

# **Changing Needs and Challenging Perceptions of Disabled People with Acquired Impairments.**

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A Thesis Submitted to

The University of Birmingham

For the Degree of

DOCTOR OF PHILOSOPHY

Institute of Applied Social Studies  
School of Social Policy  
The University of Birmingham  
June 2013

UNIVERSITY OF  
BIRMINGHAM

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## **ABSTRACT**

The point at which individuals acquire impairments can be a challenging one, for instance people may encounter shifts in financial circumstances, a need to find information, support and services while negotiating with physical changes and for some the 'stigma' of disability. The study adopts an individualised diary method combined with semi-structured interviews in order to collate in depth qualitative data which is organised and presented using participants' voices to chart the experiences and challenges encountered in relation to finding appropriate help at this time. A total of ten participants were involved in the research over a period of six months.

A critical realist perspective is applied throughout to identify what factors affect the participants' successes and limitations in getting their support and service needs met in relation to recently acquired impairments. The data collection method ensures that this material presents the people involved holistically and looks beyond simple representations of disability and identity. It explores how perceptions of identity shift and how participants negotiate these changes over time. After outlining the major barriers participants encountered, including procedural and attitudinal limitations, the thesis explores what agency and freedom to make decisions, people may have when encountering complex and extensive social structures.

The research thematically analysis the data and develops models to demonstrate the effects of negotiation for participants. The model of the 'Process of Disillusionment' is developed as a key finding and consideration given as to how individuals can break free of such a process. Recommendations are then made as to ways in which this cycle of frustration may be resolved both on a collective and individual basis.

## **ACKNOWLEDGEMENTS**

I was only able to complete this work as a result of the support, encouragement, practical know-how and belief of many people.

**To my parent's: Douglas and Maureen Fillingham have shown unshakeable belief and love in me throughout, thank you so much.**

My friends and colleagues at the University of Birmingham as a whole, and the Institute of Applied Social Studies in particular, who have been both an inspiration and a source of relief: often simultaneously. Particular mention and thanks must go to Aisha Ahmad, Rosemary Littlechild, Bob Matthews, Claire Sacre, Clive Sealey, Julia Smith, Jan Waterson, Cai Wilkinson and Hanna Wride.

My friends outside of University whose listening skills have been greatly valued though somewhat overused, in particular James Fisher, Liz Reeve, Rosemary Turner, and Richard Walsh. Lara, Myra, Shereese and Vicki thank you so much.

Thanks too to all the inspiring women of Magenta Close Harmony Choir, the University of Birmingham No Angels Football Team and IASS football squad, who between them ensured I maintain some perspective throughout, and helped me remember life outside the PhD world.

My supervisors, whose knowledge, patience and common sense proved essential so many times during my endeavours: Professor Marian Barnes, Dr Harriet Clarke and Dr Nicki Ward.

I thank the Economic and Social Research Council for their financial support which made it possible for me to undertake this research.

Finally, warm thanks are given to the participants to the research who gave so freely of their time, energy, commitment and thoughts.

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## **CHAPTER ONE - INTRODUCTION**

This thesis explores the changing needs and perceptions of people who have acquired disability and experienced recent significant change in their lives. The study investigates the experiences of people with impairments through exploring their negotiations with others (individuals and organisations) when seeking information, services and support and considering possible changes in relation to their identity which may result. Participants who had recently acquired impairments, or who had encountered change within their impairment status were recruited. This criterion was in recognition that individuals on the point of such changes and transitions in their lives are likely to require support or direction without necessarily knowing how to access these. In doing so the thesis sought to capture the experience of ten participants as they negotiated for access to information and provision and analysed their understandings to provide greater insight into the circumstances people may encounter in such situations.

The researcher was particularly interested in this area of study, having worked in Third Sector Organisations for many years and recognising the struggles many people have in seeking information and support at times of vulnerability. Issues relating to impairment and disability also hold personal relevance, as a road traffic accident twelve years ago left the researcher impaired and seeking information. This



resulted in a number of questions to consider: if some people were better at negotiating with the systems intended to assist people in times of difficulty, if some impairments were perceived with greater understanding than others and what affects the process may have upon an individual's identity.

The original outline of the research proposal had already been developed by staff at the Institute of Applied Social Studies at the University of Birmingham, and after open competition the researcher was awarded the opportunity to undertake this ESRC funded PhD research project. It was necessary to take ownership of the research project and consider how to explore this topic; these choices included an individualised diary system and a participatory route to involvement.

## **1.1 TERMINOLOGY**

**As will be demonstrated within this thesis, the term 'disability' is a contested and constructed one. Identifying a person as disabled, as this thesis will show, can also be contested and debated. Society seeks to label an individual, for instance through the administration of services such as benefits and media representations. Writers in relation to disability and disability activists may question and actively challenge what constitutes disability, and people may not see themselves or wish to be identified by the term 'disabled'. Even once these challenges have been resolved, there are some writers on disability, both disabled and non-disabled, who prefer the term 'people**

with disabilities', while others prefer 'disabled people'. I recognise that these nominative differences for some people can be political statements and have an effect on how they believe they are perceived. There is no one term which I am aware of that can reconcile these conflicting views. Within this research therefore I have applied a social and barriers model of disability and have chosen to employ the term 'disabled people'. This does not mean that I reject other ways of describing people who experience disabling attitudes, barriers and oppression; indeed I explore in some detail some of the intricacies and complexities of how people are perceived and identify with disability and all its related terms. However within this context I applied a common term of 'disabled people' in order to make the findings, and the experiences of the individuals who committed their time and energy to this research, as clear as possible.

The work will predominantly be written in the third person, except at times when personal reflection is undertaken or considered.

## **1.2 THE RESEARCH QUESTIONS**

These research questions were developed following a review of a wide range of literature, incorporating an exploration of the social model of disability: making a

distinction between impairment and disability as social oppression imposed upon individuals by the wider society (UPIAS, 1976). The literature also contributed conceptual approaches to identity and disability, indicating the importance of including identity focused enquiry in the research.

The research questions devised were intended to explore the experiences of the people taking part with the aim of capturing the circumstances they encountered, while seeking to frame these within a wider context than the individual. The following are the research questions on which this study was embedded:

- 1. What factors affect the expectations of, and services received by the participants?**
- 2. How are self-perception and identity affected by encountering disability and the resultant treatment?**
- 3. How do the methodological choices made within this research influence its outcomes?**

### **1.3 THE PARTICIPANTS**

Ten participants took part in the main research process and began engaging in the fieldwork, eight of whom completed. They had a range of life experiences, ages and impairments but all had acquired impairments. The data collection period consisted of a semi-structured interview, six months of keeping a diary to record their experiences when seeking help, support and services, and a final semi-structured interview at the end of the six-months. The researcher also kept regular interim contact with the participants throughout the data collection period.

### **1.4 THESIS STRUCTURE**

#### **1.4.1 Chapter Two – Discourses of Disability**

Chapter two explores perceptions of, and representations of disability, outlining circumstances and understanding to which disabled people were often subjected, prior to the social model of disability. The origins and development of the social model of disability are also interrogated and comparison made between different ways of seeing disability and current issues in relation to the social model of disability, in recognition of the importance of how disability is conceived and discussed. Finally the chapter identifies the implications for this research of the discussion presented here.

### **1.4.2 Chapter Three – Identity and Disability**

Approaches towards disability and identity are considered and how this may impact on self-perception and in turn how this may influence participants' negotiations. The chapter then explores issues of structure, agency and identity and how social identity theories can be applied to this research in the form of a discussion in relation to disability and identity. Finally, the implications of this area in relation to this research are considered.

### **1.4.3 Chapter Four – Methods and Methodology**

Within the methodology of this research, a critical realist approach was adopted, which is considered within this chapter alongside ontological and epistemological decisions which have been made throughout the research process. My theoretical position is identified and the implications for this research of the methodological choices made are considered. The research questions are presented and the process of research undertaken is detailed. This section demonstrates the thought process behind the development of these questions. The reader is introduced to the participants.

Chapter four also outlines the methods which have been employed within this research, outlining the key research questions. Reflective consideration is also given to my position as a researcher and as an individual to provide commentary upon the methods employed.

#### **1.4.4 Chapter Five – Data Collection**

The data collection processes of the research are outlined here and an overview of the data is provided in the form of pen portraits, case studies and time lines for four participants involved in the research. The remaining participants are also introduced and the initial findings of the research developed

#### **1.4.5 Chapter Six – Analysis From Barriers Themes**

This chapter introduces the first set of themes of analysis: that of barriers. The themes considered within this chapter relate to four different types of barriers, these are: structural, procedural, financial, and practical and were developed from previously established barriers. Each section is divided into sub-sections and these are represented diagrammatically in order to make the account provided clear to the reader. Recognition is also made of what happens when barriers are reversed and participants are offered appropriate help and support.

### **1.4.6 Chapter Seven – Inductive Analysis**

Chapter Seven considers issues of agency and identity. It identifies the themes of analysis which arose directly from the data and those which describe by the researcher as 'attitudinal barriers': those relating to professional and cultural approaches, and of legitimacy. Later in this chapter the experiences the participants, demonstrated through personal support mechanisms are explored. Where appropriate each of these sections has been illustrated diagrammatically to make the structure of this analysis clear to the reader.

### **1.4.7 Chapter Eight – Findings and Discussion**

Within the findings of this thesis, a discussion occurs into the different methods of data collection and the differing styles of data arising as a result. Here I reflect upon the degree of mediation and interpretation taking place within the analysis of this research. The barrier themes which have been analysed in order to develop models representing the perceptions of participants are combined and a model of the 'Process of Disillusionment' developed, which explains how people seeking access and support can become frustrated by the barriers which they encounter and may become unable to move forward. The findings also identify individual routes which

participants employed to free themselves from this discouraging cycle. The research questions are then revisited and resolutions considered. Finally I reflect on the research from a personal perspective.

#### **1.4.8 Chapter Nine – Conclusion**

The data and findings are reviewed in relation to this research and an outline given of the original contributions which the study makes. Strategic recommendations which may be taken forward at a governmental level are presented. Finally the thesis explores how this work could be developed in the future through further research.

**This research focuses on disabled people's lived experiences of disability and of services: the methods used and analysis conducted seeks to contribute to future research, policy debate and policy implementation which may improve disabled people's experiences of negotiating access to services and identifying what agency they may have in challenging situations.**



## **CHAPTER TWO – DISCOURSES OF DISABILITY**

### **2.1 INTRODUCTION**

The concept of discourse has a wide range of interpretations and applications, particularly noted for instance within linguistics, psychological and postmodern discourse analysis (Potter and Wetherall, 1998). The way in which discourses shape our understanding of concepts and our attitudes towards them, means that our experiences are highly dependent upon them. This thesis looks at relevant discourses relating to disability, these are the areas of discussion and exploration of ideas which are most relevant to the research presented here. These include: the normalising discourse of economic rationalisms, discourses of stigma and medical and social models of disability. They have been selected in recognition that:

*"culturally embedded discourses construct the dominant experience of disability within a given culture, time or social context and that this construction is reinforced by and interpreted through practices and social structure."*

(Corker, 1998, 221).

In explicitly recognising such discourses it is possible to consider what impact these have had upon disabled people and upon the participants in particular. For instance discourses relating to the medicalisation of disability and latterly attempts to use new interpretations and definitions to challenge the stigma and oppression encountered through disability. Indeed the use of medical and social models and the interplay

between the two areas are important to this research and they will be considered throughout the thesis. These are introduced in this Chapter, they are applied in Chapter Three to consider how identity and disability can impact upon individuals encountering disability and are applied in relation to the analysis of the data to demonstrate the impacts of such discourses upon the participants.

This chapter provides an overview of the history of disability to explore how issues of disability have been responded to and perceived over time. The history of the concept of disability has been considered, in order to gain a sense of progression, context and development of thought. By seeing how disability has been conceptualised and re-conceptualised, it is possible to understand how societies have **responded to 'it', when disagreements** have occurred between discourses and what implications this may have on disabled people directly. Within this chapter a theoretical framework will be established from which to view the research for understanding the different discourses. It is not intended to cover every aspect of such a history, but will supply illustrations of how disability has been perceived and presented within Western Societies, specifically the UK. The table overleaf provides an overview of the salient points relevant to Western thought until the 20<sup>th</sup> century.

Time period	Key ideas of Understanding(s) and Attitude(s) towards Disability
<b>BC and AD</b>  <b>Greek / Roman</b>	<ul style="list-style-type: none"> <li>❖ Understandings of disability and difference were evident. Therapeutic Papyrus of Thebes, 1500 BC, referenced medical practice and 'mental retardation' and sought to classify conditions (Theodore, 1963).</li> <li>❖ Valued physical perfection; evidence infanticide was relatively common (Langer, 1974).</li> <li>❖ Hippocrates and the development of early medical schools. Commitment to treat the <b>whole person, but focus on 'curing'</b> (Edelestein, 1943).</li> <li>❖ Deaf not capable of reason argued Aristotle as they could not demonstrate intelligence through speech (Eleweke, 2011).</li> </ul>
<b>The Bible</b> <b>BC</b>	<ul style="list-style-type: none"> <li>❖ Old Testament <ul style="list-style-type: none"> <li>• Links disability to sin (Leviticus 21.16-20).</li> <li>• A <b>person can be cursed by the Lord through "Madness, blindness and bewilderment"</b> (Deuteronomy, 28:28, p212).</li> </ul> </li> </ul>
<b>Early AD</b>	<ul style="list-style-type: none"> <li>❖ New Testament <ul style="list-style-type: none"> <li>• <b>Showing charity to the 'afflicted'</b>,</li> <li>• Individuals healed and cured,</li> </ul> </li> <li>❖ <b>Curing as a form of Christ's forgiveness and salvation</b> (Luke, 5) (John, 9)</li> </ul>
<b>Medieval / Renaissance</b> <b>UK / Europe</b>	<ul style="list-style-type: none"> <li>❖ Understanding and fascination with how the body functions and medical issues developed (Siraisi, 1990)</li> <li>❖ Mental illness observed with horror and pity e.g. treatment at Bethlem Hospital (Turner, 1999)</li> <li>❖ Illness and Disability often equated as punishment, resulted in people being ostracised (Selway, 1998)</li> <li>❖ Rise in alms and poorhouses, saw distinctions made between deserving and undeserving poor (Warren, 1988)</li> <li>❖ Requirement by 1500 for communities, register and take <b>responsibility for the poor, all of whom were 'incapacitated'</b> in some way; those with accepted and recognised impairments were permitted to beg for alms and support (Solar, 1995).</li> </ul>
<b>Industrial Revolution</b> <b>UK / Europe</b>	<ul style="list-style-type: none"> <li>❖ Change in economic productivity meant home industries collapsed and disabled people who had been previously productive in their own environments were no longer able to continue (Oliver, 1986).</li> <li>❖ Urbanisation leads to breakdown of rural state system, move of so many to cities saw a growth of asylums and institutions for those not able to be economically productive (Borsey, 2004).</li> <li>❖ Rise in philanthropic hospitals and some reduction in harsh</li> </ul>

	<p>treatment, e.g. the Retreat in York (Edginton, 1997).</p> <ul style="list-style-type: none"> <li>❖ Development of sign language and Braille (Kyle et al, 1985,: Jiminez et al, 2009).</li> <li>❖ Still common for disabled people to be segregated in institutions or exhibited in freak shows to be viewed with surprise or disgust (Shakespeare, 1994).</li> <li>❖ Development of theories of evolution for some people justified a belief in the inferiority of some people over others (Barnes, 1996).</li> </ul>
<b>Victorian Era UK/ Europe</b>	<ul style="list-style-type: none"> <li>❖ Increase in philanthropic activities (Harrison, 1966)</li> <li>❖ Parallel to which saw rise in pity, sentimentality and an increasing desire to observe, categorise and segregate (Barnes, 1996)</li> </ul>

*Table 1: Key ideas of Understanding(s) and Attitude(s) towards Disability pre 20<sup>th</sup> Century*

## **2.2 DISCUSSION OF EARLY REPRESENTATIONS OF DISABILITY**

Early examples of perceptions of disability demonstrate a mixture of responses, some involving compassion and others condemnation, but all emphasising differences between disabled people and others. There is within these perspectives an underlying assumption that curing disabled people is an aim and that physical 'normality' is a desirable state for all people to seek to attain (Morris, 1991). Many argue that these values are still evident within Western societies (Finkelstein, 1993, Barnes and Mercer, 1996; Oliver and Barnes, 2012:122).

