lived around the corner from the home, one brother had died, and one brother was terminally ill.

A family reunion took place. The sisters had presumed he had died in hospital because there was no mention of him after his admission. Joe enjoyed outings with his family and they took part in his life. Both sisters were ten years older than Joe and died in their early seventies. His nieces were introduced to him, but they had grown up without him and he was a stranger. They did not keep in touch.

Without his sister's support Joe was alone again. Subsequently, he developed health problems that required medical intervention. Joe was a member of an advocacy group and they arranged an independent advocate who had a medical background to help him make a decision about his health. After many meetings and discussions, Joe decided not to have an operation because it would make no difference to how he lived his life.

### Case study: Bernice

Bernice lives in a community home. She lives with people who are between fifteen to twenty years older and she emphasises the fact that she is the 'baby' there. On an initial meeting, Bernice's speech is difficult to understand. It takes a great deal of concentration to communicate effectively with her. However, after a while in her company, the interactions become easier, Bernice tries to meet people half-way by altering her words and breaking down what she says.

When faced with a busy clinic sometimes it is difficult to spend time with each individual, especially if they have a communication difficulty. Nurses at her asthma clinic spend time with her, showing her pictures about how her asthma affects her. This helps her to understand what she needs to do to stay well and why she sometimes cannot breathe. Having the support workers accompany her helps her to feel more confident because they help her to explain her needs to the specialist healthcare workers.

### **8.7 Conclusion**

This chapter illustrates that the lack of personal or medical specialist knowledge of the person supporting an individual with learning difficulties can sometimes be a barrier to the decision-making process. This is evident from the reports of the staff carers. For Booth and Booth's (1994) competence-promoting support to be effective, the supporter needs to possess specialist medical and personal knowledge to enable people with learning difficulties to develop skills and remain in control.

The possession of specialist personal and medical knowledge increases in importance, especially in difficult cases where healthcare choices and decisions are vital, and the person assisting needs a thorough personal knowledge of the individual, treatment choices and their outcomes. The case of Joe highlights the importance of an independent supporter, with intimate knowledge of the person coupled with specialist medical knowledge, who can assist with the decision-making process. Joe was a member of an advocacy group and could access a supporter with medical knowledge who knew him well enough to discuss the treatment options and support him in making a decision regarding his own healthcare. This was an example of a positive healthcare experience.

The lack of specialist medical knowledge is aggravated by the supporter's fears of losing their job or being seen as a 'nuisance' (Keywood et al. 1999). My study found that these fears may additionally inhibit questioning the professional to ensure that the person with learning difficulties received the best possible outcome where treatment is concerned. Some professionals created an additional barrier to decision-making because they lacked awareness of the amount of specialist medical knowledge held by staff, and routinely used jargon. They then expected staff to explain treatment, but exhibited little awareness for involvement of the person with learning difficulties in the healthcare decision-making process.

Using a circle of support: family, friends, carers, independent advocates and self-advocates appears to promote competence, and independence in some circumstances (Sanderson et al. 2002). These circles aim more towards knowing the person and their wishes, rather than promoting competence and assisting in decision-making within a healthcare context. However, when the people in the circle of support lack the relevant knowledge to promote competence its effectiveness can then become questionable.

My findings presented suggest that mainstream services and learning disability specialist services employ differing approaches to people with learning difficulties. Mainstream services appear more prescriptive and directive, with occasional examples of practitioners treating people as individuals, and trying to work with carers and supporters to gain a greater understanding of the person they are treating. In contrast, learning disability specialist services appear to have a more inclusive approach, supporting people in making a choice, but not always a decision as to the type of treatment received. In supporting people, the learning disability services and staff carers acknowledge that having a cognitive impairment makes a person vulnerable; even if they are verbally articulate, there are limits to individual levels of understanding. However, this acknowledgement sometimes promotes a deficit model of competence and does not always recognise individual abilities. Limits to individual levels of understanding lead into the next chapter where I examine proxy healthcare decision-making and the conflicting roles of staff.

## Chapter 9

### **Roles and Consent: confusion and conflict**

#### **9.1 Introduction**

In the previous chapter, I suggested that in relation to the people in my study, there was a difference between mainstream and specialist learning disability services in their approach towards people with learning difficulties. Learning disability services appeared to employ a more inclusive approach in supporting people with learning difficulties to make a decision regarding the type of treatment received. Additionally, the empirical evidence suggested that the lack of medical knowledge of the person supporting an individual with learning difficulties could sometimes be a barrier to the decision-making process.

Keywood (2003) raises a different issue in relation to staff and that is their experience of overlapping and conflicting roles. These roles can vary from gatekeeper, decision-maker, proxy, advocate, care manager, broker, enabler, problem solver...and many other roles. The overlapping and conflicting roles place a burden on staff (Alazsweski & Alazseweski 2005). I argue that the differing roles that staff adopt in their course of their daily interactions with people with learning difficulties may be a barrier to the decision-making process.

Therefore, the aim of this chapter is to examine decision-making through the conflicting and changing roles of staff, and reports from people with learning difficulties, whilst considering the question, 'Are the perspectives of people with learning difficulties on their healthcare encounters necessarily shared by staff and supporters?.'