Throughout the Middle Ages there were rising requirements to respond to the needs of the poor and by the 12<sup>th</sup> century there was a requirement to discriminate between the deserving and undeserving poor. 'The Statute of Cambridge' in 1388 (Warren, 1988) distinguished between 'sturdy and impotent beggars, the decayed and the

“lazars” (Ruffhead, 1786). The benefit of this division was that it allowed those with authority to identify and provide some very basic levels of support to those people in great need. Conversely however, in order to receive such support a person needed to be defined negatively by others, thereby defining the “lazars” as indolent. Such perceptions and criticisms of being disabled remain prevalent today, which will be demonstrated later within this chapter.

**The recognition of ‘the disabled’ as people entitled to fair treatment rather than** responses solely grounded in a form of compassion was slow to develop, as has been demonstrated by the range of negative and segregationist actions outlined within the table. An instance of this is evident in the assumptions made by Aristotle relating to deaf people, as highlighted within the table; it was Cardano an Italian physician in the sixteenth century who challenged this (Sirasi, 1997). His realisation and articulation that deaf people were capable of reasoning, had taken nearly 2000 years to change the official understanding of deafness. It is clear that dominant values and assumptions about disability therefore have a longevity and resonance which must be recognised to provide appropriate context to this research.

The shift in economic activity from cottage industry to a focus on productivity effectively sidelined disabled people and instead normalised the concept of economic rationalism (Oliver, 1990). Whereas some disabled people had previously been able

to financially support themselves at home, the new systems and industrialisation meant that this was no longer possible, firmly placing disability outside the 'normal' process of income generation.

While the Victorian era did demonstrate an increase in charitable support it also presented a growing desire to categorise and medicalise; themes which were evident throughout this overview. It is plain, that by the end of the 19<sup>th</sup> century, although disabled people may not have been quite as reviled as they had been previously and while in many cases within the UK pity had superseded distrust, the segregation and ostracisation of disabled people continued. It was within the 20<sup>th</sup> century that collective challenges to the dominant views of disability and disabled people became palpable. It is here therefore where consideration of the effects of such views will be considered in greater detail.

## **2.3 20TH CENTURY: PERCEPTIONS AND REPRESENTATIONS OF DISCOURSES OF DISABILITY**

### **2.3.1 1900s – The First Fifty Years**

Throughout this period there was continued growing scientific knowledge and understanding of medical issues; disabled people have argued that this growth was also aligned within an increasing medicalisation of disability (Barnes, 1996). Parallel

to the expanding scientific and medical knowledge saw the formal development of, **and subsequent adoption of, the 'science' and policy of eugenics (Galton and Galton, 1998)**. A large number of key thinkers and politically active figures within the UK advocated eugenics, including John Maynard Keynes, HG Wells, George Bernard Shaw, Sidney and Beatrice Webb, William Beveridge and Winston Churchill (Brignell, 2010). **Advocates spoke of 'compulsory sterilisation', and an end to 'our social rubbish' (ibid)**. **Gross abuse through** abusive approaches towards genetics was also closely aligned to Nazi actions within the Second World War alongside mass extermination. Indeed at the start of World War Two, one hundred and forty thousand disabled people were killed by the Third Reich as **part of the 'final solution'** (Galton and Galton, 1998). However, this did not end the process of pathologising disability and oppressing behaviour which was seen as deviant (Ford, 1987). Western societies then did not recognise or respond to the oppression of disabled people with any sense of immediacy. While eugenic ideas in the UK may have focused more upon class than disability (Black, 2003) the ideas were thriving and vigorous within the UK particularly until 1945 (ibid). The willingness therefore of the UK, to see disability as a problem to be resolved was apparent through this period.

Wars have always increased the amount of disability evident within society and can provide alternative perceptions of disability; in that the people injured had been **seeking to 'protect' their countries through fighting (Eldar and Jelic, 2003)**.

Traditionally the support offered to people disabled when fighting for their country

has been of a higher standard than the support and provision available to people whom encountered disability through other routes (Reznick, 2000). In the USA the frustration and increasing lack of provision, recognition and opportunities to earn a living, resulted in the Union of Disabled War Veterans being formed and collective action began to be recognised as a way of ensuring the voices of some disabled people were heard (Fleisher and Zames, 2001). In the UK, British reintegration was not state organised and was very ad-hoc and voluntary with limited opportunities for future work, yet disabled veterans did not organise or articulate themselves in similar fashion. Cohen (2000) in comparing the UK and US, asserts that different reactions of the public to returning veterans made the difference. UK veterans were held in a degree of reverence and high-esteem by the wider British public. This facet of the relationship between perception, political will and public attitudes will be explored in greater detail in Chapter Three, **when considering how identity relates to a person's** reaction and response to encountering disability.

This period also saw fluctuations in the response to disabled children in the UK, for instance there was increasing formalisation of isolation and segregation. The 1921 **Education Act ensured that 'handicapped' children were educated only in 'special'** schools (Armstrong, 2007: 562). While the intent behind such legislation was not ostensibly around segregation (ibid): the intent and the impact had different outcomes, again in terms of discourses it is possible to see how the use of specific



language and isolationist policy further reinforces ideas of normalcy and difference from that normality.

The introduction of the Welfare State and National Health Service in the UK, alongside the National Assistance Act, which in 1948, saw rising of expectation of state provision for the needs of the people (Cutler and Waine, 1997). The National Assistance Act also saw an end to poor laws which had been in place since the Elizabethan period (ibid) and recognition that people who could not work or pay national insurance were also offered a safety net and were recognised as a part of post war Britain and entitled to support. Slowly the profile of disabled people was changing, for instance the first National Stoke Mandeville Games introduced the concept to the general public that disabled people could be involved in activities which were at odds with the traditional representation of passive objects of pity such as competing in sporting activities: these later became the Paralympic Games (BPA, 2011).

### **2.3.2 The Nineteen Fifties and Sixties**

The civil and human rights activism of the 1950s and 1960s influenced disabled people, who began to fight for their rights in much broader and more collective ways. The rise of new social movements saw an increase in focus and activism

amongst many people, not only those experiencing disability (Barnes and Bowl, 2001). The focus of such movements is action relating to a specific issue and / or the development of a collective identity rather than challenging the class divisions which traditional social movements sought to challenge (ibid: 135). In fact such new social movements are a more diverse group; including for example: environmental pressure groups, black and minority ethnic groups, the peace movement, **women's issues and latterly the disabled people's** movement. For disabled people, on a collective level, Oliver (1996) saw the way forward for disabled people to challenge oppression was through the materialisation of new political activities, referred to directly as new social movements (Oliver, 1996: 112). Oliver asserts that such groups are looking to challenge the way capitalist societies are run (ibid: 113), again this presented a way for the normalising discourses of economic rationalism to be critiqued and alternative accounts and options explored. Not all disability activists and academics saw the primary change as a challenge towards capitalism, but the emphasis at this time period began to incorporate more of the voices and views of disabled people themselves, rather than terms and understanding being purely **defined by 'professionals'**.

**The Disabled People's Employments Acts of 1954 and 1958 sought to regulate and encourage disabled people within the workplace.** In terms of mental health issues the Percy Report in 1957 identified the weaknesses within systems of segregation. In 1959 The Mental Health Act sought to develop a legal framework seeing mental

health issues in a similar way to physical illness, by facilitating and encouraging non-compulsory admissions and to develop provision for people not requiring inpatient treatment. It also removed some of the previous grounds for detention relating solely to promiscuity or immoral conduct (Cope, 1995) through the abolishment of the Board of Control. The constructions of the concept of what constituted disability and treatment was changing as a result, so were the discourses surrounding the subject. This was evidenced through challenges to the powers which professionals had to **dictate and evaluate each aspect of some disabled people's lives.**

The 1960s saw a growing awareness of the inequality experienced by many disabled people. While this did not result in equality, it indicated a growing trend towards understanding disability and willingness of disabled people to challenge the way they were treated. Academically and in terms of research, people were questioning the status quo of ideas and theories relating to many areas around exclusion and control, including disability. In 1963 Goffman published a seminal piece of work in relation to stigma, it incorporated recognition of the arbitrary nature of the exclusion from mainstream society and identified stigma as *"the situation of the individual who is disqualified from full social acceptance"* (Goffman, 1963; 9). While considering that stigma was a label which was externally imposed upon an individual, the work also recognised that stigmatised people themselves can hold the same stigmatising values, which in turn can affect their internal perceptions of themselves. This is particularly relevant to this research when considering the impact of acquired

impairments upon the participants. In related works the ideas of how wider society shapes perceptions towards and treatment of disabled people were evident. For instance research in the USA in relation to blind people resulted in a book by Scott (1969), which illustrated how professionals could have vested interests in keeping blind people reliant upon such services: this effectively involved socialising blind people into passive individuals and suggested that “*the disability of blindness is a learned social role*” (Scott, 1969; 14). Ideas about how external approaches influence the internal perceptions that disabled people may have of themselves will be considered further in Chapter Three in relation to Disability and Identity.

### **2.3.3 The Nineteen Seventies**

During this period self-determination including through social organisation and increasingly vocal forms of activism, continued to increase: both in the UK and other Western Societies. This can be seen as a response to the difficult and isolated lives which many disabled encountered. Barnes, C. (1990) and Finkelstein (2001) argue that prior to the development of the social model of disability in the UK, most disabled people were ostracised from society and defined by their disability. Many people with physical impairments were placed in institutions in conditions which allowed them little or no control over their lives. As a study inquiring into both voluntary and local authority institutions in 1972 famously put it, disabled people

within such institutions faced “*social death*” (Miller & Gwynne, 1972), and the likelihood of a lengthy internment:

*“...[T]he function of these establishments is to perpetuate the distance between 'social death', the point when the individual enters the institution and physical death as long as possible.”*

(Barnes C, 1990: 28)

The segregation which disabled people faced within institutions was mirrored by structural and attitudinal oppression for those who were not institutionalised. Limited employment and educational opportunities coupled with inferior housing, inaccessible buildings and services resulted in disabled people being greatly impoverished (Finkelstein, 1993).

Indeed Finkelstein likened the situation for disabled people to the repressive regime he had experienced in South Africa as he developed the idea of ‘social death’. He goes on to say;

*“I couldn't help but conclude that 'social death' aptly expressed that status of disabled people in society as a whole – we are virtually invisible in the media (television, newspapers and magazines); social and environmental barriers prevent us from playing an active role in society (particularly those who have been incarcerated in institutions); we have no serious influence on government (compared to service providers with abilities who 'care' for us); we are all to depend on 'state charity' as a source of income; and so on.”*

(Finkelstein, 2001: 6-7)

The dominant perception of disabled people in the last century up to and including the 1970s then was for their situation to be seen as a personal tragedy which

occurred to an individual. It is the person who is disabled in such a perspective, through their own misfortune.

*"This kind of individualism is closely linked to personal tragedy theories of disability and thus to biological determinism."*

(Priestley, 1999: 47)

Priestley suggests that closely aligned with the idea of personal tragedy, as a method of interpretation, is the medicalisation of disability. While both of these are individualising perspectives on the experiences of disability, he effectively argues that viewing disability in terms of a personal tragedy has facilitated core values which *"have been translated into mainstream services that are often preoccupied with care, medicalisation and segregation"* (2004; 258). The medical model asserts that an **individual's disability arises through his or her own circumstances, shortcomings and medical condition(s) or injury** and it is this that makes them disabled (Borsay: 1986, 117).

Challenging the dominance of professionals, in the way in which they defined and delineated the lives of disabled people, saw a shift in government policies and approaches, often brought about through direct action.

*".. [A] fundamental aim is to challenge dominant orthodoxies which have defined how 'mental illness' and 'disablement' are understood within a medical paradigm, which in turn serves to structure policies and services to address the nature of the 'problems' experienced."*

(Barnes, M. 2002: 323)

What had changed by the 1970s was the willingness of many disabled people to challenge the prevailing views of themselves. In frustration at the way they were being treated and the lack of control they had over their own lives, a growing number of disabled people joined together to voice their dissatisfaction and seek solutions. These changes were reflective of a range of New Social Movements and political perspectives seeking to change and challenge the dominant discourses of the time. Many discourses were confronted including the medical model, the concept that professionals knew best and traditional views of disabled people. Some groups within the UK such as the Disablement Income Group (DIG) and later the Disability Alliance focused primarily upon a national disability income (Oliver, 1996: 20). Other disabled people wanted to challenge a wider range of issues rejecting the way they were treated, perceived and controlled through cultural ideologies such as the medical model. One group which sought far wider changes was the Union of Physically Impaired Against Segregation (UPIAS). In 1976 UPIAS met with the Disability Alliance and were frustrated by what they saw as the elite, academic nature of the Alliance, and so felt it necessary to develop a criticism towards this (Finkelstein, 2001: 6). The challenge to the Disability Alliance resulted in the UPIAS **'Fundamental Principles' document.**

*"Fundamental principles to which we are both in agreement: disability is a situation, caused by social conditions, which requires for its elimination, (a) that no one aspect such as incomes, mobility or institutions is treated in isolation, (b) that disabled people should, with the advice and help of others, assume control over their own lives, and (c) that professionals, experts and others who seek to help must be committed to promoting such control by disabled people."*

(UPIAS (1976) Quoted in Finkelstein, 2001: 6)

This document and the related ideas and impetus came from Vic Finkelstein and Paul Hunt, founder members of UPIAS. Mike Oliver, a fellow member, then took up these ideas and promoted, developed and articulated what came to be known as the social model of disability. This and parallel alternative interpretations of disability in different parts of the world have given rise to great debate and a shift in thinking and which, in conjunction with the ideas of civil rights and independent living, have continued to shape, challenge and inform attitudes towards disability and disabled people ever since (Oliver, 1999).

### **2.3.4 The Introduction of the Social Model of Disability**

The rise of the social model in the UK grew from an increasingly vocal group of activists frustrated at the approach of existing organisations, which they felt maintained the overriding perceptions of disabled people, rendered dependent



**through their personal 'tragic' circumstances arising from** medical abnormalities or bodily impairments including injury. Instead they rejected a medical model that a person should be defined and constricted by a medical diagnosis, often imposed upon a disabled person by professionals. The social model of disability arose then from the needs of disabled people to have control over their own lives, challenge discrimination against them and assert their rights to appropriate and accessible services, employment and full involvement in social activities. The key distinction which the social model makes between the impairment, as the functional limitations, and disability, as the barriers which society imposes upon the disabled person, meant that disabled people were able to challenge discriminatory societal practices.

*"...[I]f a disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance."*

(Oliver, 1990: 2)

The clear distinction between the impairment and disability allows for an exploration of the barriers which disabled people face. It also emphasised the responsibility for disability on society as a whole rather than the individual: providing further evidence of the dominant discourses being challenged, the increases of alternative interpretations and discourses provided alternative ways of viewing disability. How these distinctions and shifts in perception have affected disabled people, particularly those who have acquired impairments, can be evaluated within this work.

The United Nations Declaration of Rights of Disabled Persons in 1975 called for economic and social integration of disabled people (Equal Rights Trust, 1975). It was a further example of a shift in focus, and it seemed that more non-disabled people allied themselves with disabled people and were able to recognise the inequalities which disabled people face and seek to work with disabled people to try to change **the situation. Disability activism has increased dramatically since the 1970's, much** of which appears to be related to the development of the social model of disability, while the medical model has lessened in its authority and importance in some areas. Indeed Finkelstein (1999: 2) argues that

*"... the growth of the world-wide disability movement has shaken this comfortable cultural dominance."*

This demonstrates that some shifts in thinking had occurred, and the nature of these changes for the participants of this research can be considered.

### **2.3.5 The Nineteen Eighties**

The 1980s saw an increase in anti-discrimination legislation and direct action, both internationally and within the UK. For instance 1981 was International Year of Disabled People (Disability Action, 2011), followed in 1983 by the United Nations Decade of Disabled People (United Nations, 1993). On a national level increasing organisation and action continued including the first Coalition of Disabled People in

the UK formed in Derbyshire (Davis and Mullender, 1993). Many disabled people however were unable to use conventional methods of involvement with political processes to challenge policy and provision as they continued to face inaccessible buildings, limited employment and educational opportunities and other structural and attitudinal barriers (Barnes, C, 1996). This activism within the disability movement became a way in which disabled people could build a collective identity and seek to challenge the way they were treated. The collective force of disability activism and **on a personal level some disabled peoples'** self-perception, has a close link to the social model. Many activists and disabled people testify to the importance that it holds for them, both on a personal and collective level (Oliver, 1990; Morris, 1991; Mulvany, 2000; Tregaskis, 2002).

On a personal level for example, a disabled activist and academic attests to the freedom experienced through adoption of the concept of the social model:

*"How liberated I felt when I realised I was not the problem and no longer had to apologise for my existence."*

(Campbell, 2002: 472)

Such positions of course do not represent the views of all disabled people and some of the perceptions of people who were not freed by the concept are considered on page 39.

Prior to the development of the social model of disability, and decades of activism, life for countless disabled people involved institutionalisation and oppression. Such models were predated by individualist and tragedy conceptions of disability, which are associated with the medical model (Crow, 1996). As a result, discourses including the social models and approaches can be seen as seeking to challenge organisational structures and perceptions. However it had a much greater impact as it challenged the way in which disability is seen, and seen to be constructed, and it is this element that has significant consequences regarding how disabled people are perceived and the policies and procedures relating to disabled people as a result.

Disability activists appear to have varying degrees of success depending upon the government, issue, funding, political climate and other variables, but as Colin Barnes pointed out,

*..."[T]hroughout the 1980s there was a growing campaign to persuade the British Government to introduce anti-discrimination legislation in order to enable disabled people to participate fully in the mainstream economic and social life of society. Increasingly, disabled people and organisations controlled **by them have come to play an active role in this campaign.**"*

(Barnes, C, 1991: 1)

The legislation which is included within this review is by no means exhaustive; it is intended to illustrate how the challenges to oppressive practices and regulation made by and with disabled people facilitated changes in approach, thereby showing shifts in responses to disabled people within the UK, and arguably the perceptions of disabled people themselves.

The early nineteen eighties also saw the first Centres for Independent Living (CILs) established within the UK and the establishment of the Independent Living Fund. This propounded the idea that disabled people had a right to independent living which should be provided by right, rather than at the discretion of professionals (Morris, 2011). However a dominance of governmental preference for supporting organisations run for disabled people rather than by them remained in evidence. **Indeed even disabled people's organisations were run for disabled people by professionals;**

*"...shaped by the traditional assumption that people with impairments are unable to make basic decisions about their own individual service needs."*

(Oliver and Barnes, 1998: 44)

In 1989, the Government awarded £7 million to charities and organisations run for disabled people and £35,000 to organisations run by disabled people (CDP, 2011). While a larger number of charities are run for disabled people rather than by them, (ibid) this indicates a disparity in how organisations run by disabled people were perceived at this time. If disabled people are only offered services when administered by professionals, without the opportunity to shape those services, they can be placed in a position of perceived helplessness and are arguably reliant on the munificence of non-disabled people in order to access provisions. There were increasing cuts, benefit changes and a process of deinstitutionalisation of many **people through 'care in the community' policies at this time (Parker and Clarke, 2002).** It is clear that the dominant discourse of professionalism was still holding

relevance at political levels and policymakers still viewed professionals as often the best people to make decisions regarding disability policies. Professionals used their perceptions and assumptions of disabled people to shape service provision instead of disabled people articulating their own needs (Oliver, 1990). Disabled people therefore had been assumed to be incapable of taking control of their own lives; **effectively locating the 'problem' with disabled people and the 'solution' with the non-disabled.** However the fact that any monies were given to organisations run by disabled people indicated that recognition of alternative discourses had been established and some discourses now allowed for the possibility that disabled people may have some relevance in shaping their own experiences.

It was not that professionals sought intentionally to suppress disabled people; they were, contends Borsay, *"operating under perspectives which dictated their actions and lead them to believe the only effective option was to identify the condition, see it as a problem and seek to treat or cure it"* (1986:127). Further evidence of the dominance of discourse at this time, shifting the emphasis and causality of disability away from solving a medical defect within the individual and instead concentrating on the structures which disabled people with impairments allows policy development and service provision in relation to disability to be challenged by disabled people. The new models also offered other ways for disabled and non-disabled people to perceive and comprehend disability.

The change in the way disability was viewed and defined then can be seen to have been instrumental in bringing about a shift in thinking in relation to disabled people.

*"The social model works well on a large scale – it is succeeding in tackling discriminatory social structures and demonstrating our need for civil rights legislation."*

(Crow, 1996: 56)

However Crow goes on to critique the social model for what she sees as the limitations of the position and this is considered on page 41.

### **2.3.6 The Nineteen Nineties**

The focus of the legislation considered within this chapter has been predominantly intended to inform the understanding towards attitudes regarding disabled people. It has therefore focussed upon anti-discrimination legislation. In particular, after years of disabled people and activist groups striving towards anti-discrimination legislation, the Disability Discrimination Act of 1995 was introduced. It was enacted in response to decades of campaigning on the part of disabled people and since the first attempt to introduce legislation in 1982, fourteen other attempts had been made to put legislation in place to improve civil rights and outlaw discrimination. The DDA 1995 however, was not a panacea, and can be seen as a contentious piece of legislation (Disability Research Unit, 1996), which whilst spurred on by an increasingly vocal and

organised collective of disabled activists, was felt by many to not go far enough to address the discrimination that disabled people experience. For example by considering the meaning of disability ascribed within the Disability Discrimination Act 1995, (DDA) it is possible to see an inherent tension between the discourses of the medical and social models of disability. The Act utilises the word impairment, more commonly associated with the social model; yet it is the impairment that has the **'adverse effect' rather than the disability which society may present (OPSI DDA, 1995).**

A further set of legislation within this time period, the NHS and Community Care Act 1990, is considered here in recognition of how it indicated the changing and increasingly complex relationship between government, legislation and disabled people (Parker and Clarke, 2002). The Act introduced a range of duties and requirements upon Local Authorities and NHS, dividing the role of purchasers and providers of services. Therefore Local Authorities were required to assess people for the support they may be entitled to, and seek the services in an internal market based economy rather than supplying them directly. It also sought to provide community care for people with long term needs in their own home, with adequate support. The discourses and rhetoric around these changes emphasised the choice and control which disabled people would be able to have in making their own decisions about accessing services and engaging in direct participation and greater



control over their own care (Bowl, 1996). These changes were controversial and confusing and moved the focus of providing services to those in need to a wider range of possible sources, resources and competing priorities and providers (Ajayi et al, 1995; Hudson and Hewood, 2002).

The community care elements of this legislation also saw the development of carer focussed approaches alongside these reforms (Langan, 1990). Some disabled people have been critical of such approaches and asserted that placing expectations upon informal carers, recognising their needs and assuming the people they care for to be **'dependants' detracts from the rights and needs of disabled people themselves** (Morris, 1997). Whilst the concept of carers has been recognised for many years to be based upon a set of gendered assumptions surrounding who should undertake such care (Land, 1978). In terms of this research therefore a context and discourse has been presented which suggests a complex and unsettled set of procedures and perceptions of disability, care and disabled people.

Evidence of changes into the way disabled people were perceived and the way government sought to perceive them were also evident during this time. In the public realm this was encapsulated when Glenn Hoddle, manager of the England football team, was sacked in 1999 for linking disability to sin (Haller and Ralph, 2001). **Considering the public response to Hoddle's perspective, it is evident that**

views had changed from the prevailing ones of previous centuries, outlined in the table earlier in this chapter and disability was no longer seen as a form of punishment for the majority of people in the UK. The Labour Government also **launched a 'See the Person' Campaign** in 1997, seeking to directly challenge how disabled people had traditionally been viewed, though this was criticised by disabled people for predominantly focussing upon physical impairment (Shakespeare, 2001). It is important for a broader range of experiences and impairments to be included within representations of and approaches towards disability, to allow more disabled people to be recognised as such. The research considers the experiences of people with a range of impairments, both those which are physical and those which are not, and those which are visible and invisible. Thus querying how disabilities have been perceived and how these manifestations can create limitations for disabled people whose experiences and impairments are not accurately represented. Further consideration of how identity and stigma relate to representations of disability will be considered in Chapter Three.

### **2.3.7 The 00s**

The beginning of the 00s then was a time when general awareness of disability was increasing and there were some opportunities for disabled people to break away from some of the confined roles and opportunities which had been previously open

to them. One indicator of this was 'Improving the Life Chances of Disabled People', a report from the Prime Ministers Strategy Unit, which laid great emphasis on the need for disabled people to have control over their own lives and explicitly endorsed the social model.

*"Disability is the disadvantage that comes from barriers which impact on people with impairments."*

(PMSU, 2005: 19)

On one hand the recognition and inclusion of disabled people, their ideas and ideological vocabulary, particularly evident on the 00s, shows that policymakers recognise the need to involve disabled people in the development of policies and services. On the other hand this acceptance could suggest that government and policy makers now espouse disability activist language in a bid to avoid criticism and increase acceptance of their policies (Morris, 2011).

Government policies have now developed in such a way that statutory authorities are required to consult with disabled people and other traditionally minimised groups, but the inclusion of public involvement as official policy is a motivating factor in the consultation process. For example Section 11 of the 2001 Health and Social Care Act places a duty on all NHS organisations to involve patients in the planning and development of services and decisions affecting the operations of those services (Health and Social Care Act, 2001: 11). There are however many allegations that such consultation can be tokenistic; see for example research undertaken by the Joseph Rowntree Foundation (2003, report no 683).

The Disability Discrimination Act 2005 (DDA) widened the remit of anti-discrimination, for example increasing the organisations and services which must ensure that they do not discriminate against disabled people and placing a duty to promote equality of opportunity on every local authority. However it did not substantially alter the definition of disability, although the removal of a clause in relation to mental illness and the meaning of disability within section 18 [(2) paragraph 1 (1), accepted that an individual could be experiencing mental illness whether or not it had been clinically recognised as a basis of their disability. This lessened the importance attached to professional diagnosis for people with mental illness to have been professionally categorised in order to be defined as disabled, suggesting that the challenges made to the Act by disability groups and that the cultural values imbued within disability discourses are slowly changing (Roulstone and Prideaux, 2012: xvi). The dominance of the medical model is declining in some areas, as the Act now appears to recognise that a person does not have to have been clinically diagnosed and authorised in order to be recognised as having impairment.

An indication of the shift in emphasis by the government of the day in relation to disability issues is shown by the Disability Rights Commission (DRC). The Commission was formally opened in 2000 as a result of continued campaigning about the inadequacies of the Disability Discrimination Act. It gave voice and platform for

disability awareness and policy into the mainstream agenda. It included amongst its policy makers many disabled people, including Bert Massie as chairman and Jane Campbell; disabled people therefore were involved in evaluating and developing policies relating directly to disability. In September 2007 the DRC was closed down, and in October 2007 a merged Equalities Commission was established which combined the roles of the DRC, the Equal Opportunities Commission and Commission for Racial Equality (Direct Gov, 2008). While this may have limited the power held by each individual commission, it illustrates that disability has become an issue within the mainstream policy agenda. Whilst there was concern that this new single body should recognise the specific needs and experiences of disabled people (Massie, 2004); it is evident that activism and the social model have enabled disabled people and supporters effectively challenging both policy and perceptions of disability (Oliver and Barnes, 2012: 22). Though the degree to which arguments concerning conceptions of disability have been resolved or reduced remains a contested issue. Facets such as individualised budgets and direct payments are hard to negotiate and in times of austerity can also be viewed as easier to cut (Morris, 2011: 11). There remains a danger that personalisation may again revert to individualisation and a loss of the power of collective voices and action (ibid: 12-13).

## **2.4. ONGOING ISSUES IN RELATION TO THE SOCIAL MODEL OF DISABILITY**

There remain criticisms with the social model of disability, although it can be seen to have directly influenced a great deal of political activism and enabled disabled people to challenge how they are perceived and treated to develop collective action. Yet the models open to disabled people with which to challenge the orthodoxy did not and do not fulfil all the needs of all disabled people.

Disabled people with different impairments at times have distinct and incompatible requirements.

*"How, for example, do we resolve the conflict between visually impaired people who need public buildings, such as supermarkets and health clubs, to be brightly lit, and those who need the lighting to be dim, or those who need yellow stripes on steps and those who need them to be black or white?"*

(French, 1993: 21)

The implications of these competing needs make it harder for governments to respond to the needs of all people who may wish to use a service or become involved in local activities that may or may not be related to disability. Consider for example a Local Authority, which will inevitably have a fixed income, it is unlikely that provision will be made to facilitate all people with impairments on each occasion. If a public meeting is to take place for example, how should a Local Authority seek to ensure the building can respond to the needs of all and ensure that it is wheelchair accessible, has Braille signage, has contrasting colours, a sign language interpreter

standing by, that material is available in a broad range of formats and a wide variety of other requirements which disabled people may require in order to attend? The range of resources required and responsibility regarding which agency should meet the costs would be significant. Unless such a meeting specifically related to disability issues it is unlikely that all potential needs would be met. It may not be possible to identify all the requirements beforehand or justify this as an effective use of resources. From the perspective of this research therefore it is possible to compare the resources, provision and information accessible to the participants who have different impairments and disabilities.

There remains some trepidation in critiquing the social model of disability and related concepts. French asserted this is why disabled activists for many years:

*"have found it necessary to present disability in a straightforward uncomplicated manner in order to convince a very sceptical world that disability can be reduced or eliminated .....dwelling on examples which fail to fit the social model of disability comfortably might provide ammunition for those with the power to oppose and prevent progress."*

(French, 1993: 24)

However she cogently argued that the broad range of impairments and experiences of disabled people must be acknowledged and taken seriously in order to avoid alienation, develop understanding and seek creative ways to reduce disability (French, 1993: 22-23).

Other disabled people also began to engage with this topic and were speaking out around this time. Liz Crow **in her work** '*Including all our lives: renewing the social model of disability*' (1996), whilst acknowledging the values of the model, (considered earlier in this chapter) she recognised that creating a silence around the issue of impairment and excluding it from analysis is far from helpful:

*"The experience of impairment is not always irrelevant, neutral or positive."*

(Crow, 1996: 209)

The changes which have occurred as a result of activism are evident; the inclusion of disabled people within local policy development for example shows a dramatic shift in the approach of service providers towards disabled people. However there has been criticism that some disabled people do require care and that disability activists have devalued this. For example Priestley (1999) has argued that this highlights fundamental debate between policy and disabled activism over the extent to which care and control overlap or are seen as synonymous, while Hughes (2009) asserts that there are increasing numbers of disabled people who are **within 'social movements in health'**. Many disabled people themselves endorse the need of medical diagnosis, treatment and the possibility of cures (Brown and Zaverstovski, 2004).

We have seen that the social model of disability has had tremendous impact on **many areas affecting disabled people's lives; yet there remain on-going debates and challenges** in relation to the social model. When the model was developed the vast majority of those involved were wheelchair users, (Finkelstein, 2001) and were white



and male. For many people debating the social model, questions remain about precisely who can or should be included within the collective identity of disabled people, this will be considered in greater detail within Chapter Three.

Some people working in areas related to disability have challenged elements of the social model and the way it has been used, suggesting that it excludes certain groups, such as older disabled people (Priestley, 2000; Oldman, 2002); or that does not take into account the nature of different impairments and their longevity or brevity (Burchardt, 2000). There has been very little research undertaken regarding the diverse range of impairments and the attitudes of disabled people towards **people with different impairments to their own. Deal's (2003) work examining disabled people's attitudes towards other impairment groups cites the limited** exploration in relation to the area of research, but concludes that:

*"...not only does a hierarchy of impairments exist for non-disabled people toward different impairment groups, but disabled people also hold differing strengths of attitudes towards different impairment groups."*

(Deal, 2003: 906)

Deal has personally experienced disabled people with some impairments disassociating from people with other impairments when undertaking disability equality training (Deal, 2003: 898). In particular it seems that people with a physical impairment are often keen to distance themselves from those with learning difficulties. Deal (2003: 903) goes on to cite debate on the University of Leeds,

Centre for Disability Studies web-site ([www.leeds.ac.uk-disability-studies](http://www.leeds.ac.uk-disability-studies)) under the heading *'An open debate to neuro-diversity! – no labels'* in which disabled people debate what constitutes disability. Neuro-diversity as defined by the Developmental Adult Neuro-Diversity Association (DANDA) refers to people experiencing a range of **conditions including Dyspraxia, Asperger's Syndrome, and Attention Deficit (Hyperactivity) Disorder**. DANDA is a registered charity run by adults with one or more of these conditions (See <http://www.danda.org.uk/>). Within the debate about **what should be defined as disability, opinions include the need to 'validate' certain impairments and the belief that 'newer impairments' are often 'socially constructed'**. Indeed some contributors questioned the inclusion of mental illness, non-visible **impairments and anyone who can appear 'socially acceptable', asserting that those** who have not suffered the oppression of special schools will have more social skills and dominate the disability movement. Contributors asserted that neuro-diversity is a **'reinforcement' of non-existent new impairments** and that including people with the newer impairments will reduce the finances and importance attached to disability rights in general. While other contributors strongly challenge such perceptions, it does suggest that for some disabled people there is a significant hierarchy of impairments.