## 9.2 Risk and consent in healthcare decisions

'Risk' and 'consent' are two problematic words that have different meanings dependent upon the context in which they are used (Alaszewski and Alaszewski 2005). Risk in particular has a troublesome history when associated with people with learning difficulties because of the amount of intervention in their lives to 'protect' them from harm or exploitation and in the guise of institutions that provided rigid, oppressive and controlling regimes (Atkinson & Williams 1990). Risk has a negative dimension and this is addressed in current policy guidance in terms of protection from abuse, not only by the actions of others but also from the consequences of an individual's actions (DOH 2001b, para. 8.2, p.90). However, within Valuing People (DOH 2001b) there is no explicit discussion of risk and the main emphasis is on empowerment through '*rights*', '*independence*', '*choice*', and '*inclusion*' (p. 3). Framing risk objectively appears to be a problem, especially when the argument surrounds 'protecting' vulnerable people.

For example, Alaszewski & Alaszewski (2005) argue that health and welfare agencies emphasise empowerment and support for people with learning difficulties, but are bound by a duty of care to consider the safety of people with learning difficulties and the staff that are employed to care for them. This creates a tension between empowerment and safety. The need to consider risk resulting from actions or decisions creates the tension, and can reduce empowerment. Therefore, Alaszewski & Alaszewski (2005) argue that if the consequences of the risk are potentially harmful, and not taking the risk means a missed opportunity, then the outcomes of choice and decision-making would differ significantly. This means that the individual would be guided towards missing the opportunity if the staff carer felt that the consequence of taking a risk entailed potential harm for the individual.

Edge (2001) argues that all decision-making involves an element of risk, and not allowing people to take a 'risk' inhibits their coping skills because they

are not learning. Furthermore, protecting people from taking a 'risk' inhibits competence-promoting behaviours (Booth & Booth 1994). However, there is also a tension here because of the implications in relation to healthcare in terms of the seriousness or irrevocability of a decision.

One example by Goodley (2000) illustrates the tensions between risk and empowerment. Transport is provided for a young woman with learning difficulties to travel 500 yards to the day centre. The reason for the transport is that the psychologist has written that the young woman would probably never be able to cross a road safely. Providing transport avoids the 'risks' of allowing her to cross the road. However, when the young woman arrives, she then crosses the main road alone to buy milk for the people at the centre. These actions have been taking place for a considerable time, with no follow up to the original assessment. Whilst this is only a mild case illustrating empowerment and risk, more problematic cases can arise when decisions and choices need to be made concerning healthcare.

In Chapters 6, 7, and 8, I argued that close associates could support people with learning difficulties to make decisions. However, in the previous chapter, close associates highlighted the fact that professionals expected them to explain treatment that they barely understood to the people for whom they had a duty of care. This lack of medical knowledge acted as a barrier in the decision-making process, making decisions practitioner-centred rather than person-centred. This echoes Parr et al.'s (2004) study concerning people with aphasia, where it was found that service cultures were often unsupported and the physical needs of the cared for person were prioritised rather than their communication needs.

Bramstedt (2003) adds to this argument by suggesting that some staff themselves have questionable decision-making capacity, due to psychosocial issues, conflict of interest, or the projection of their own personal values, instead of the individual's, into the decision-making situation. One example of the problems with staff decisions, provided by Gillespie et al. (2002), highlights the fact that decision-making and choice are essentially Western

philosophical constructs and this may differ amongst cultures where a more fatalistic approach may prevail, and choice and decision-making are based on collective or community ideas. Therefore, for some staff, and the people they support, cultural issues could affect the decision-making process.

Alazsweski & Alazsewski (2005) argue that whilst people with learning difficulties may need help and support in making decisions, there is little explicit and formal training for staff in relation to decision-making processes. The assumption is that professionals and other carers are competent adults who know how to make decisions, yet there appears to be little evidence to support this assumption. Additionally, Medora and Ledger (2005) identified that people with learning difficulties can be ready to make their own decisions, as long as they are adequately supported, but staff were worried about issues of consent. They were especially concerned about decision-making involving people with profound learning difficulties who did not use speech to communicate, or had high support needs.

McPherson & Addington-Hall (2003) argue that for people with profound learning difficulties, an individual's caregiver (proxy) may be more aware of events concerning the person they care for and therefore better able to report on their experience. They also found greater inconsistencies in carer (proxy) reports, relating to the subjective experience of the person they cared for, depending on the level of cognitive impairment of the person, which conflicted with their earlier findings. Additionally, Krosnick (1991) argues that carers as proxies may misinterpret the meaning of questions, leaving responses as vague or ambiguous, thereby causing more confusion. Furthermore, because they are not experiencing the health phenomenon themselves, then they are reporting on non-visible cues, and this is a potential for bias.

Much reliance is placed on the communication and interpreting skills of staff as proxies. Whilst reliance on proxy communication and interpretation skills may not be problematic in every situation, Cohen et al. (1999) suggest that

inaccuracies, perhaps resulting from poor communication and the complexity of clinical information, lead to detrimental outcomes for the individual.

For Keywood (2003), conflicting staff roles predispose to an ambivalence about the professional caring role at an ethical, policy, and strategic planning level. Brammer (2005) clarifies the situation somewhat and argues that under current law, proxy decision-making is only recognised in respect of legal and financial matters through the Court of Protection. She identifies that there is an absence of any formal machinery to delegate decision-making in health and other areas, reinforcing ambivalence to the roles of staff and family carers.

The Mental Capacity Act 2005 has aimed to improve and clarify the decision-making process for people unable to make decisions by themselves, underpinned by the presumption of capacity. This means that the individual has a right to be supported in making their own decisions, and to be allowed to make decisions that might appear unwise. Picking & Pain (2003) suggest that the right to be supported is reliant on the relationship each individual has with his or her carers, and professionals. From my empirical evidence in chapters 6, 7 and 8, I suggest that in addition there is also the relationship between the carer, the individual, and the professional to consider. This is because of the importance and the irrevocability of some healthcare decisions and additionally the number and range of parties whose involvement is required.

There still appears to be a considerable amount of uncertainty when involving proxies for people with learning difficulties in their healthcare decision-making. Relationships appear to be crucial to many decisions; arguably, if these relationships fail to acquire a more solid footing then an exchange of information will not occur between all the parties concerned in the healthcare encounter. Consequently, this may create a barrier for the healthcare decision-making process. The next section looks at the changing roles of staff.

### **9.3 End of life decisions: the changing roles of staff carers**

I have included this example of Nick and his changing needs partly because I have just assisted with caring for my father whilst his health deteriorated, and his needs changed dramatically. As my father's level of communication dwindled, it became apparent that we, as a family, were more accurate at interpreting his needs and his wishes to be cared for at home, by people he knew, and who knew him as a person, until he died. We could not manage alone and had paid carers to help. Some carers were empathic, and read him very well, but the quality of their approach was highly variable. What stood out was that we knew dad far better; we knew how he felt regarding his healthcare needs and could make decisions for him creating an environment where he felt safe and cared for in his final days.

I therefore revisited my research data and looked at staff carer reports of people who had encountered dramatic changes to their health. There were many similar reports of people with dementia and Alzheimer's. I chose two because they were contrasting reports and reflected how a person could be treated with respect and dignity in their final days. The first case is Nick, retold by me, the researcher, from the original story gained from the learning disability team who cared for Nick in the home where he lived and died. The second case is Tommy, retold by me, the researcher, from the original story gained from the support team who care for Tommy where he lives.

#### **Nick**

The learning disability team know many of the people in their care. They are visibly affected when recounting stories of people whom they have nursed, and who have died. The learning disability team singled out people with Down's syndrome, identifying that Alzheimer's appeared to hit this particular group the hardest.

Jim (anonymised), a learning disability nurse who had cared for Nick, said he was very outgoing person and had led a full and active life. Nick was diagnosed with dementia. From the diagnosis, he deteriorated rapidly, almost overnight. Jim felt that it was fortunate that the home where Nick lived had an added room that could house people requiring intensive nursing care, whilst still being a part of the home where they had lived for most of their lives. He felt that it was important that Nick did not have to be re-housed. Nick died within six months of his initial diagnosis. Jim, and the other carers, said that they found it difficult watching Nick's rapid deterioration. They felt that the plus for Nick was that they knew him so well that, hopefully, they anticipated his needs when he could no longer communicate.

A lot of the information about Nick was carried around in the heads of the staff, for example, things concerning his personality, what he enjoyed doing, how he preferred to be spoken to, what kind of food he enjoyed, whose company he preferred, who irritated him. Small things perhaps, but they all added to his quality of life in his last months, making him as comfortable as possible. If Nick's home had not been adapted, he would have been moved to a home with staff who did not possess, and did not have time to learn, the intimate knowledge of Nick and his circumstances that helped make his final months as comfortable as possible.

Nick was cared for until he died, but the staff said that they experienced conflicting emotions whilst caring for him as he deteriorated. As he deteriorated, staff roles changed. As he became ill, they became advocates, helping him to understand his illness and make choices. As his decision-making skills declined, they became gatekeepers for the

healthcare services, deciding which to access. As his communication skills declined, they became interpreters in his healthcare encounters. When his communication failed, they became decision-making proxies, making decisions for him based on their intimate knowledge of his preferences.

### **Tommy**

Tommy, in contrast, is undergoing a process of assessment with psychiatry and the psychology services. His moods have changed during the past few months and his staff are unsure whether it is related to the death of his partner, who was the more talkative of the two. Tommy has Down's syndrome and staff question whether he may have early onset dementia. In contrast to Nick, Tommy's home is not adapted to allow for any individual fluctuation in health need. If he does have Alzheimer's then a move is inevitable.

This means he will be with people who do not possess the same unique knowledge of him as an individual. Tommy will also be in an unfamiliar environment, surrounded by unfamiliar people. He will have no choice because of the lack of foresight when he was originally re-housed in to the community.

In Tommy's case, it could be argued that a lack of foresight, when housing people with learning difficulties into the community, has caused unnecessary distress when vulnerable people have to be moved if their health deteriorates.

Another concern is the relationship Nick had, and Tommy has, with the staff. Nick's staff could anticipate and interpret his needs, with some degree of accuracy, when his communication failed. The ability to interpret and anticipate was based on their knowledge of Nick, built up over time.

However, the carers carried much of that intimate non-clinical knowledge in their heads. In contrast, moving Tommy from the home he has lived in for the past seven years means losing cumulative staff knowledge, and a very vulnerable Tommy will be coping with strange faces and a strange environment in his final days. The role of personalised records here does help, but only if Tommy's preferences are carefully documented and the subsequent staff read, understand, and clarify their meanings. For example, in chapter 7, I presented a case where personalised records were ignored, and as a result, the individual experienced a reduction in their autonomy and their standard of care.

If diagnosed with dementia, Tommy will move to the hospital-based units. The units are structurally very different from the home where he now lives. They are run like a mini-hospital; the staff are employed on a different pay and promotion structure, meals arrive from the hospital canteen, laundry is sent to and delivered from the hospital laundry, and staff are identified by colour coded uniforms. There is, at present, no option of moving existing staff with him. Travelling distance is greater for the staff to the core units; it would leave the existing home with reduced staff and the core unit would then be overstaffed. There is also the issue of whether the staff would want to change their existing roles and work in an institutionalised environment.