Similarly the social role valorisation model adopted by some disabled people particularly within the area of learning disabilities (Race et al, 2005), asserts that

**vulnerable groups are subject to common experiences or 'wounds' (Race, 1999: 44)** which result in them being devalued within society, leading to stigmatisation and segregation. It has been strongly rejected by disability activists advocating the social model of disability, such as Gilbert (2004) and Walmsley (2001) as the value of achieving social accepted social roles, asserts critics, is too high a price to pay in that it is too closely associated with normalisation (Race et al, 2005). This demonstrates further some of the fears associated with the social model directly, that any development or nuance which is perceived as at variant with the model results in a process of compounding the oppression and moulding individuals into what the wider society wants (ibid :513).

Tom Shakespeare has often been challenged by others in the disability movement, and his work has been described as **"controversial"** (Edwards, 2008). This was **particularly evident in the response and 'backlash' from his 2006 book, *Disability Rights and Wrongs*, which was substantial within the disabled people's movement in the UK (Sheldon et al, 2007).** Shakespeare asserts that the UK version of the Social Model of Disability is stagnant (Shakespeare, 2006:1) and that refusing to acknowledge the importance of issues such as biology, pain, impairment and the possibility of cures disadvantages disabled people further. His insistence that ***"Comparatively few restrictions experienced by people with impairment are 'wholly social in origin'"*** (ibid: 41) appears to inflame other disability activists. Instead

Shakespeare makes a plea *"for a more nuanced, interactional approach that does not mistakenly bracket bodily difference or dichotomise impairment and disability"* (Sheldon et al, 2007: 210). Some people within the disability movement assert that this approach *"undermines any attempts at social change"* (ibid). The apprehension that facilitating inclusion of gradation and variation will lessen the strength of the position is understandable, and possibly even correct, but it does not ameliorate the challenges which disabled people may experience who feel that they do not fit within the existing paradigm.

Other critiques of social and barrier models arise from the difference which disabled people encounter in their lives to each other as well as to the mainstream society. Ed Roberts coined the term **'TAB' for people who were temporarily able bodied**, (Scotch, 1989); this recognition that many people are disabled at some points in their lives illustrates the fluid nature of what constitutes disability. There are many people whose impairments **do not fit into simplistic and distinct representations of 'impaired' and 'disabled'**. For instance if an individual who has been impaired is 'cured', it may be hard for them to reconcile with binary distinctions of disabled and not disabled. Whether or not the memory of the oppression which a formerly disabled person encountered is recognised, it is hard to see how the same people either represent that very same oppression or are accepted as disabled in the same way, by other disabled people as their experiences have changed (Beauchamp-Pryor, 2011). Deal

(2003) asserts that disabled people also often have their own prejudices in relation to other disabilities. This can result in a person whose disability may be perceived by **some other disabled people as 'socially constructed'**, unable to feel accepted or recognised despite the oppression and barriers they face.

The debates amongst disability activists have not abated, for instance, Oliver and Barnes recent work retains a distinction in conceptualisation between impairment and illness (2012:40). Yet for many disabled people and the participants considered here, it is not evident that such a distinction can be maintained. As Oliver and Barnes rightly state, responses to disability and impairment are rarely uniform and instead there are a myriad of responses, which can be as individual as the people who encounter them (ibid:41). The tension between the individual nature of responses towards disability and the societal barriers which disabled people encounter cannot be suppressed. This does not negate the social model or the substantial benefits brought about by it, but for some disabled people there is a need to locate how, for example, people with learning difficulties, mental health issues, non-visible disability or dual sensory impairment can be included and empowered within the model. This has been borne out by the consideration within this review of how different impairment groups perceive each other (Deal, 2003), the need for social models to be aligned with mental health service users (Beresford, 2002) and people with learning difficulties (Williams and Heslop, 2005).

There are two particularly important discourses considered within this chapter: the medical and social models of disability. It has been demonstrated that neither can entirely capture the experiences of disabled people. This research applies a critical realist perspective, which will be outlined in Chapter Four. It recognises therefore that seeking to describe or analyse a situation from one single such perspective has limitations. In considering the structural, macro elements of disability and the individual, micro personal perspectives and being clear about the tensions between the two, a deeper understanding of the experiences of the participants is sought.

Unsteady understandings or conflicting discourses of disability can leave some individuals unable to position themselves within such a paradigm, and be unclear in **assessing where they 'fit' in such a rigid definition which does not reconcile with their personal experiences. It is not someone's impairment alone however, or the nature of the disability which they face which necessarily shapes a disabled person's life. An** individual is constructed by a range of different aspects and experiences; disability is **only one facet of a person's identity. There are many other ways in which a** person may perceive themselves, as a woman, a member of an ethnic minority or as a lesbian, for example (Fawcett, 2000). The issue of identity and disability will be considered in Chapter Three, but it is useful here to recognise other elements of a disabled person in addition to barriers and oppression they encounter. The tendency by some disabled activists to present disabled people as a homogenous unit has

been considered, which leaves little room for a different sense of identity or incorporation of dissimilar aspects of life experiences. There is a danger that such actions could result in a form of cultural oppression and oppressive practices in themselves (Ghai, 2002:94-98).

## **2.5 CONCLUSION AND REFLECTIONS IN THE CONTEXT OF THIS RESEARCH**

It has been demonstrated how the dominant discourses in relation to disability have shaped attitudes towards, and legislation in relation to, disabled people. Simultaneously reference has been made to the attempts of disabled people to improve the way they are perceived and treated by the wider society within the UK.

In this chapter an exploration of the perceptions and societal responses towards disability has also been considered. These demonstrate some of the macro, external structures which disabled people encounter. Historical analysis presents the medicalisation of social problems as a process by which disabled people became categorised and defined by their impairments and were limited through this **'embodiment of disability'** (Morris, 1991; Clear and Gleeson, 2002). Therefore instead of seeing a person (with an impairment or disability), the process of medicalisation **resulted in the person being lost in the stereotypical representation of 'their'** disability. The ownership of that disability, and by implication the responsibility for it,

was also placed upon the individual; effectively distancing the wider society from any responsibility. The process of medicalisation is asserted to arise from western values, in particular the rise of science and development of professionals. This resulted in the categorisation and definition of medical conditions and in turn limiting and one-dimensional labels being applied to disabled people (Oliver, 1990; Finkelstein, 1993 & Priestley, 1999). Such labels had a dual effect both on the individual person and in distancing society from how disabled people are treated.

*"... [T]he medicalisation of social issues tends to depoliticise them. Thus, the embodiment of disability depoliticises discrimination and obscures the lack of state intervention for its amelioration."*

(Priestley, 1999: 49)

Such was the dominant discourse which framed discussions, policies and understanding of disability prior to the development of alternative models. The next chapter will consider how this approach has affected disabled people on an individual level.

The social model of disability has been shown to be a radical force in reframing **disabled people's experiences, but one which could not be expected to resolve all** inequality facing disabled people. While some disabled people with different impairments and experiences may not be able to align themselves directly with the social model, its existence has enabled many disabled people to organise themselves and oppose discrimination. Despite these facts most people with impairments remain disabled and often isolated by a lack of resources, including information, attitudinal



barriers and inaccessible structures. Indeed many disabled people are not aware of the social model and view themselves as disabled due to their own circumstances rather than having a disability imposed in addition to their impairment; such a distinction is not one which all disabled people have made. Other disabled people shy away entirely from seeing themselves as disabled, because of the negative connotations which they associate with the term (Finkelstein, 1993: 13). However many non-disabled people are not aware of such models either, and continue to perceive some disabled people as tragic figures. The range of different experiences encountered by the participants, in addition to the complexity of disability related concepts, means that no assumptions can be made at this stage as to whether the social model of disability has resonance with the experiences of the people contributing to the research.

This research therefore recognises a model of disability which relates to something externally imposed upon an individual by the wider society. It recognises that many, though not all of the barriers which disabled people face are as a result of structural, physical, interpersonal and ideological barriers. The methodological decisions which have been made in relation to data collection will be considered later within the thesis and are intended to analyse the nature of these barriers. The research will also explore the subjective experiences of impairment, the micro perspectives of the individuals. As was considered earlier the social model works well on a large scale

(Crow, 1996: 56) but such a structural approach is not sufficient in trying to understand individual experiences. In addition not all disabled people are aware of the social model and therefore do not apply it to their own experiences. The participants within this research have personal and unique experiences and impairments; the thesis therefore will seek to reflect those experiences individually while recognising that wider structures in which they live their lives.

Chapter Three will next look in greater detail at the micro, individual aspects of, and responses towards, disability. This will be achieved by considering theories in relation to disability and identity.

## **CHAPTER THREE: IDENTITY AND DISABILITY**

### **3.1 INTRODUCTION**

This chapter considers how identity will be applied in the context of this research, specifically in relation to disability. The concepts of structure and agency in relation to identity in this thesis are outlined, before a detailed consideration as to how social identity theory can be applied in two distinct strands. The chapter then explores disability and identity, beginning with how the social model of disability considered in Chapter Two can impact on disabled people and challenge the ideas and assumptions which have been associated with disabled people. The broader issue of perceptions of disability both amongst disabled and non-disabled people will be used to inform how an individual may be able to respond and relate to their own disability. Finally the implications of the findings of this focussed review of identity literature will be considered in relation to this research.

### **3.2 DEFINITIONS IN THE CONTEXT OF THIS RESEARCH**

The exploration of the interplay between the micro and macro, structure and agency is a core aspect of this research. The concepts of structure and agency within social sciences have a long and complex history and it will be considered in detail within Chapter Four relating to methods and methodology. But it is important to point out

at this stage that there are on-going debates and discussions regarding how much freedom an individual may have to act in a way of their choosing and to what degree those actions are shaped by the wider structures of the society in which they live. The structural elements of a society or situation may be viewed and described as the **'macro'** and the immediate field of agency of action for the individual as the **'micro'** (Lee, 1990).

Identity then as this chapter demonstrates, can be viewed as the negotiation of the individual in a wider society and the interplay between self and others. Participants sought to access information, services and support at a time when they had encountered a change in their lives in relation to acquirement of impairment. Later in this chapter, consideration will also be given as to how such a process may also bring about an individual's negotiation with their own identity.

There are many ways in which to analyse and theorise about the concept of identity, such as the subject of language, philosophy through Descartes, Nietzsche, Heidegger and social anthropology (Edwards, 2009; Hall, 1992 and 1996; Holt, 2002, Martin and Barresi, 2003; Hall, 1992 and 1996). In the area of psychology, through the work of Erikson, Marcia, Laing and Harré (Gross, 2010), various applications relating to identity and the self-have been established. Here it is explicitly applied through social identity theory and so in this context I will be using identity as a tool with which to link the lived experience with the wider social systems and to explore the

dissonance which can occur between how a person sees their own identity and the ascribed identity which may be applied to them. Identity here refers to processes and understandings that affect everyone, both internally and externally.

'Structuration', is a concept devised by Giddens, as a way of explaining and exploring the interaction between human agency and social institutions (Giddens, 1984). It will be developed more fully in Chapter Four, but the interface between structure, agency and reproduction and development of the social world is considered important to understand the way in which individuals operate. In terms of identity it is useful to see how structuration can be applied.

*"Identity is a meta-concept that, unusually, makes as much sense individually as collectively, it is strategically significant for social theoretical debates about 'structuration' and the relationship between the individual and the collective."*

(Jenkins, 2008:18)

### **3.2.1 Identity in the Context of Structure and Agency**

The degree of agency which an individual may or may not exhibit in a given structure within the context of a wider society is something recognised and debated extensively within theories relating to identity (Smith and Sparks, 2008). Identity is relational and our understanding of ourselves and others is shaped by both structure and agency: identity then can be seen as a process (Barth, 1969; Tajfal, 1981), by which individuals are classified and may classify themselves and others. Social

categorisation research is a major field within social psychology and indicates that such classifications are rarely neutral (Jenkins, 2008:6), as will be considered in detail below in recognition that self-identity and ascribed identity imposed or applied by others. However identity is never completed, therefore it is an on-going and reflexive process.

Identity then is not static or fixed, but in continual development (Jenkins, 2008, 5). People can often be defined or define themselves through one role or aspect of their personality within a certain context, and perceive themselves and be perceived completely by different criteria in another setting. For example a man could be defined and see himself as a strong and aggressive boxer in one part of his life and a gentle and nurturing father could be an equally valid classification as another role in his life and part of his self. It is the relational and contextual elements of identification then which illustrate its fluidity.

In time our understanding and perceptions of ourselves and others may change as we develop understanding of further information or develop insights into other **aspects of a person's life. As a reflexive process it is never complete and so can be viewed as "continually under construction" (Galvin, 2005:394).** Narrative identity has a wide range of interpretations; those which are particularly pertinent here recognise that individuals employ narratives in order to create and maintain a sense of cohesion about themselves and seek to integrate and explain life events into that

narrative (Singer;2004, 439). The temporal nature of narrative identity, as considered by Mead (1929), strengthens the idea that a narrative identity is hugely responsive to the circumstances which a person may encounter. In light of this, the experiences of the participants when seeking resources at a time when their identity has been challenged or possibly altered by impairment and / or their own or others reactions towards it, is of great interest.

In terms of social identity, individuals decide how to treat other people depending upon how they define and identify them, and such classification is not consistent. It is therefore as much about what is seen as different and distinct, as what is seen as **aligned and the same**: "*identities are constructed through, not outside, difference*" (Hall, 1996;17). Aspects of what constitute a social identity for any individual cannot be assumed or presumed at this stage. A process of difference is not the only way in which people define and perceive others, but community, social life and sense of belonging are as much shaped by what we do not feel ourselves to be as much as what we are (Butler, 1993).

### **3.2.2 Structure, Agency and Identity in the Context of this Research**

This research considers how people negotiate structures within society to access information, services and support; it is helpful therefore to explore how much the individual has agency to influence the outcomes of their search for such resources,

or indeed whether or not they choose to seek such services at all. Although this issue will be considered in greater depth in Chapter Four, it is foregrounded here in relation to identity. It is not individual actions or reactions to the wider structures which create an identity, but the cumulative collection of actions which people sew together to create a narrative understanding of themselves and their lives (Smith and Sparkes, 2008). The question as to **whether 'dispositions'** (Lemke, 2008), or tendencies to act in certain ways are shaped more by the decisions made of the individuals concerned or by the circumstances which they find themselves encountering, is not one which I propose to answer at this stage, but may be illustrated by the data collected. The issue of structure and agency is raised here to highlight some of the areas which will be explored by the research.

There are conflicting demands and expectations placed upon individuals which may have consequences upon the identity of that person. For instance governments, agencies, employers, and mass media all have representations of how model citizens should behave (Potter, 1996; Woodward, 1996). If an individual is unable to move away from these ascribed roles, they are left to negotiate a compromise between what they want and what society will allow. The on-going structural patterns which people face can establish pathways. For example, if a person repeatedly encounters challenging situations, they may come to expect these to continue in the future and deal with further situations retaining expectations brought about by past events (Carr et al, 2001). People who have repeatedly experienced difficulties and delays in



accessing benefit provision for example are much more likely to anticipate future challenges and approach service provision with trepidation (Wilding, 2009). In terms **of this research, it is likely that people's experiences will be affected by how they see themselves**, which in turn will be informed by how they may think wider society perceives them and how they relate to and account for the those perceptions and the experiences which they encounter. It may be that some participants do or do not see themselves as disabled for example, or that their attitudes towards their own **and other people's experience** of disability alter throughout the research period

Identity can and should mediate between lived experience and socio-structural approaches (Lemke, 2008). As considered above, identity is not fixed but changes substantially between the roles we inhabit and the social identities to which we are assigned or ascribe to ourselves. **The very "multiplicity and hybridity of postmodern identities" (Lemke, 2008: 18)** means that sometimes we are forced to pretend, or at least undertake activities and positions which we believe are expected of us, rather **than accurately reflect ourselves, through being "taught not to reveal in public realities which contradict the illusion of cultural norms" (Lemke, 2008: 20)**. A significant element of our identity then is made up of how we feel we are expected **to behave, or concealing our 'real' identity during our interaction with other people**, as these can shape our own understanding of ourselves. The degree to which the participants may be forced to undertake such roles in order to access what they need is therefore of interest.

The contradictions with which people are faced do not automatically allow space to negotiate with the differing perceptions placed on them. For instance if a person is asked to demonstrate incapacity to work in order to access benefits, this does not mean that they cannot or should be not able to access some pastimes and leisure activities of their choice. There is evidence to suggest that negative perceptions, **such as that many people accessing disability benefits are 'scroungers'**, has a significant effect upon some of the people who feel they are described by such terms (Garthwaite; 2011).