#### **9.4 Carer roles and accessing services**

Bigby (2000) highlights the vulnerability of people with learning difficulties with poor informal social networks, who are dependent on formal service provision for their well-being. Bigby (2000) notes that the transition from parental care has traditionally been portrayed as a time of crisis, but this need not be so, especially when individuals have a strong informal support network.

My next story concerns Mary, who owns her own home and lives alone. I have chosen the story because I feel it illustrates the benefits of support, and proxy involvement, when used to maximum effect. Mary has the support of

the learning disability team, but her life may have been different if the original team who intervened on the death of her grandmother had not possessed the foresight to support Mary in her own home. I interviewed Mary on the suggestion of the learning disability team because she was, they felt, a success in terms of support and integration. Mary was quite happy to be interviewed but one condition was that she had Anita (anonymised), her learning disability nurse, present.

### Mary

Mary has lived alone since she was twenty-five, when her grandmother died. She is now fifty-six. Neighbours contacted the learning disability team because they were concerned for her safety. Mary was unkempt and wandered the streets late at night. One learning disability nurse, Anita, has taken care of Mary for the past eleven years. I observed the relationship between the two women. It appeared more of a supportive friendship. Anita treated Mary with unconditional positive regard. Mary clearly enjoyed her company.

Anita helped Mary tidy and organise her house, which was previously '*lacking in love*'. It is now well decorated, clean and welcoming. Anita found courses for her to attend at college; Mary loved the cookery courses in particular. However, she still could not cook a meal and survived on sandwiches. Anita taught her how to use a slow cooker to prepare a meal that could be left to cook whilst she was out during the day. Mary smokes, and admits she smokes more when bored, and was finding the cost of cigarettes eating into her food budget. Anita talked to Mary about the dangers of smoking. Mary decided she would still smoke but try to cut down. Anita helped Mary by devising a system whereby Mary bought seven packets of ten cigarettes (one packet

for each day of the week) and placed them on her mantelpiece. Mary is happy because some weeks she still has two packets left over and this means she is smoking and spending less.

Mary attends the nurse at her GP practice regularly, for smear appointments (when Anita finds the hidden appointment cards) but she has not seen her GP for sixteen years. Mary prefers this because her GP is a man and she does not feel comfortable discussing intimate details about her health with a man. Two years ago, whilst helping with the washing, Anita discovered that Mary was having continence problems. Anita referred Mary to the continence services, explaining, encouraging and supporting her with information and the exercises that she needed to solve the problem. Mary's continence problem is now solved.

Mary decided to move home from a terraced to a detached house that could be adapted if her health deteriorated as she aged. Anita had discussed ageing with Mary, but left any decisions up to her. With her move has come a new lease of life. Mary's new neighbours have welcomed her and she now attends the local church meetings and ladies' coffee mornings. Her social networks have begun to increase, and Mary radiates a happiness that was not present on my initial meetings with her.

Mary is supported to make her own decisions by the learning disability team, with Anita playing an important role. Anita had the foresight to discuss age-related problems with Mary. If Mary's health does deteriorate, she can now be cared for at home until the end of her days. Anita supports Mary with her choices, allowing her to make mistakes and learn from them (similar to a mentor). She helps Mary to access the relevant services that will attend to Mary's health care needs, and supports her whilst she is attending. Mary is articulate, but lacks confidence when dealing with medical professionals.

Anita is invaluable in these circumstances because she ensures that Mary's voice is heard, and her preferences are taken into account if any treatment is necessary.

However, in chapter 7, I presented two case studies concerning Edward who needed help with his mobility and Arthur who needed help with his hearing aid. The staff disregarded Edward's request and lacked the training to help Arthur with his hearing aid or to access further assistance. This gives a contrasting example of staff with the negative role of gatekeeper to services.

### 9.5 Roles, support and consent

As I travelled around the Brancaster area talking to people it became apparent that some staff members struggled with their roles. Sometimes with people with more profound difficulties, this role was burdensome. A comment made by a staff member in one of the homes highlights this burden:

*"You know, we can't get everything right. Some of our residents have a mental age of six months and trying to understand their needs is very difficult, if not impossible. It's like shooting in the dark; you hit the right target more by luck than anything else. We just have to take what we are told by the consultants as to what is the best course of action, or treatment for each individual. It's not ideal but it's the best we can do."*

Another learning disability nurse echoed the staff carer with this comment:

LD Nurse 9: *"We just cannot do everything. Some of our residents have very profound difficulties and sometimes there aren't the resources that can help. Psychology services are thin, and sometimes we need help with behaviour that we don't understand. We are not experts in everything. Physiotherapy would help for some, but there's a staff shortage, and there's no occupational therapists either. You*

*know, it's very difficult when someone cannot tell you the problem and you have to guess. Sometimes our GP gets very upset with us when we take a resident with a 'problem' but cannot tell the GP exactly what the 'problem' is. I've just been told off by our GP because I took Stella to see him. She had a temperature and her behaviour wasn't right, but I couldn't give him any more information. We are up against this on a daily basis."*

The frustration from this nurse was apparent; the many roles undertaken seemed to eat at the nurse's confidence. Additionally, the duty of care for Stella's health meant interpreting physical symptoms as a possible problem when there was very little communication from Stella, apart from 'behaviour'. This illustrates a key contextual point in dealing with uncertainties in people's lives, and the improbabilities of having to make decisions in such circumstances. This is reminiscent of chapter 7, and the case study of Rosemary who has taken to the hospital in pain but the care workers could not tell the doctor where the pain originated.

In her analysis of care, Brechin (1998) suggests addressing the experience of both parties (carer and cared for) in the healthcare encounter. In Rosemary and Stella's cases, the GP, who is the primary care provider, lacks awareness concerning the complexity of roles of staff and fails to support them. Additionally, there is the issue of power with competing discourses operating at a cultural level (nurse v doctor) and their potential for conflict (Thompson 2001). There is a failure to work 'collaboratively' and 'in partnership' which gives weight to Dalley's (1993) suggestion that professional collaboration may never happen because of poor communication between professional groups and a lack of respect and trust for one another.

Then there is the contrasting case of Henrietta who refused to leave her old home and laid on the floor of the lounge, refusing to move 'in protest' for over a week.

### Case study: Henrietta

Henrietta has profound learning difficulties. She moved from home to home because her 'demanding behaviour' wore out many care staff. Her latest home adopted a different strategy and observed her closely, noting her behaviours, and their contexts. They did not expect Henrietta to 'fit in' with the home routine. They noticed that she exhibited severe distress when moved from her home environment. Furthermore, her behaviour mirrored another resident who had autism. They monitored her closely in terms of the risk aspects of her behaviour, or the dangers to the staff and other residents. The staff contacted the consultant psychiatrist with their observations, proposing that Henrietta had been misdiagnosed. The consultant listened to the staff and changed her medication. Henrietta's behaviour altered and she became more manageable. The staff keep her trips out to a minimum because they cause high levels of anxiety. They are currently finding ways of improving Henrietta's communication skills by using music therapy.

The staff here have many roles; behavioural observers, negotiators (for treatment changes), proxies for decisions regarding treatment, interpreters, supporters, befrienders, and so on. The consultant psychiatrist appears to be aware of the complexity of these roles and listens to the staff. The more profound the impairment means that the carers experience a higher number of conflicting roles. Each role centres on their duty of care, but because of their terms of employment, they additionally need to consider 'risk'. Risk in this home, is seen more in terms of general safety and Alaszweski and Alaszweski (2005) argue that there is a tension between a 'person-centred' approach and a 'health and safety' approach. This tension can result in the reduced autonomy of a person with learning difficulties, as indicated by the next case study of Derek.

### Case study: Derek

Derek has no family and has always lived in community homes. He is now in his late thirties. He is a highly articulate and genial young man. Derek enjoys socialising and frequents the local pub for a pint and a game of darts or dominos. He was offered the chance to live in a flat by himself, because a risk assessment indicated that he was not a 'danger' to the community and therefore would be suitable for re-housing.

Derek's key worker was concerned by the assessment because nobody had talked with her regarding his self-care skills. Previously the care staff had cooked his meals, done his washing and ironing, and escorted him on shopping trips. This was because a 'risk assessment' had indicated that it was safer for the staff to carry these functions out for the residents. When he moved, Derek had to do everything for himself without support. To assist him, and in her spare time, the key worker instructed Derek how to use the cooker in his new flat because he had never cooked a meal before. She helped him by writing notes by the plugs and cooker to remind him to turn them off after use.

Derek had very little knowledge about either his nutrition, or his general health because the staff had always taken responsibility for these areas of his life. The negative aspects of 'risk' had created a barrier for Derek, reducing his autonomy and preventing him from being involved in decisions concerning everyday choices and tasks that most people would take for granted. Consequently, Derek was re-housed into the community with very few coping

skills that would ease the transition from institutional care to independent living.

A few weeks after his move, I observed him at the day care centre. It was a bitterly cold day. Despite the cold, he was wearing thin shorts and an un-ironed t-shirt. I had a brief chat with him and asked how he liked his new flat. He looked tired and said he felt lonely and found it difficult doing the everyday things that the staff carers had always done with or for him.

Derek was not the only person who had had his autonomy reduced by the negative aspects of 'risk'. I noticed that concerns with safety were routinely used to restrict choice and activities. For example, as I visited the homes, I noticed that many kitchens had locks on the doors to prevent residents from entering, even to make a cup of tea, in case they 'scalded' themselves. Using 'risk' in a restrictive fashion appears, as Booth and Booth (1998, pp.205-6) suggest, a risk factor in itself.

## **9.6 Staff roles and service cultures**

In the previous chapter, my empirical evidence indicated that some staff lacked medical knowledge, and in some circumstances, this was a barrier for healthcare decision-making. I argued that for people with profound impairments, the need for supporters with medical and personal knowledge became even more important when they were involved in the decision-making process in the role of proxy. However, I have a conflicting account in the form of a case study, taken from three interviews with Jack.

### **Case study: Jack**

Jack lives in a hospital-based secure unit. He has had mental health problems since he was sixteen; he is now nearly fifty. Jack's parents are now dead, but his brothers

and sisters visit him regularly and phone to speak to him. He loves his brothers and sisters and has a close relationship with them. Jack had a great deal of difficulty with his medication for his mental health; he had hallucinations that terrified him. He knew that he did not hallucinate before he started taking his new tablets; naturally, he identified the cause as the tablets. He talked to the nursing staff, and the psychiatrist, who told him to 'keep taking the tablets'. He told his brothers and sisters who sat and listened to him. His brothers and sisters made an appointment to see the psychiatrist and accompanied Jack; they insisted the tablets were changed and that Jack saw someone who listened to him. Without this external support, Jack would still hallucinate.