### **3.3 SOCIAL IDENTITY THEORY**

Social identity is a field across a number of disciplines and there are a great many theories related to it: here Social Identity Theory is applied. Developed by Tajfel and **Turner in the 1970's and 80's**, Social Identity Theory **is the part of an individual's** self-concept relating to their perceived membership of a given social group (Turner and Oakes, 1986). The theory suggests specific intergroup behaviours occur based upon how that group relates to others around it (Tajfel and Turner, 1986). For instance if a group are considered marginalised or oppressed, social identity theory may suggest that the lack of status of such a group could affect how others relate to **such a group and so how they perceive themselves: a person's** understanding and thought processes therefore can change in group settings (ibid).

Social identity theory suggests that we define ourselves in terms of our social rather than personal identity, taking on characteristics of a particular social group (Hepburn, 2003: 33). Tajfel (1981) argued from his social psychological research that group membership, however constructed, e.g. even under artificial laboratory conditions, itself generates identification with a group and can mobilise people, but focuses primarily on inter-group conflict. It is an essential part of personality and can be seen as a:

*"universal and fundamental cognitive requirement for positive differentiation from others and that this drives our anti-social behaviour"*

(Hepburn, 2003:33).

There have been critiques of such an approach, for instance Brown (1996) was unclear where the personal and social elements of a person begin and end, instead charging Tajfel with over-generalisation. It is clear that certain aspects of our identity or group affiliations may become more salient than others at different times or with differing life experiences.

Turner later modified the theory into one of self-categorisation, where the personal and the social are not seen as different forms of identity, but different forms of self-categorisation and so are not fixed (Turner and Oakes, 1986). There remain however, critiques of this refinement, for instance suggesting that it does not precisely explain exactly how people define and make choices and retains the assumption of separate and definable categories (Hepburn, 2003: 43). It has

resonance with the experiences of people who acquire impairments and so may negotiate with a new facet of their identity, both within themselves and how they are perceived by other people. I will apply social identity theory to two distinct strands here, and consider how effectively this can be used to view disability and identity.

### **3.3.1 Strand One - Social Identity: stigma, labelling and roles**

Traditional views of disability and identity saw disability as a process of loss which disabled people had to negotiate with (Kendell and Buys, 1998; Harvey, 1998). This was assumed to be as a result of the stigma which was attached to disability (Reidpath et al, 2005) while at other points, **the idea of a person having a 'spoiled identity' was espoused by Goffman (1963)**. Such stigma has been recognised as being linked to identity, this will be considered in greater detail below in terms of how such a stigma can be transmitted and people socialised into undertaking ascribed roles. The concept of disability as a tragic loss (Sapey, 2004) and a person **being 'spoiled' has been repeatedly contested over many years**. For instance Anspach (1979) presented the idea that being involved in disability activism and politics could be a stage of identity development and could liberate a disabled person from a passive state and being perceived as tragic. Identifying with the disability movement therefore could in itself create a persona for a disabled person and challenge the stigma and reject the notion of personal loss (Anspach, 1979:766). This also ties into the collective action, voice and identity discussed within the section relating to the

social model of disability considered earlier within this thesis on page 25.

**Disabled people's experiences of disability** as shown above are affected by the stigma and reactions of other people but also by how those understandings shape service provision. In the same way the social model of disability presents society as causing the disability, the way in which services for disabled people are developed, run and structured is often shaped by the attitudes and expectations of non-disabled people. Research over forty years ago showed how stigma can be seen to operate. **Goffman's seminal work in 1963 illustrated how an attribute which is deeply discrediting can be seen as a stigma and being seen as having a stigma is "the situation of the individual who is disqualified from full social acceptance."** (Goffman, 1963;9). Goffman considers how when meeting any new person we make assumptions and have expectations which we attribute to new people and it is difference which shapes our approach to these. This reinforces the ideas presented above in relation to identity as the way people are perceived and treated will impact upon their understanding of themselves. The work refers to any people who can be or could have been subjected to stigma at the time of writing, for instance homosexuality, illegitimacy and disability, as the work is broader than considering disabled people alone, it is possible to see parallels in some the areas it considers. For example Goffman explores how people whose stigma is not visible at times seek to 'pass' as their stigma is seen as discreditable, rather than discredited (ibid: 92), these findings were echoed in Davis (2005) work exploring the implications of

invisible disability. As this research considers the experiences of people who have acquired disability, the specific group which Goffman cited as corresponding to this **condition are stigmatised people who previously would have been seen as 'normal'** and so have developed their values and understanding about stigma before changes occurred.

*"The painfulness, then, of sudden stigma can come not from the individual's confusion about his (sic) identity, but from knowing too well what he has become."*

(Goffman, 1963:158)

The recognition that it is the stigma which causes the pain in this context rather than the disability or impairment itself, can be seen as a forerunner to ideas such as the social model because stigma is attached by other people and placed *upon* the individual. Stigmatised people therefore need to learn another way of relating and responding to themselves and others with the same stigma (Goffman, 1963:47). This demonstrates the process of negotiation and period of adjustment considered earlier within this chapter and it is at this stage when the participants are likely to be seeking help, support and services, when they can arguably be seen to be at their most vulnerable.

**Rose's 1998 work 'Inventing Our Selves'** questioned assumptions about a coherent self and showed how emphasis on similarities within theoretical and psychological positions historically have been unrealistic in their representations of likeness

between individuals and how they see themselves (Rose,1998:4). He argues that governments have applied social psychology in particular in relation to the roles which they have ascribed to individual citizens. The emphasis of the freedom of a person can be used by Western governments to apply expectations

*"Governing in a liberal-democratic way means governing **through** the freedom and aspirations of subjects rather than in spite of them"*

(ibid; 155)

If individuals are unable or unwilling to attain these expectations, the normative political discourses can appear at odds with what people feel is possible to attain and as individuals are taught through such discourses to have responsibility for their own lives and choices. The emphasis and success or failure of their endeavours is their own responsibility, rather than that of the society in which they live, or the governments which lead them.

For disabled people such a position could mean that the idea of unifying under a concept of oppression distracts the responsibility away from those governing society and instead emphasises the need of the citizens to take collective action. Hughes **(2009) developed this idea further in suggesting that the Disabled People's** Movement has forced its proponents to stand outside medical descriptors and understandings. Other work in this area: (Rose, 2001 & 2007; Rabinow, 1996; Gibbon and Novas, 2007), suggests that biosocial communities are evolving around certain medical conditions and that while such people may be described as disability

activists, they are also biological citizens and derive elements of their identity through recognition of medical conditions; *"They, therefore, politicise as well as medicalise their collective illness identity"* (Hughes, 2009:679). While such a position could in itself create a division between those people delineated as belonging to specific group and those whose conditions and perceptions stand outside it, it does offer an alternative way that disabled people can join together and seek to effect change.

### **3.3.2 Strand Two – Post-modernism and Diffuse Intersectionality**

Recognition of the post-modern nature of societies will aid this research, as it follows directly from the points made to date in this chapter in relation to identity. In **asserting that a person's experiences will always be** relative and responsive to context, and subject to change, it is also possible to see parallels between the varying ways in which disability can be perceived and responded to, and how these have altered over time, when alternative definitions and understandings have been presented (Davis, 2002:33-46). The reactions which disabled people encounter therefore, **and the continuing "cult of normal"** which they are likely to face (ibid:39) can be challenged through recognition of and facilitation of alternative stories, and interpretations. Therefore the social identity theories can facilitate both a reason and explanation of how disabled people can come together to challenge the values and expectations imposed upon them.



However post-modernism also recognises the myriad of dimensions which can apply to an individual. Bell Hooks illustrated how the oppression of being a woman, was also combined with that of being black for her (Hooks, 1982:45). Intersectionality considers how people can experience multiple patterns of discrimination or oppressions (Crenshaw, 1989). If the concept is applied it is possible to identify a huge range of categories and sources of oppression and privilege, all of which may be valid elements of one person (Hulko, 2009). For instance, being a woman, black, **Muslim, with physical impairments and heterosexual are all elements of a person's** intersectionality. Often this will mean that there are a range of oppressive factors which can result in many forms of discrimination encountered simultaneously (Knusden, 2006).

It is no longer helpful or sufficient to represent all disabled people as having a single or similar experience to each other. However recognising that groups are not homogenous does not negate the existence or importance of them; it simply acknowledges the somewhat nebulous nature of a collective. The social reality of groups then is in part their abstract and changing nature. Similarly how we think about individuals is likely to include some aspect of our understanding of the groups with which they align and identify themselves. For example, I may have a different perception of an individual if I know that they are actively involved in the humanist movement, a rugby association or a far right political group, and likely to have

another concept of a person if I know they are involved in all three simultaneously. It is reasonable to assert therefore that external perceptions of a person resulting from their group memberships are an intrinsic part of that association. Jenkins **(2008) cogently argues that identity and a person's interests are intertwined with the** collective identity, which they become part of, and so how a person defines themselves shapes their interests, and vice versa for example in the case of this research, although there may be benefits brought about by group identity, either chosen by a person or placed upon them, it does not automatically make it a comfortable place for many people who may be defined as disabled to position themselves.

Above I have briefly explored some of the ways which identity can be interpreted and applied, demonstrated that identity is a process and that there exists a relationship between the structures and agency through which a person identifies themselves or are identified. Then exploring how group membership or being identified with a specific group can affect how an individual perceives themselves or is perceived by others. These contextual factors will now be taken into consideration when exploring issues relating to disability and identity.

### **3.4 DISABILITY AND IDENTITY**

It has been shown here that presenting disability as a state of structural oppression that a group of people encounter does not in itself offer a place where all disabled people can happily position themselves. People, whose needs are not met by the social model of disability, may of course still seek to establish a sense of their identity around the impairment, medical condition or experience of difference which they encounter. While the concept of disability as personal loss can be seen as closely aligned with the medical and personal tragedy model of disability, the idea of a coherent, collective disability identity can be similarly aligned to the social model of disability. As illustrated above, the social model of disability does not necessarily fit **all disabled people's experiences**: equally a form of identity relying predominantly upon the concept of disability as a primary attribute does not fit each disabled person's sense of identity.

Corker (2002) suggests that this representation of disability identity can constitute a form of dualism, marking a division between disabled and non-disabled people: this **echoes the 'us and them' scenario developed by Shakespeare (1996)**. The focus upon a disability identity may rely upon the structural barriers that create oppression, but as Corker suggests this disregards the importance of cultural aspects in exploring disability and identity. For many disabled people their value base, sense of belonging and other elements of their lives are primary aspects of the identity, but they may be

defined by others purely by their impairments. **This is supported by Dossa's work** (2005) exploring how women who are refugees, disabled and have a range of employment skills, feel that they are evaluated purely in terms of their disability rather than any of the other elements of their culture or experiences. The implication of such assumptions are that there is a danger of disabled people being identified, solely with one dimension of their identity, that of disability, disregarding a myriad of factors and other elements of themselves. This multiplicity of selves is something which must be kept in mind as a researcher working with disabled people.

#### **3.4.1 Social Model of Disability and Identity for Disabled People**

The social model has been a more effective concept for certain impairment groups **than for others. The original 'authors' of the model were male, white, wheelchair users**, though Oliver (2004) has strongly argued that this does not ameliorate the validity or power of it or mean that it automatically excludes others. Nevertheless a **model describing people as having 'an impairment' does not fit with how some people view themselves**; the social model of disability therefore does not necessarily engage with all people who consider themselves to be, or are defined by others as disabled. In light of this it is understandable that people with different impairments, for instance learning difficulties, mental health support needs and non-visible impairments may have difficulty in positioning themselves within such a framework. People from different impairment groups have therefore organised themselves

separately, not using the social model as an organisational framework.

For example, people describing themselves as survivors/users of mental health service provision may not view themselves as disabled due to the episodic nature of their experiences, or because they feel it is their experiences of service use which shape their collective identity and therefore through that which they define themselves (OECD, 2010). Beresford and Wallcraft (1997) saw both similarities and differences between survivors and other disabled people. The similarities relating to oppression and discrimination are contrasted with the differences relating to impairment. They cogently argue that survivors often do not consider themselves as having impairment and so reject the social model in its original form, and instead focus upon the shared elements of their experiences.

*"They interpret their madness or distress in terms of different understanding, experience or perceptions, rather than as an impairment. The social model of **disability, therefore, cannot simply be transposed to the survivors' movement.**"*

Beresford and Wallcraft: 1997, 67-68

Beresford (2002) did not believe that a social model of madness and distress or mental health had been established, though argued the development of one would offer a fundamental new method to understand and assist both mental health service users and people working within the field (Beresford: 2002, 584).

Barnes, M & Bowl (2001) identified a range of sites in which users / survivors have

organised themselves in order to develop “change strategies” (p47), such as a range of organisations developed by **service users, rather than ‘for’ them** (ibid). Such groups have different objectives to the social model, indeed Barnes and Bowl present a much broader range of aims and premises under which user / survivor groups coalesce.

*"The objectives of such groups include personal empowerment through valuing the experience and knowledge of survivors as well as by strengthening social networks and demonstrating the possibilities of collective action."*

(Barnes, M and Bowl, 2001: 47)

The forms of organisation and issues which unite mental health service users therefore may not directly align with the social model and it is not clear therefore that people who may describe themselves as mental health service users or survivors can immediately identify with the model which inspired such catalytic change for many disabled people. This research therefore intends to be aware of the dangers of presenting social model of disability as a catchall concept in which the participants can be situated.

Older disabled people are another group who are often excluded from direct consideration within debates, policies and depictions of what constitutes disabled people, despite the fact that around 70% of all disabled people are aged over 60 (Priestley, 2002: 361).

*"There is a sense, then, in which older people with impairments are not seen by policy makers to be 'disabled' in quite the same way that younger adults and children often are."*

(Priestley, 2002: 362)

Disability in older age therefore can be viewed as a relatively common occurrence, while disability at other points in life as more unusual. The normative **adults' roles for** younger people include economic independence from the state and as considered earlier, this form of need or dependence upon the state is negatively presented and perceived by many people, including the media and policy makers (Garthwaite, 2011). Normative discourses therefore can be seen to isolate disabled younger people.

Older people and disability activists have tended to campaign in relation to similar issues, such as housing, transport, and income levels in parallel tracks rather than joining together (Priestley, 2002: 369). The social model seeks to overcome barriers which society places before people with impairment, but with little specific recognition of older disabled people who make up the majority of disabled people. It is hard to see how the attitudinal barrier discounting the experiences of older disabled people has been challenged either within or without the disability movement. This may prove relevant for the research in terms of participants who may be encountering double disadvantage, through experiencing disability in later life and not seeing services and policies relevant to them. The normalising discourses

relating to political and economic perspectives can be seen to further alienate older disabled people, who may not be in a position to contribute economically: yet feel outside the discussions which do take place in relation to disability policy as it makes no reference to people in their situation.

### **3.4.2 Disability and Socialisation**

The wider society has a set of expectations regarding how people with stigmas, such as disability should behave (Goffman, 1963:68). This idea was developed further by the work of Scott (1969), who researched how many organisations set up to offer services and support to blind people in America enforced expectations on the people **they worked with. Scott outlines an “increasingly formalized (sic) interest”** (Scott, 1969:1) in the way non-**disabled society responds to and ‘manages’ blind people. He illustrates how “the disability of blindness is a learned social role”** (ibid:14), which is acquired not through blindness, but social learning attached to the condition. This **research ably demonstrated how a person’s perception of themselves, their** behaviour, attitudes, and what they see as their personality is guided and filtered through the way they are socialised and treated by others. Socialisation can be seen as the process by which individuals learn, develop and disseminate cultural norms and values throughout their lives (Fine, 2001). Self-conception then is acquired through socialisation brought upon by an internalisation of the ideas other people **have about disability as well as one’s own.** In the case of blindness the expected role



for blind people in America at the time the research was conducted was that of social dependency.

Not all people passively accept the role which they are directed towards, Scott explores how even those people who reject such roles are in some way responding to them. For instance he demonstrates how blind beggars of the time had broken away from the conventional role set for them, and in order to survive moved around and did so effectively which required a strong skill set. He asserts that the focus of **blind beggars is on exploiting sighted people's fears of the blind. Begging is lucrative,** and for many people would be more interesting than dull repetitive jobs offered to blind people at the time, such as making brooms. Begging also meant that the person was not so evidently patronised for their blindness, and how they presented themselves gave greater choice to the individuals concerned.

*I will be the helpless, pathetic person you ask me to be, but for this I demand payment.*

(Scott, 1969:112)

Such a position does mean that the person concerned has a greater level of freedom and choice than many others in a similar condition were offered at the time, yet it requires the individual on some level to react and respond to the expectations of the wider society in order to subvert and challenge such limiting perceptions. This echoes much of the work of Judith Butler in relation to performativity is recognising that the audience i.e. those around an individual will also place expectations and

constraints in relation to behaviour upon that person (Butler, 1993).

Individual conceptions of identity have been considered, together with the powerful influences of wider society and other people's expectations and difference can shape a person's experiences of disability. Again and again the diversity in how people respond to disability has been demonstrated, in light of this, attention will now be placed upon how individuals react to their disability.

### **3.4.3 Individual Experiences of Disability**

In the same way that each person has different life experiences based upon their gender, sexuality, ethnic origin etc., each disabled person is likely to have a different perception of what it means to be disabled. For some disabled people these experiences will include pain and the need for regular medical care. In reality a large proportion of disabled people do experience symptoms such "*as pain, for example those with arthritis and spinal cord injury*" (French, 1993: 19), while for others their impairment does not require regular medical intervention. The social model presents the barriers which disabled people face as the disabling factors of how society operates rather than a person's impairment(s), in light of this there has been a tendency to downplay the pain which some disabled people experience. This creates a challenge for the social model to accurately reflect disabled people's experiences.

There is increasing dissension relating to the social model of disability not taking into account individual experiences of impairment, (Shakespeare, 2001; Davis, 2002; Thomas, 2004) not only in relation to pain, but also issues such as care and identity. Some argue that

*"...suppression of our subjective experiences of impairment is not the answer ....engaging with the debates and probing deeper for greater clarity might well be."*

(Crow, 1996: 71)

However the concern amongst some people within the disability movement is that by opening up and articulating subjective experiences, through such form as post modernism, the emphasis upon individualisation will dissipate the wholesale oppression which disabled people face. Riddell and Watson assert that some people within the **disabled people's movement are concerned that by abandoning the fight** for

*"equality in favour of an emphasis on difference and diversity it could potentially lead to an uncritical acceptance of structural inequality as an expression of cultural difference."*

(Riddell & Watson, 2003: 3)

The tension between the individual and collective experiences of disabled people notwithstanding, the social model has provided disabled people with an opportunity to challenge the way they have been treated and represented and offers a way to improve their life chances and gain more control over their own lives.

Shakespeare (1996) suggests that the relationship between identity and disability requires a much more nuanced approach than presenting or perceiving a situation in simplistic binary terms, between impairment and disability. **While Galvin's work on researching disability identity at the onset of impairment recognises that the impact and sense of self changes over time and that at the earlier stages the impact is greater, the more years which go by the more the impact of other people's reactions to disability and a vulnerable self-concept of identity lessen (Galvin, 2005: 399). This may become part of the narrative identity participants may seek to maintain or build.**

*"Although the loss of one's comparatively privileged subject position may be very sudden and momentous according to the particular nature of the accident, illness or injury, the overall summoning to a new level of identification is a gradual process whereby the doubts from within, the stares and snubs from without, and the lack of access to previously available social locations and resources, erode one's prior claim to social acceptability."*

(Galvin, 2003:2)

Disabled people may therefore at this stage need to develop a new type of identity and space in which to act, which takes into account the change in status and their disability (see Hogan 1998 for a detailed consideration of this element). Yet as **considered earlier, the need to accommodate a different aspect of one's identity into** how a person sees themselves does not mean that disability is a significant part of their personality. Particularly for people who have acquired impairments, the shift in perception and understanding as demonstrated in this chapter will affect identity

Disability has been illustrated to be a fluid term that shapes some aspects of a

person's life, but by no means all. The stigma related oppression which disabled people experience has an effect on how they perceive themselves, particularly when they have recently acquired impairment(s). However this is not wholly how people define or identify themselves. An identity involving disability is in fact a reflexive process of looking inside oneself, selecting and rejecting elements which appear relevant (Watson,2002; Shakespeare, 1996), and negotiating with the discourses a person has about themselves. Through this process it is possible for disabled people, particularly **those which acquired impairment(s) to 'carve out a space' for themselves** in which to act (Hogan 1998).

It has been shown that a personal loss model (which was considered in Chapter Two) or one which solely identifies a person by their experiences of oppression or the structural barriers that they may encounter cannot encapsulate the whole of a person. The question to consider next then is to ask what other elements connect disabled people, beyond that of oppression? Wendell (1996) suggested applying the concept of social disability as the only commonality between disabled people is a '*false universalization*' (Wendell, 1996:30). The majority of disabled people are likely to have an increased reliance upon the state, or be more likely to seek statutory or third sector organisations to direct them towards services and support, and this is one of the central areas which this research explores, but their experiences are likely to be diverse and complex (Shakespeare, 1996; Watson,2002; Corker,2002). The variety of circumstances which disabled people experience vary greatly according to

an assortment of factors, including the nature of their impairment, age, gender, class, income level, employment status, how they are perceived by other people and how they themselves perceive disability (Pane, 2003; LoBianco and Sheppard-Jones, 2007). The implications of this discussion for this research are that it must be conducted without wholesale assumptions about what or how participants perceive themselves or relate to disability or the impacts which this may have for them.

This research will be looking specifically at people who have either acquired impairment or have had a substantial increase to their impairments. Research suggests that people who acquire impairments are much more likely to undertake a process of transition while they experience a shift in their own position and that of other people around them. Denzin (1992) suggested that this was a negotiation and redefinition of self from a person of relative privilege and process where the sense of identity an individual may have is in a process of change, a view reinforced by others.

*"It takes time (for newly disabled people) to absorb the idea that they are members of a stigmatised group."*

(Wendell, 1996:25).

**While it is possible that many disabled people experience a process of 'marginalized identity'** (Galvin, 2003), there is nothing to suggest that all people undergoing this process experience it in the same or even similar ways. For instance disabled people with invisible disabilities often face a battle to be believed and are forced at times to

justify a definition of disabled (Stone, 2005), while disabled people, whose impairments and conditions have not been medically recognised face further challenges.

*"Denial of their experience is a major source of loneliness, alienation and despair in people with unrecognised disabilities"*

(Jeffreys, 1982:25).

Disabled people with acquired disabilities whose experiences are recognised and are easily identified by others are also dealing with physical and emotional changes and in some cases difficulties in communicating with other people. For instance people who have had a stroke may not be able to communicate their experiences and needs but are encountering many new circumstances, and are likely to have a need to reconcile their own feelings about what has happened and reactions from other people (Clarke and Black, 2005; Ellis-Hill and Horn, 2000).

According to Shakespeare (1996) there are negatives and positives relating to this sense of collective identity. He illustrates two related versions of the word identity which illustrate different aspects of the process. Firstly identity is an active verb, and as with other forms of process development and redevelopment, relating to uncovering and discovering – **in this context 'disability'. In the second meaning,** identity refers to a reflexive process of looking within oneself and this will be developed towards the end of this section. The first meaning can be seen as new ways in which disabled people can find to see themselves and so move away from

the traditional representation of disability as a personal loss (Morris, 1991). The recognition that disability can be seen as far more than a personal loss to be mourned over, creates what can be a liberating range of possibilities and the **dominant discourse is challenged. As Shakespeare puts it “new stories are being told” (1996:94), these new representations can challenge stereotyping and build a** sense of solidarity amongst disabled people (ibid: 102). Stereotyping can take a variety of forms, such as the ideas considered above: that disability is physical, evident, unchanging and debilitating (Grewell et al, 2002), or that disabled people are passive, are or should be asexual, and are unattractive and self-loathing (Reeve, 2002).

In order for group identity to unite people, some form of common experience must take place from which a collective identity can be formed. The common experience that unites disabled people is that of oppression (Oliver, 1996; Shakespeare, 1996; Wendell, 1996). Later theories have sought to encapsulate loss as an intrinsic part **of all people’s lives and sought to remove the distinctions made in separating out** disabled people from others in the way they experience and manage loss (Watermeyer, 2006;2009).

The concept of identity in relation to disability as a single and consistent process therefore is easily rejected and many people will encounter different ways of responding to the changes which may occur to their identity and sense of self. If, as



illustrated, identity is able to change and adapt so widely, it is viable to support the assertion that a fragile, incomplete and continually evolving form of identity is much *“more amenable to reconstitution than was previously thought possible”* (Du Gay et al, 2000:2). This flexible and transitional notion of identity can mean that people are able to challenge expectations and adapt their expectations and understanding of themselves and of disability over time, yet it can also mean that their sense of self can be challenged and possibly damaged by other people’s actions and responses.

#### **3.4.4. Perceptions of Oneself and Others**

How others may perceive them can have a substantial effect on some disabled people and can be an essential factor shaping their own sense of identity (Galvin, 2005). One of the reasons why disabled people may reject identifying themselves as disabled is that this is not the only element of their lives, yet they are treated by many non-disabled people as if this is the only facet of their personality (Hogan,1998; Lenney and Sercombe, 2002; Beauchamp-Pryor, 2011).

Watson (2002) undertook small-scale research with disabled people and found that how other (non-disabled) people defined and saw the participants affected their self-perception substantially and this was particularly true for people who had recently acquired impairment. People who have experienced the whole of their lives as a disabled person are likely to hold differing attitudes towards their identity than those

who acquire it.

Research demonstrates that people without impairments have perceptions relating to disability, for instance asserting that people held differing ideas about what constituted being disabled but that for the majority of non-disabled people, disability related to physical impairment, it was visible, was permanent and static and that it resulted in people being dependent (Grewal et al 2002). It has also been suggested that non-disabled people may project their negative emotions and feelings about disability onto disabled people (Tregaskis, 2000: 346).

Yet for people who acquire impairments their own pre-existing perceptions about **disability don't just disappear immediately. The process of reconciling** the stigma attached by the wider society and their own ideas about disabled people, were it not for the illness or impairment that has happened to them, is not an easy task.

*"In the early stages of impairment, the combination of others' attitudes and the person's own preconceived ideas concerning disability had the greatest impact on identity by imposing a diminished sense of self"*

(Galvin, 2005: 399).

It is not helpful to make generalities about how disabled people see themselves: as illustrated disabled people are not a homogenous group either in their impairments or their reactions towards impairment. Identity can be appropriately viewed as a narrative process where experiences which occur to an individual either reinforce or challenge how a person may see themselves. In a battle of reconciling dominant

discourses (Sands, 1996), this again echoes the debates relating to this facet in Chapter Two and will be considered further in relation to the methods and analysis of this thesis. Participants within the research may choose to use this narrative process as a way in which they make sense of their negotiations with wider social structures, but it is not something which can prejudge the data collection and analysis process.

As illustrated above, the views of other people as well as internalised attitudes towards disability are likely to have some effect on all disabled people, but it is at the initial stage of reconciliation of the self in relation to acquired impairment which is a crucial time in this process. Over time people become able to challenge and interrogate the oppression relating to the stigma of disability.

Many people, who others may define as disabled, do not see themselves in this way (Watson,2002; Beart,2005). They reject the idea that they could or should be defined purely or largely in terms of their disability (Wendell,1996; Watson,2002) and see the multi-faceted elements of their lives. Disabled people feel that other people **are 'more disabled' than they are, and that they can** undertake many activities **viewed as 'normal' but just in different ways (Watson, 2002)**. Impairment can be experienced as a fact of life rather than an intrinsic element of day to day life; it is *"nothing out of the ordinary"* (ibid:516).

### **3.5 CHAPTER SUMMARY AND RELEVANCE OF THIS CHAPTER FOR THE RESEARCH**

This chapter has demonstrated that within this research, identity may be seen as '*continually under construction*' (Galvin, 2005) and shaped by relational aspects and further informed by social categorisation and Social Identity Theory, however these are of course only one element of the world which people acquiring impairments and encountering disability may encounter. Disability is for many a stigmatised and heavily laden term, which can place a greater range of expectation and limitations upon the individual labelled as such. When disability, impairment and stigma are placed together, they produce a powerful agenda which participants may have to negotiate with. The ideas presented here will therefore inform the two research questions relating to how self-**perception and identity may impact upon a person's** search for appropriate resources, and the factors which affect the information, services and support which individuals accessed.

However the wider range of multiple roles and identities which we acknowledge and adopt, the more it is possible to recognise conflict between these and so explore where we actually feel we want to position ourselves away from the dictates and imperatives placed upon us. The question of what we identify with can be seen as a reaction against, recognition of, or need to find allies in, challenging situations and also to delineate those who are likely to be against us, depending upon the space

between the individual and the social structures which they encounter. It is the interplay between agency and structure and questions regarding which areas a person can affect and which they cannot, which makes the individual negotiations of identity so interesting and relevant for this work.

The literature reviewed in the last two chapters has created a basis of understanding from which the methodological choices employed within this research can now be considered.

## **CHAPTER FOUR – METHODOLOGY AND METHODS**

### **4.1 INTRODUCTION**

The introductory chapter within the thesis has outlined the intention to explore how people who had recently acquired impairment sought to access support, services and information. Chapter Two has considered the pertinent literature in relation to discourses and perceptions of disability, by disabled people and the wider community, in order to consider the impacts of such discourses upon disabled people. Chapter Three extended the ideas relating to how disability was perceived and could be linked to identity. This was particularly apposite in the case of people who acquire impairment and therefore are likely to have an alteration in the way they are perceived and perceive themselves. This was linked particularly to Social Identity Theory in order to explore how people may seek to negotiate a new sense of identity when that identity may be considered by others and possibly themselves as 'spoiled'. The research explores how people encountering such a set of circumstances may seek and may receive help.

This chapter presents an explanation of the methodology which has been selected for this research. It introduces the research questions that the research seeks to answer and explores the ontological and epistemological decisions which have been made. This chapter then explicitly looks at critical realism in relation to disability,

which is applied to this research; it situates the researcher's theoretical position, outlines the methods employed and finally identifies the implications for the research of the decisions taken.

## **4.2 KNOWLEDGE CLAIMS**

The ontological and epistemological and background of research is crucial to address this thesis for two key reasons. Firstly, in order to effectively situate the research and the position of the researcher. Secondly, in recognition that the choices made by the researcher shape the way the research is conducted and analysed: only by making clear what these decisions have been, can the research be seen in a broader context.

Similarly within the research it was essential that the ontological and epistemological underpinnings of the research could allow the researcher to respond to two criteria. Firstly, that I perceive the structural mechanisms which the participants encountered were tangible and secondly, that the individual experiences were not discounted purely because of the subjectivity of their nature. The existence of the barriers and opportunities which the participants encountered, as is considered below and demonstrated within the analysis, relies upon the interplay between the micro and macro perspectives.

### 4.2.1 Ontology

Ontology relates to the philosophical concept of what entities exist and what is the fundamental nature of reality: it explores the question of whether or not reality is autonomous from our understanding of it. In relation to this research, as Blaikie (2000:8) outlines, ontology explores claims about social reality. A pivotal question is to what degree is social reality established within structures, what is the nature of such structures and how do people perceive and respond to such structures (Kerr, 2003). A foundationalist perspective represents the belief that there are definite **knowable truths independent of knowing about them or that “reality is thought to exist independent of our knowledge of it” (Grix, 2004:21).** My initial position in relation to this was that of an anti-foundationalist, in that I did not accept this approach. However as I considered the nature of the research I was seeking to undertake, and thought about how to encapsulate the individual participants’ experiences alongside the structures with which they interacted, the more I recognised that in this context an anti-foundationalist approach could not capture all I sought from the research. There have been a number of critiques of anti-foundationalism which have argued persuasively that they challenge all general claims, except the one presented by their own understanding (Mouzelis, 1995). Said (1978) also judged certain forms of anti-foundationalism as facilitating too great a degree of cultural relativism and so losing sight of real human experiences.



**This research explores participants' experiences of** interacting with structures to access support, services and information: it was essential for the research to fully grasp the points of view of the participants themselves in addition to the structures as they were encountered. The term structures will be defined below in terms of structure and agency, however it is necessary to clarify immediately that the multiple structures which people encounter may be internal, external, and visible or invisible. If a perspective was adopted which advocated that independent truths and reality existed, and that individuals simply reacted to such structures, it would be much harder to incorporate the perspectives of those people involved as having relevance and impact on their experiences. To this aim the research was initially heading towards an entirely interpretive approach, particularly as from the **participants'** perspectives their experiences might appear very distinct from the external organizations which they encountered. The research could not reject that a form of **reality external to an individual's experiences existed, but was wary of it dominating** the perspective of the participants. It was the interpretation of experiences and events by individuals which constituted reality for them: the research therefore required a way of situating a perspective which could incorporate both the agency which individuals applied and the structures they met, which will be considered below.

### **4.2.2 Epistemology**

The relationship between ontology and epistemology is a close one: the former making assertions about what there is to know and the latter about how it is possible to know those things. The epistemological position can then be seen to arise from ontological belief (Grix, 2004:61). The ontology therefore makes claims about what exists and the nature of reality, only when a belief has been recognised about what is the nature of such reality is it possible to adapt a theory of knowledge in order to shape the research (Smith, 2006).