In this situation, the staff appear to have little expertise in formal decision-making and consequently failed to support Jack appropriately. There is a conflict in roles for these staff because they work within a unit that has a rigid and controlled regime. There are structural restrictions on the way they interact with Jack. Additionally, staff are not experiencing the phenomena themselves, so they are therefore ill placed to report on something that Jack describes. Fortunately, Jack has a supportive family who listen to him. His family challenged the nursing staff and consultant. They insisted that his medication was changed, along with the consultant who saw him originally. The situation here is complex and involves more than an exchange of information from Jack, the staff, and the consultant, because Jack's voice had been ignored. It took Jack's family to exert pressure and change the situation. Without this external support, Jack may still be hallucinating. This situation echoes guidance within section 35 of the Mental Capacity Act 2005 for proposed appointments of independent mental incapacity advocates who may support an individual. An independent mental capacity advocate may have assisted Jack in his healthcare encounters and removed the burden from

his family. Jack was amongst the few people interviewed who still had visiting family; many other people were reliant on staff to assist them.

## **9.7 Conclusion**

Keywood (2003) suggests that the overlapping and conflicting roles of staff may cause barriers in the decision-making process. Alaszewski and Alaszeweski (2005) suggest that the negative and defensive practices associated with 'risk' may themselves cause barriers in the decision-making process. However, the empirical evidence in my study suggests that staff roles do change, and can be conflicting and contextual, but can additionally have negative and positive dimensions. Examples of changing staff roles are; a proxy, during end of life decisions, as a supporter to empower an individual to make decisions and ensure that their voice is heard, as a negotiator assisting the individual to access and negotiate services, a friend, an interpreter, and a gatekeeper restricting access to services. Additionally, my study suggests that staff roles become more conflicting and complex with people with more profound impairments. Professionals need to be more aware of the complexity of staff roles. Staff appear to need more support and their experiences validating by healthcare professionals, as in the case of Henrietta.

The negative aspects of 'risk' may (as Alaszewski and Alaszeweski [2005] have suggested) act as a barrier for some people with learning difficulties, reducing individual autonomy and involvement in decision-making processes. Consequently, 'risk' prevents some people with learning difficulties from acquiring the coping strategies necessary for them to participate in decisions concerning them. However, it is the negative interpretation of 'risk' restricting some people with learning difficulties from decision-making opportunities.

The structure of service cultures appear to inhibit the decision-making process by enforcing restricted and restrictive practices, with little guidance or clarification. In the case of Jack, the staff had little or no training in

formal decision-making processes and their role within the service culture meant that they concentrated on the physical needs of their residents, rather than what the residents were communicating. It appears that staff roles themselves play a major part in decision-making encounters and additionally may influence the outcomes negatively or positively.

## Chapter 10

### Conclusions

The main research question for this thesis was:

- **‘To what extent are people with learning difficulties and staff carers involved in the healthcare encounters of people with learning difficulties?’**

My objective therefore was to explore healthcare encounters from the perspectives of people with learning difficulties and their staff carers.

I began by evaluating literature around the individual model of disability and linked it to medical knowledge, outlining recent policy recommendations (DOH 2001b) relevant to people with learning difficulties. The literature revealed that the biomedical account of healthcare remains dominant whilst policy appears, implicitly at least, to acknowledge that different types of knowledge are important because they broaden the potential for more meaningful involvement by people with learning difficulties in healthcare encounters. Using medical knowledge alone makes the healthcare encounter practitioner-centred and actively serves to disable and marginalise people with learning difficulties in the healthcare decision-making process. The research literature also revealed tacit assumptions regarding the competence of people with learning difficulties to make decisions (Booth and Booth 1994, Jenkins 1998, Keywood et al. 1999, McCarthy 2001). These assumptions may result in people with learning difficulties’ exclusion from decision-making processes because of attitudinal barriers. In other words, they may be viewed in terms of arbitrary and deficient classifications bound up in taken-for-granted notions of ‘handicap’ founded on an individual model understanding of disability.

I then introduced the social model of disability (Oliver 1990). I argued that using medical knowledge alone acted as a barrier, actively excluding people

with learning difficulties from their healthcare encounters and preventing individuals from being treated 'holistically' (Liaschenko 1997, Liaschenko and Fischer 1999, Mead and Bower 2000). In addition, I suggested that using medical knowledge reinforced existing power structures because it failed to utilise other types of knowledge that could empower people with learning difficulties and help professionals ensure that support is available during the healthcare decision-making process. Keywood et al. (1999) suggest that using staff and family carers as facilitators and proxies could enhance the healthcare decision-making process. However, over-reliance on family and staff carers by professionals led to negative outcomes as this may result in the voices of people with learning difficulties being silenced (Keywood et al. 1999).

### **What can we learn about people with learning difficulties who do not use speech in their healthcare encounters?**

In chapter 4, I outlined an argument concerning people who lacked verbal articulacy, presenting the case for an interpretive research approach that could result in a more inclusive approach to research with people with learning difficulties. I suggested that collecting data using more traditional qualitative methods meant excluding a large proportion of people who are inarticulate or preverbal. In addition, I argued that the skills and experience of the researcher were of importance during challenging interview situations.

My argument was further developed in chapter 5, where I considered Booth and Booth's (1996) proposals that one of the challenges for researchers is trying to communicate with a person who lacks the facility of speech. I described the challenge and reported my own experiences of experimenting with different methods of researching with people with limited verbal articulacy. At the same time, I represented differing experiences of the healthcare encounter from people with limited or no verbal articulacy. I defended my mainly constructivist stance because it best fitted my research aims in working together with people with learning difficulties to actively construct meaning concerning healthcare encounters.

## **What can we learn from people with learning difficulties themselves about their healthcare encounters?**

In an attempt to answer the above research question, I examined literature on person-centred planning, expecting to find within my data numerous examples of interdisciplinary teamwork (Sanderson et al. 2002). What I found was an absence of consistent evidence of interdisciplinary teamwork. Many professionals relied on the questioning and procedural models during healthcare decision-making (Smale et al. 1993). In addition, I found that many professionals exhibited little awareness of person-centred approaches and the complexity of the carer/cared for relationship. Professionals also appeared to underestimate the importance of carer knowledge and expertise about fluctuations in a person's state of health and the best ways of managing health. In many situations, medical knowledge took precedence over other types of knowledge that may assist in the healthcare decision-making process. There were gaps in both women's and men's healthcare with medical criteria being used to assess ageing related diseases, with treatment being withheld if the individual had not reached the medically defined age of onset. The health status of many people with learning difficulties remained unmonitored, with some GP's failing to access personal history details, and regarding many people with learning difficulties as asexual beings.

In Chapter 7, I examined 'partnerships' and 'collaboration' and found that the empirical evidence indicated that there were some examples of involving people with learning difficulties in their healthcare decision-making. However, these examples were isolated and the majority of people experienced the 'top down' approach (Callaghan and Wistow 2002), where professional information was regarded as the most valuable and involvement in decision-making was, for many people, non-existent. This was in contrast to the models of informed or shared decision-making, proposed by Charles et al. (1999), emphasising partnership and collaboration. My examples of partnerships in this chapter do not involve the service users, indeed there is little evidence of any service user's active participation on an equal basis.

Additionally, my study found that staff can also exclude people with learning difficulties from involvement in their healthcare encounters because of structural influences and a lack of awareness about what is important to the people for whom they have a duty of care. Staff can also exclude people with learning difficulties from involvement because of a lack of awareness of the need for more specialist help coupled with a lack of knowledge of how to assist in supporting people with the healthcare process. This is in contrast to the suggested guidance in Valuing People (DOH 2001b) for interagency working.

In some cases, medical practitioners failed to access specialist help and intervention and therefore failed to work in partnership with one another, the care staff and the person at the centre of healthcare. On the surface, groups appeared to be working collaboratively, fulfilling their legal and ethical requirements, but not actually operating in partnership. This benefits the services but not the service users. Support and training appeared necessary for professionals, carers, family members, and others involved in the decision-making process in order to support people with learning difficulties with their healthcare.

**Are the perspectives of people with learning difficulties on their healthcare encounters necessarily shared by staff and supporters?**

In chapter 8, I proposed that decision-making making did not occur in a vacuum, and some people with learning difficulties were reliant on a third party (Keywood et al. 1999) to make their wishes known. I found that staff carers and supporters were sometimes excluded from the decision-making process. This was because the lack of medical knowledge of the person supporting the individual could sometimes be a barrier to the decision-making process. In order for Booth and Booth's (1994) competence promoting support to be effective, the supporter needs to possess medical knowledge to enable people with learning difficulties to develop decision-making skills and remain in control. This was particularly evident in dentistry. Professionals expected staff to explain treatment when they had

little dental knowledge. This in turn questioned the effectiveness of the circle of support in the decision-making process, because if the circle of support lacked relevant knowledge then how could it influence the decision-making process?

**What can we learn from staff carers of people with learning difficulties about people with learning difficulties' healthcare encounters?**

The possession of personal and medical knowledge increases in importance, especially in difficult cases where healthcare choices and decisions are vital. The person assisting needs a thorough personal knowledge of the individual, coupled with medical knowledge regarding the treatment choices and their outcomes in order to provide adequate support regarding healthcare.

My study found that mainstream and learning disability services adopted differing approaches to people with learning difficulties. Mainstream services appeared more prescriptive and directive. Learning disability services appeared to adopt a more inclusive approach in supporting people to make a choice. The acknowledgement of the cognitive deficits of people with learning difficulties, by both services sometimes promoted a deficit model of competence and did not always recognise individual abilities. Interpreting individual abilities and levels of understanding appeared to be reliant on close supporters.

In chapter 9, I examined the roles of staff carers and their influence in the decision-making process. Alaszewski and Alaszewski (2005) suggest that negative and defensive practices associated with 'risk' may cause barriers in the decision-making process. My empirical evidence additionally suggested that staff roles changed and could be conflicting and contextual, but additionally had positive and negative dimensions. One main aspect in relation to decision-making was that carer roles became more conflicting and complex as individual impairments became more profound, or an individual suffered from a decline in cognitive capacity. From the empirical evidence, it appeared that carer roles themselves play a major part in decision-making

and can influence the outcomes negatively or positively. However, there was little or no training in formal decision-making and little support for staff carers to guide them through the decision-making process. Supporters, staff and family carers may therefore unwittingly be 'carriers' for 'disablism' (Thomas 1999) because of the ambiguity of their roles.

Previous studies, (Lancioni et al. 1996, Charles et al. 1997, 1999, Stewart et al. 2003) suggest that people with learning difficulties remained uninvolved in their healthcare encounters because of the dominance of professional knowledge. Additionally, they were reliant on a third party (staff or family carer or advocate) to make their views and preferences known (Keywood et al. 1999). In line with Liaschenko (1997), my study found that personal knowledge of the individual was important in facilitating the healthcare encounter, especially knowledge of how an individual communicated and understood information. Contrary to guidance within Valuing People (DOH 2001b), medical and different types of knowledge did not complement one another. This was mainly because professionals demonstrated a lack of awareness concerning the complexity of staff roles and underestimated the importance of staff carer knowledge regarding healthcare. The outcomes effectively excluded people with learning difficulties from their healthcare encounters. Sanderson et al. (2002) argue that person-centred planning means putting the person at the centre of the planning process. I found little evidence of the person at the centre of the process, in many instances the person with learning difficulties was at the periphery of the planning process. Supporters joined the individual, in many instances, at the periphery of the planning process and felt unable to challenge professionals perhaps not because they were frightened of being labelled a troublemaker, or losing their jobs as Keywood et al. (1999) suggest, but perhaps because they lacked the knowledge and support to challenge professional decisions.