However, before a decision could be made, some of the major perspectives, in particular the primary knowledge claims made by positivism, interpretivism and critical realism in order to define and situate my approach in depth are considered. The crucial elements within these are highlighted to demonstrate what shaped the researcher's thinking. While discussing general elements of such epistemology, it is important to note that these perspectives are broad entities incorporating many different degrees of adherence to key tenets and a variety of understandings within them (Bryman 2001; Grix, 2001; Creswell, 2003).

The key attribute of positivism posits that there exists an external reality and that the knowledge derived is predominantly technical and factual in nature (Delanty, 1997: 12-13). Other theorists have asserted that a further key characteristic of positivism

is that of causal relationships: that one element is substantially affected or resulting from the first (Denscome, 2002:9). These causal relationships, affirm positivists, allow researchers the ability to predict future events based upon patterns of what has happened in the past and in light of the causal relationship. However within social sciences the ability to predict future outcomes by observation of causal relationships is rarely seen as an appropriate methodology (Bhaskar, 1989:5).

Interpretivism is an alternate epistemology originally derived in direct opposition to positivism (Clarke, 2009), which recognises that an individual acting within a social setting has choice and agency within their own actions.

*"The focus of interpretive research is on those life experiences that radically alter and shape the meanings persons give to them and their experiences."*  
(Denzin, 2001:1)

A key feature of interpretivism is the assertion that **the 'objects' of study in the** social sciences cannot be observed and explained in the way that natural sciences are; as such these cannot be studied in the same way. In simplistic terms positivism seeks to explain human behaviour, social activities and outcomes, whilst interpretivism seeks to understand it (Bryman, 2001:13).

An epistemology which readily engages with multiple perspectives of knowledge and understanding fits well with some of the areas this research seeks to explore. For example, a perspective that could recognise the factors affecting the expectations and services received by participants may be individual in origin or may be structural.

However interpretivism has flaws and weaknesses inherent within its use. One of the strongest criticisms of interpretivism is that of the epistemic fallacy: if all perspectives about any given subject or approach towards life are equally legitimate, how do we evaluate what is the truth amongst a plethora of truths?

*"This suggestion invites a general and subversive relativism, where all beliefs are related to features of their social context, whatever their intellectual rationale."*

(Hollis, 2004:87)

This does not negate the productive aspects of interpretivism, in particular that it allows for an account to consider events from a micro level and from an individual perspective. It is vital that research such as this facilitates the individual articulating their experiences, **when seeking to identify people's perceptions.**

As discussed earlier, the concept of an external reality from which causal predictions can be derived, does not fit with the knowledge to be captured here, namely the process of individuals negotiating with the complexity of social structures and accessing services. As positivism does not recognise the density of the topic, few areas to be explored in the social sciences can be definitively observed or involve easily identified causal relationships. For instance, interdisciplinary concepts such as social exclusion, perceptions of participants and attitudes of and towards specific groups are much harder to define, observe and measure than specific observable behaviours or psychological responses. However there are different ways of seeking

to incorporate an external reality and simultaneously value the perceptions and realities experienced individually. The apparent inability to incorporate dualism, encountered with many ontological and epistemological debates, relates to the need to integrate the subjective nature of an individual experience with the wider perspective of observing structures and entities much larger than the person.

Positivism as considered can be seen as one end of a spectrum, while anti-foundational perspectives, such as interpretivism can be seen as the other. The introduction of approaches which seek to be somewhere in between these positions also includes the rise of post-positivism. Many researchers within the positivist tradition have now moved into a post-positivist standpoint, rejecting some of the more absolutist tendencies of positivism but maintaining some of its core criterion;

*"Postpositivism reflects a determinist philosophy in which causes probably determine effects or outcomes."*

(Creswell, 2003:6)

The work of post-positivists, in particular Popper and Kuhn, sought to challenge some of the assumptions of what can be known. For instance through his theory of falsification, Popper demonstrated that while it may not be possible to know whether something is true, it is possible to show if it is false (Jeffery, 1975). **While Kuhn's** work on paradigm shifts broadened this understanding to encapsulate the concept that at times worldwide perceptions and understandings may also need to change on rare occasions (Hairston, 1982).

In seeking to find a methodology which moved away from the dualist dichotomy, post-positivism offers for me a more tenable alternative. As post-positivism recognises that all observations are fallible and that there is no one fixed and definitive truth, it positions the researcher as someone who is prepared to learn throughout the process of research rather than someone who is testing a hypothesis (Ryan, 2006:18).

Critical realism is one of the key perspectives within the post-positivist spectrum and for some is indeed the core of such approaches (Grix, 2004: 84-85). Critical realism then offers a philosophy which seeks to understand and explain the world and was therefore the approach the research adopted. It will be considered in greater detail later in this chapter. First however the research questions are introduced.

## **4.3 RESEARCH QUESTIONS**

### **4.3.1. Research Question One**

The areas considered previously have illustrated how people have a complex and individual attitude towards disability, mediated through many different sources, **including their own and other people's attitudes towards disability and the structures** which they encountered. The primary and most immediate question therefore which

arose from this was the exploration of what shaped the expectations of, and services received by the participants in seeking support, services and information. While the services which people may have received can be subject to a great many variations which may not be possible to fully grasp their understanding of what they expect at each point may be captured. Research question one therefore asks **'Which factors affect the expectations of, and services received by the participants?'**

Clearly this could be a very broad question and approached in many different ways. As the research was to be undertaken **in order to understand the participant's** experiences, any form of understanding must reflect this position. The remit of this question therefore was to outline apparent external factors, such as the nature of the impairment(s) participants encountered and the geographic region in which they lived, together with personal individual factors, such as their gender, age, response towards impairment and disability and so forth. Simultaneously the research seeks to explore participants individual actions and reactions to the situations which they encountered to facilitate an understanding of the interplay between the structures and agency they encountered.

### **4.3.2. Research Question Two**

The second research question recognised, as considered in Chapter Three, that people often have complexity in the compilation of their own identity and that the point of encountering or acquiring impairment, is a crucial time in how many people negotiate with external structures while seeking to respond to possible internal dichotomies brought about by their change in circumstance. The second research question therefore asks **'How are self-perception and identity affected by encountering disability and the resultant treatment?'**

The final research question arose from the data collection method concerning the use of diary methods and will therefore be considered later in this chapter, once those methods have been outlined.

## **4.4 CRITICAL REALISM**

### **4.4.1 'Structure' Within Critical Realism and This Research**

Structure relating to critical realism is not a physical entity, but a set of rules, systems and processes established to be able to deal with actions regularly (Layder, 1994:135). It is referred to throughout this thesis and so requires clear explanation. Within this context structures can be seen as the conditions under which people act,



and as such are defined as sets of internally related objects and ways of acting (Sayer, 1992). This is the context within which the research participants operate; this applies both to the structures they encountered and to the way in which people perceive their experiences, through an internal, psychological representation of reality. The structures are not static as they are influenced by the interplay between the macro and the micro, though such structures are established prior to interaction taking place.

*"Agency-structure issue focuses on the way in which human beings both create social life at the same time as they are influenced and shaped by existing social arrangements."*

(Layder, 1994:5)

All individual experiences and actions therefore are situated within such structures (Tsang and Kwan, 1999:762). It is this understanding of the underlying structures adopted for this research. For instance if a participant seeks to find information about a service, they will be encountering the structure(s) underlying the service, the individual(s) with whom they communicate and their own perceptions of that experience incorporating the social arrangements, previous experiences and so on.

It is the point at which the individual and the structures intersect which is crucial to this research. If the world has events and people experience these events, both are valid; though one is analytically prior to the other. For instance structures relating to policy and governance may not be experienced, either in the way they are intended or the way they were set up. This does not negate the reality of either the structure

or how it was perceived. Such structures are long standing, though they may often refer to patterns which are reproduced relating to social organisation and power (Layder, 1994:6). As demonstrated this does not make them static entities.

*"There can be no experience without someone to experience. The world "out there" is inextricably tied to the world "in here"."*

(Patomaki and Wright, 2000:218)

#### **4.4.2 What is Critical Realism**

Critical realism is derived principally from the work of Roy Bhaskar and offers a theory which seeks to be both explanatory and interpretive. It is theoretically positioned somewhere between positivism and interpretivism in that it allows for interpretation but has a foundationalist base (Denzin, 2001:151), i.e. post-positivist.

**Foundationalism is a theoretical position which asserts that "knowledge constitutes a structure the foundation of which support all the rest but themselves need to support"** (Alston, 1976:165). In this context it refers to a reality upon which foundations can be laid.

When considering social sciences as opposed to natural ones, there are differences about the nature of reality, for instance, the way in which behaviour can be observed and predicted. Social sciences therefore differ substantially to natural ones (Bhaskar, 1989:67-70). Ekstrom described difference and the nature of reality in terms of social sciences as social reality (1992) and asserted that its nature is not a static entity; it is

changeable, open and complex. Because social reality is independent but not fixed, the causality element of such prediction is much less clear (ibid:115-116).

Bunge (1993) suggests that we must return to the epistemology / ontology debate and go back to first principles by asking, what can we know? If the answer was that there was no external reality, then our understanding of the world collapses and we can rely upon and know nothing. Without any form of external reality he cogently argues there are no foundations on which to build knowledge. There is a truth and objective reality **'out there'** but our understanding of it remains limited and at any given time we will be seeing only a portion of it (Bunge, 1993). Society is constructed through representations and our perception of it is mediated through third parties, media, documents and / or our own individual perceptions (Bhaskar, 1979). However our understanding of such a reality is always subjective and differentially experienced.

In terms of this research, participants receive information and perspectives from a wide range of resources such as the media, official documentation, informal discussions, their friends and family and in dealing directly with service providers when seeking to access services, all of which are likely to shape their understanding of reality. When evaluating how we can respond to such a form of knowledge, it is important to recognise that we can never know all of such a truth or reality but the more knowledge we uncover, the more it becomes possible to revise our

understanding and reshape our focus in light of the new information identified. Although we keep exploring and redefining our understanding of reality, we do not know in advance the range of possible outcomes open to us. We have no way of looking at them all, or ascertaining whether our knowledge is complete: the truth therefore will only ever be partially known (Patomaki & Wright, 2000:225). The options which are open to us on a micro level are generative mechanisms which are negotiated in situ (Bhaskar, 1979). Whereas causal laws with strict rules can only operate in closed systems, where predictions can always be made and explanations for causations established, generative mechanisms can operate within closed systems and open systems (Bhaskar, 1998). An open system is one which is "*outside the conditions which enable us to empirically identify them*" (ibid:36). Many generative mechanisms can be operating at the same time – if there was only one this would in itself become a closed system (Collier, 1999). The complexity of generative mechanisms therefore cannot be underestimated, however this does not mean that individuals cannot shape and influence their own worlds and experiences (Kerr, 2003: 122).

#### **4.4.3 Generative Mechanisms**

Generative mechanisms then can be seen to arise from pre-existing structures, the **interplay between this and an individual involved in agency can** "*give rise to certain events and institutions*" (Archer, 1998: 377). Bhaskar (1989:85) makes clear that

there is a possibility of causality when individuals at singular level interact with structures at a wider one, but that this does not guarantee causality will take place. Conditions must exist for something to occur, but this only offers the potential for an event to happen. It is this interplay between the micro and macro level, the individual and structures which is of particular interest within critical realism and within this research. This is why a range of people were recruited to explore how each individual was able to interact with the macro levels and seek to effect change or maintain consistency dependent upon the context in which they operated. The intentional action on the part of the individual in response to such structures demonstrates that a person may have some control over their actions and choices. An individual experiencing structure can either undertake a process of reproduction or transformation (Bhaskar, 1998:218).

*"Critical realism portrays actors as constantly drawing upon (pre-existing, possibly inadequately understood) social structures in order to act, with the ensuing actions subsequently bringing about (intentionally or otherwise) the reproduction or transformation of those structures. The existence of social structures is a necessary condition for the exercise of intentional agency."*

(Lewis, 2002: 19)

The concepts of reproduction and transformation within critical realism arise through the way in which society socialises individuals, but they in turn can reproduce or transform the social reality which they inhabit through action. Both reproduction and transformation are necessary in order to maintain and shape the wider society which people encounter.

*“On this conception, then, society is both the condition and outcome of human agency and human agency both reproduces and transforms society. However there is an important asymmetry here: at any moment of time society is pre-given for the individuals who never create it, but merely reproduce or transform it. The social world is always pre-structured.”*

(Archer et al, 1998: xvi)

These ideas are relevant to the analysis of this research in identifying how self-perception and identity are affected by encountering disability and the treatment of participants as a result.

The degree of choice and control which an individual may have or experience may vary, which is considered within this research. However people are not passive recipients, purely responding to the roles and structures they encounter:- *“They possess causal powers, capacities for bringing about change in reality, this through conscious and intentional activities” (Estrom, 1992:115). Indeed when actions and events do occur, the relationship between the individual and structure are so entwined that it is hard to confidently state whether causality took place or not. In order for an event or reaction to occur, the requisite conditions must be in place, however that in itself does not mean an event will definitely happen. Even if an event does occur, it is not always possible to say that this was as a result of a decision, choice or action of the agent or as a result of the structure. Such processes cannot be easily established as the relationships are so enmeshed.*

**People's personal experiences of structures and of their own lives, both have** relevance and reality about them. Approaches such as interpretivism, as discussed, do allow for multiple perceptions and realities, but this can result in a form of fragmented relativism. Critical realism asserts that there is a reality, but that our understanding and perceptions are a representation of that. Different experiences then can be incorporated, but with the stability of a reality at its base (Bhaskar, 1989:80). This stops the impasse between foundationalist and anti-foundationalist perspectives, and provides the social science researcher with an opportunity and way to move forward (Patomaki & Wright, 2000:215). The individual and micro levels have been demonstrated to hold value and relevance within critical realism (Goldspink and Kay, 2004), and it is shaped by and also shapes the wider society and the structures in which they inhabit.

There are a range of criticisms of critical realism, some of which also apply to the theory of structuration outlined on page 54. Structuration was introduced to demonstrate the divisions and inter-relationships of structure and agency; however it **has been critiqued repeatedly. Initially these criticisms centred upon its 'lack of ontological depth' (Jessop, 2005:45). Although Giddens** later developed his work which became more nuanced (ibid), challenges in relation to the way in which it explains the interactions between structure and agency over time and space remain (Archer, 1995). However similar critiques have also been made in reference to certain versions of critical realism (Bates, 2006). Whether or not the philosophical

underpinnings of some forms can fully account for the duality of structure / agency debates does not negate the strength of the approach for understanding and making sense of the ways in which individuals encounter life experiences. It also has explicit application towards disability.

#### **4.4.4 Critical Realism and Disability**

There are parallels between critical realism and definitions of disability; indeed critical realism has been applied to certain elements of disability which has previously **produced some interesting similarities between the two. The 'reality' of disability and the reality within critical realism are comparable concepts.** As illustrated within the literature review, disability is not an easily defined term; this is also supported within the work conducted in relation to disability from a critical realism perspective (Potheir and Devlin, 2006). The existence and situating of it can lead to debates and ambiguities.

*"[T]he vital question is not whether the disability inheres in a particular person, but what is society's response to a particular person's circumstances. This is why we emphasize the importance of context. Whether a person is "disabled" is highly dependent on the social organization of society."*

(Potheir and Devlin, 2006:5)

The disabled individual within a wider structure therefore acts as an individual but their experiences are inevitably linked to the views and structures of the society at large for the barriers which disabled people encounter can be seen to echo the



existing social arrangements influencing all individuals. Danermark (2002) offers the example of dyslexia in a society, where she asserts that generative mechanisms are applied and are operating at different levels simultaneously. For instance dyslexia can be viewed as socially determined in that it has no relevance in non-literate communities, but **it can also be seen as a "dysfunction of the brain"** on a biological level (Danermark, 2002: 6).

Disabled people have been challenged by a range of barriers, as demonstrated within the literature review, and have a long tradition of encountering oppression. From a critical realist position, a perspective is offered which begins by presenting the idea that people have some autonomy and a degree of control over certain elements of **their own lives, where "social actors are not simply passive bearers of social forces or judgemental dopes within a cultural order"** (Bohman, 1991:13). This approach therefore can offer a more empowering option than the assumption or assertion that individuals have no control over the decisions which they make and the way in which they choose to act.