My study adds to existing knowledge by identifying that staff struggle to support people with learning difficulties because they lack essential medical knowledge and support, which creates a further disabling barrier in the healthcare decision-making process. In addition, I found that staff roles were

complex and conflicting. The level of complexity and conflict in many instances intensified in tandem with an increase in impaired individual cognitive capacity. This highlights the tension between the individual and social models of disability.

Exploring the healthcare encounters of people with learning difficulties meant that my role as a researcher had to be adapted with each individual that I encountered. This was mainly because many people had limited articulacy. However, I found the use of narrative a useful way of representing voices that may otherwise remain unheard. Using narrative may also be useful in a healthcare situation to inform and guide the professional and supporters of people with learning difficulties through the decision-making process. In addition, I suggest the use of advocates with medical knowledge who could work with supporters to discuss treatment options and support people with learning difficulties, and their carers, in healthcare decisions.

### **Recommendations**

How we can best support or involve people with learning difficulties in their healthcare encounters means examining the factors involved in making healthcare experiences positive. These factors include:

- Deciding the seriousness of the healthcare issue and understanding how this would affect the quality of life for the individual. However, this raises further questions as to who decides the seriousness of the issue.
- Ensuring staff, family carers and supporters of people with learning difficulties are in possession of support and medical knowledge to facilitate the healthcare decision-making process. Thereby promoting a competence-enhancing environment.
- Professionals exploring intimate knowledge of people with learning difficulties and getting to know patients as people.

- Understanding that individuals communicate and take in knowledge in different ways and employing visual/audio/written aids as indicated. This would result in the person being treated as an individual rather than as 'an impairment'.
- Encouraging professionals to address people with learning difficulties directly, even if they lack verbal articulacy.
- Encouraging professionals to listen to staff, family carers and supporters of people with learning difficulties, and to people with learning difficulties themselves, and to be prepared to work in partnership.
- Using narrative approaches to inform the decision-making process for people who are pre-verbal or who lack articulacy.
- Supporting staff and family carers to find different social outlets for people with learning difficulties, away from day care centres, in order to expose them to different experiences and opportunities for decision-making.
- Training for professionals, staff and family carers and supporters of people with learning difficulties to raise awareness of differing roles and responsibilities, and to promote a competence enhancing approach to healthcare.
- Training in the process of decision-making for everyone in the encounter.
- Making everyone in the healthcare encounter aware of the barriers that serve to exclude people with learning difficulties from decisions about their own healthcare.
- Assertiveness training for staff, family carers, supporters and people with learning difficulties themselves in order to challenge decisions about which they feel uncertain or unhappy.

### **Strengths and weaknesses**

Particular strengths of my study are the representations of voices (that would otherwise have remained silent concerning healthcare experiences) through

the use of narrative when working with people with limited or lacking in verbal articulacy. This technique could also possibly be used within the healthcare encounter. The use of narrative has also provided a rich and textured account of the circumstances and accommodation of the people with learning difficulties in my sample, as well as their healthcare encounters.

Weaknesses of the study are the relatively small numbers of people involved and that it is reliant on the subjective experiences of individuals. Therefore, it cannot be generalised to the whole population. Another weakness was that there was not as much control as I would have liked over whom I accessed and interviewed. Constructivism as a tool of analysis is wholly reliant on the interactions of the researcher and informant building meaning together. It is therefore reliant on the researcher being able to build an adequate trusting relationship to enable this process. This is dependent on the skills and abilities of the researcher to use a reflexive and critical stance to the information gathered and to representing the data in text.

### **Implications for practice**

My study revealed that people with learning difficulties managed to access healthcare services for treatment. However, having access to services and receiving quality care are two different things. The healthcare already received is a testament to the tenacity of some staff in pursuing healthcare as a right. However, the data suggests a number of areas (bullet pointed above) where healthcare encounters could be improved and experienced in a more positive light. What appeared necessary in my study was the need for support and training for everyone involved in the healthcare decision-making process. This support and training needs to raise awareness concerning valuing each individual, coupled with the importance of knowledge and roles that may enable people with learning difficulties to take a more active part in healthcare decision-making processes. Furthermore, building on the bullet-point recommendations above, the training should be aimed at enabling professionals to work 'collaboratively' and 'in partnership' with staff, advocates, people with learning difficulties and others, in order to further

develop existing collaborative approaches, and in the process acknowledge people with learning difficulties as true partners, in what are after all, their own healthcare encounters.

### **Further research**

There appeared to be a lack of professional awareness of the roles of staff carers. Additionally, the more profound the learning disability meant that the roles of staff became more complex and varied. The temporality of staff roles across the life course, which shape experiences of the decision-making process, remains unmapped. Further research effort could be directed at analysing the conditions under which staff roles become more complex and varied. In particular, the healthcare decision-making process, which may have life altering consequences for people with learning difficulties throughout their lives.

Many accounts of staff assume a state of stasis, and therefore overlook the factors that shape the evolving staff experiences of healthcare decision-making over the life course. Prospective studies concerning staff and people with learning difficulties are needed to capture the diversity of experiences and the stages of healthcare decision-making.