It is possible with disability therefore to see duality between the individual and wider social context. It has been demonstrated that the oppression process through which a person is disabled is so heavily based upon the context within which actions occur (Marks, 1999:78). This is why context is so important to critical disability theory, because it is theory that emerges from the bottom up, from the lived experiences of

disabled people, rather than from the top down. In light of this, the assertion of Potheir and Devlin (2006:9) that the two key insights informing disability theory politically are the issues of power(lessness) and context, reinforces such a position. The aspects of disability relating to power arose from the disabling barriers and attitudes which an individual may encounter, therefore applying a critical realist perspective to this research recognises the constraints which disabled people encounter in mainstream society.

Thomas (2004b) seeks to revive social relational theories partially developed by Finklestein, asserting that there is a need to explore the nuances of a social relationship. This relationship can be aligned directly with critical realism by exploring the intertwined relationship between the structure and agency perspectives, which is at the heart of the social relationship.

#### **4.4.5 The Critical Realist Researcher within the Research**

The approach within this research is of a critical realist knowledge base and asserts that although the world exists independent of our individual human consciousness, this does not diminish the importance and reality of the individual experience.

A social researcher is part of the world being studied and the social world cannot be controlled or predicted in the same way natural sciences are as it is so subject to

many more variables. Certainties cannot be produced therefore, but this does not negate its value. The relationship between the person as an individual agent and the society and social world which they inhabit must be considered in sufficient depth to consider these variables and make meaningful conclusions, i.e. to make research effective. Additionally **within critical realism relating to social sciences** "*reality is always mediated through 'perceptual filters'*" (Frauley and Pearce, 2007:4). I recognise that my individual actions in turn affect how this research is undertaken. As a critical realist involved in qualitative research I believe that the researcher is inevitably present within the research and that the researcher cannot be value free (Snape and Spencer, 2003:20).

If a purely social model of disability is applied to this research therefore, the assumption that the oppressive societal barriers which disabled people encounter is the only change which needs to occur to remove all barriers (Danermark and Gellerstedt, 2010). Disability has been shown to be far more complex than such a representation however and **is a** "*multifaceted phenomenon involving many crucial factors*" (ibid:341). Therefore, an approach allowing analysis and understanding from more than one level will improve this research. As critical realism is willing to accept that people can act in ways which are individual, unique and can result in different outcomes, they can therefore act **with their** "*own agency within structural parameters*" (Grix, 2004:62). **Some people are more successful in accessing help, support and information than others**, which may indicate that understanding causal

relationships are far more complex than simple observation: "*People do not just 'perceive' society: they sustain or alter it by acting on others*" (Bunge, 1993:228).

The research considers the participants' experiences and explores in what ways they may alter society by engaging within it through the concept of generative mechanisms considered above. This will be considered further within the findings and through the introduction of the 'Process of Disillusionment' (page 327).

## **4.5 PROCESS OF RESEARCH**

The way in which the research was developed and approached will be explored, as will methods, the process of sampling and recruitment and the pilot studies. Ethical considerations were part of the daily decision making process involved in the research and so will be demonstrated throughout the remainder of the chapter. However, it will also be explicitly considered in section 4.

### **4.5.1 Developing the Research**

The original draft for the research had been written by academics at the University of Birmingham before the researcher was appointed to undertake the research, and so to some degree the remit had been fixed. The framework attracted the researcher: there were areas of specific interest, in particular negotiating with acquired disability and use of qualitative methods to explore this process experientially. On this

occasion the use of diaries as a data collection method had already been established prior to involvement. It was important to find a way to take ownership of the research and develop ideas and discoveries through the research process: this is demonstrated below.

Reliability within qualitative research cannot be directly reproducible, but it can be '*open to public scrutiny*' (Dey, 1993) and I have therefore illustrated how and why decisions in relation to research were made. The question also exists as to how can **a qualitative researcher show that their work is 'correct'? I don't identify with this as possible or desirable within such research, I hope instead to employ transparency through focus and reflexivity to show how the findings have been achieved.** The relationship between any researcher(s) and participant(s) is a crucial one, particularly within qualitative work (Finlay, 2002). The researcher will therefore have an effect on the outcome and as a result needs to be situated within the work. Without my life experiences for example I would not relate academically to issues of impairment and disability in the way that I do. Discovering that other researchers are also "*keen to deconstruct what I consider to be artificial boundaries which are often used to understand my academic profession and person*" (Cloke, 2004:93) was a great relief. How successful I was in segregating the two boundaries cannot be assessed at this stage, but my approach towards disability and impairment will be made clear.

This led to concerns about how to situate myself. I have been impaired and disabled in the past, though now experience only mild and intermittent difficulties. I am conscious that some of the research conducted by academics without disability is argued to not accurately represent disabled people's experiences, (Oliver, 1996: 9) and that debate on this topic is long running amongst activists and academics (Barton and Oliver, 1997). I was unclear at this stage whether I identified myself with the term disabled or impaired, though there are some elements of my previous experiences which are likely to shape my perceptions and understanding, this needed to be acknowledged. For instance, I have clear memories of not being able to articulate my needs, of being marginalised because of them, negotiating with benefits agencies, health professionals and service providers – often to my detriment.

Amongst disabled people there are a wide range of groups, perspectives and attitudes; disability does not form a homogenous group, see Witcher (2005) for a broader discussion of this issue. For some disabled people with substantial impairments, it may seem offensive for me to perceive myself as ever having been disabled: I have not experienced the degree of oppression, stigma and disadvantage that they have. There is, as Deal points out (2003), **a 'hierarchy of impairments',** and I did not feel it accurate to call myself a disabled researcher, but my insights inevitably shaped my reactions towards the research, data collection and the experiences of the participants. In relation to disability then, my personal battles

needed to be acknowledged, but they were not the focus of the research. I shared this information only with some of the participants if it seemed appropriate or they asked me directly about the subject, but it did not dominate any conversation. I also made the decision not to discuss this with participants within the first few months of the data collection process, in case they felt any degree of comparison or judgement may arise. On the one hand, I did not want to present myself as an all knowing or distant observer, independent and isolated from the research and the participants. On the other hand, the research was not about me and I did not want some perceptions of myself as the researcher to shape the data provided any more than is inevitable within the research process.

In my previous work life, prior to an accident which caused the above impairments, I had been an advisor and advocate for many people while working for third sector organisations. I now am employed as a service user and carer co-ordinator within the Social Work programmes at the University of Birmingham and work with a range of service users and carers with very different experiences. I had to be vigilant as there was a danger of me helping participants when I had information that they did not, which may have improved their situations, but could have ethical implications (Macfarlane, 2010). This can be a challenge for any researcher, but for myself seeking to represent and analyse the experiences of the participants, without acting as their advocate, was something I needed to be aware of throughout the research period and when considering the ethical issues relating to the thesis. My reflections

on the process of research will be considered within the findings of this research. However recalling that disabled people had themselves a hierarchy of impairments (Deal, 2003), as well as people who are not disabled (Grewell et al, 2003), it followed that it was inevitable that some beliefs and assumptions would arise, whether or not the researcher was disabled themselves.

#### **4.5.2 Developing the Research Approach**

Prior to designing the data collection and recruitment processes of the research, I considered the contribution of the Social Model of Disability regarding research relating to disabled people. My intent was to ensure that the research I developed bore in mind how disabled people had been treated, and how some perceived the process of involvement within research, and to avoid repeating disabling approaches towards those people involved. The research sought to ensure that participants have control over their involvement, in relation to what is included and how they are represented. Nevertheless I did not ascribe to the concept of a unifying political response towards disabling practices, as demonstrated above and throughout this research; disabled people are not a homogenous group who respond in the same way to a given situation (Joseph Rowntree Foundation, 1999; Meekosha, 2004; Deal, 2003).



The research already had some degree of its framework established; it was to be a qualitative piece of research asking participants to keep diaries and those people should be recently impaired. However, I was keen from the start to make this research as participatory as possible. The pre-existing approach had to some degree already been laid out, in any event I recognise that emancipatory research requires research to be driven and directed by users themselves (Hanley, 2005). As a researcher and person who worked in areas relating to disability, I had some insight into the experiences of disabled people and I recognised, as discussed in the **literature review, sometimes disabled people's needs and interests are in conflict with** each other. In these circumstances I neither felt emancipatory research was possible or appropriate. I am conscious that the participants within this research have personal and unique experiences and impairments; I therefore seek to reflect those experiences individually, whilst placing this understanding within the wider social structures in which they operated.

I was also conscious that I did not have the financial resources to pay for anyone to be involved within the research and expected participants to volunteer their time to work with me for free. While the paying of research participants is a contested matter, (see DoH 2006, for a detailed discussion) some people asked to participate in research without payment have criticised such an approach (Plummer, 2006:215-216). **Nor could I guarantee that anyone's involvement would result in changes**

occurring to the way in which services were run or delivered, which may encourage and motivate people to become involved. I therefore sought to be as participatory as possible. An excellent breakdown of dimensions of participation within research is offered by Barreteau et al, (2010) suggesting the importance of actors being involved in the process, flows of information and how they are represented within the text. Participants chose how much they were involved, in what ways and what information they chose to give. They also saw and commented upon a pen portrait and examples of how they would be represented within the script. As I will illustrate within the analysis, some participants were excited about the prospect of using the data derived from the research to raise awareness, and where appropriate, to attempt to challenge practices within their areas. I also felt that the diary process could facilitate for participants a space in and a role from which to reflect on their own circumstances, which again will be considered in analysis.

### **4.5.3 Methods**

The data collection began and ended with semi-structured interviews, where I visited participants in a place of their choosing (all chose their homes) and I asked them a series of questions relating to the research questions and adapted within the pilot stage to improve clarity. These are attached as appendix 1. The interviews were (with their permission) recorded and later transcribed. Participants sent diary entries throughout the data collection period. Audio diaries submitted by post were sent

monthly, or when each tape was full, depending upon the individual. Handwritten diary entries were sent when the participants wished, but usually on a weekly basis. Email entries were received immediately, while as outlined two participants reported their experiences by telephone. The data was then transcribed. The methods resulted in a large amount of data: there were over 300,000 words of data to analyse. The initial and final interviews averaged one hour and seven minutes in length, the shortest interview taking place with Mrs Haynes\* and the longest two hours fifteen with Patrick\*. The intermittent contact between the researcher and participants varied for each individual; dependent upon how often they felt interim contact was necessary or helpful for them. The longest I went without contact with any participants who completed the data collection period was three weeks with Flavia\*, when she felt unable to communicate with the outside world and did not answer her phone or contact the researcher directly.

#### **4.5.4 Sampling and Recruitment**

I decided upon two distinct geographical areas for the participants in order to seek to compare whether and how different local authorities of similar size and structure responded to supporting and working with people who had acquired impairments. I contacted both Local Authorities, for the areas which will hence be known as A and B, I used reference information, local Voluntary Services associations, the Internet and local newspapers to identify **voluntary organisations, disabled people's**

organisations, third sector organisations and support groups in order to contact as broad a range of disabled people as possible. I also made appeals on local radio stations and produced literature informing people of the research, see for example appendix 2. I contacted organisations by phone, letter and email and in total was in contact with just under one hundred organisations. In order to protect the anonymity of the participants the geographic areas will not be revealed.

I spoke directly to twenty five prospective participants, however after negotiations and discussions, I eventually worked with ten people who had either recently experienced a change to their impairment status or had recently acquired impairment. The participants were clear about the lengthy nature of involvement of maintaining a diary for six months. While I established a selection criteria to seek to capture as broad a range of experiences as possible (see appendix 3), in practice I was not able to be as prescriptive about the diversity of experiences of participants as I may have wished. The significant criteria which was important to me and I retained, was that there had been a change in their impairment status or the way they perceived their impairment status as this is a time in which I anticipated that disabled people would seek help, or react differently to structures, seeking help and so on.

Nine of the ten participants were from areas A and B, six came from area A and three from Area B. The final participant, Edward\* was recruited from a small village

for contrast. He had originally been asked to take part in the pilot study, and was known to the researcher, therefore employing convenience sampling. After the pilot study I recognised that Edward\* had a wealth of experiences relevant to the research and upon discussion discovered that he was willing to take part throughout the data collection period. Alaszewski in his work '*Using Diaries in Social Research*' (2006) asserts that sampling is not quite so crucial or meaningful in qualitative data processes in comparison to survey and quantitative work because the same aims are not made of the research.

*"Generalisation does not take the form of making statistical inferences about the characteristics of a population from a representative sample, but rather consists of gaining insights into social processes and the rationality which underpins observed actions and events."*

(Alaszewski, 2006:48)

Aiming to span as wide a range of experiences therefore was a reasonable aspiration. Although this was only partially successful it does not negate the wealth and quality of data received from the participants who did take part.

#### **4.5.5 Pilot Study**

The main aims of the pilot study were to ensure that the questions I was asking were clear and relevant and that the prompts I had developed for the diary data collection were effective (Lampard and Pole, 2002). Changes occurred to the questions in light of wording which could be ambiguous or difficult to understand my

intended meaning within the questions employed. These were relatively easy to rectify. Appendix item 4 shows the questions asked at the start and the end of the six month period. I piloted both the semi-structured interview question prompts and the initial outline of diary with disabled people who had encountered a change in the nature and level of impairment. The individuals taking part in the pilot interviews were recruited via contacts known to the researcher, but whose life experiences were applicable to the situations I sought to capture in the research. I then reviewed the material which had been received, reshaped the questions and diary prompt and again piloted with another disabled person.

The diary prompt system however proved much harder to develop appropriately. It felt essential to offer participants examples of the kind of experiences I would be interested in collecting data upon. I recognised that for many people the concept of **'negotiating with structures'** would not be an easy idea to grasp. I devised three drafts within the pilot period, examples of which can be found in the appendices: 5, 6 and 7. These ranged from informal approaches to intensive form filling, but I became aware during the pilot process that this presented a detailed and concentrated request for information which may not be easy to digest for some participants. Within pilot studies it was shown that such methods worked effectively in mapping experiences, I rejected these as it did not provide a sufficiently broad range of data. In particular I felt these drafts lacked sufficient provision for a qualitative approach to the data, required within the research to aid in developing an

**insight into people's perceptions of their experiences.** Reflecting back, none of the diary prompting systems I think were particularly useful. It gave participants some idea at the initial stages about what sort of information was desired, but every participant developed their own way of recording their experiences and so developing their voice over the research period. I was perhaps too prescriptive in the initial stages, but was able to recognise that this did not offer the participants what they needed and instead worked individually with the participants to ensure that they were happy and willing to engage with the process. The final diary prompting system which I piloted included a blank space in which participants could articulate their experiences with the aides mémoire details of the organisations which they may encounter. See appendix 8. The efficacy of which will be considered within the next chapter. I discovered through this process that the open format of diary allowed a greater range of data which was rich, descriptive and reflective (Hawkes, et al, 2009).

The diary method of data collection has both strengths and weaknesses. It captures a wealth of detail, real opportunity to hear the voice of the author and allows access into a continuous stream of information not immediately available from other methods (Alaszewski, 2006:113). This method therefore allows frequent entries close to the points when events actually occur (Bolger, Davis and Rafaeli, 2003). Yet the method also has weaknesses: it is highly subjective, labour intensive for both the participants and researcher and is likely to result in people self-selecting for

involvement who may be by nature more articulate or prone to reflection. Nevertheless, as the wealth of data and resultant analysis will indicate, it offered an **opportunity to an insight into a challenging period of the participants' lives in great depth**; "*This method allowed for an understanding of participants as they lived experiences and offered a deeper insight into the perspective of the participant*" (Day and Thatcher, 2009: 258).

#### **4.6 ANALYSIS PROCESS**

I used a process of thematic analysis, which I undertook manually in order to develop full familiarisation with the data. Thematic analysis is primarily a process of interpreting and understanding data (Matthews and Ross, 2010:373). Although the analysis was based upon my own interpretation of that data, this did not negate my critical realist approach. The critical realist position I adopted within this research shaped the way in which I analysed the data as it led me to seek a system which sought to understand and analyse both the structural and agency elements from the participants' perspectives.

I sought initially to encapsulate the macro structures with which participants negotiated and interacted **and so adapted Hudson and Hardy's** (2002) barriers model as a first stage. However the original subdivisions (see appendix 9) did not reflect the



experiences of the participants, or what areas they could be expected to know, and so these were adapted. Further discussion will follow in Chapter Five.

The second set of themes for analysis were derived from the topics which the participants raised within their entries. These are found in Chapter Seven. The two level approach recognises the importance of individual agency perspectives as well as the barriers and structures considered in Chapter Six

#### **4.6.1 Research Design**

One of the most important aspects of the design of the research was the importance of building effective relationships with the participants (Finlay, 2002). I chose to begin and end the diary collection period with a semi-structured interview, as I wanted to establish a relationship with the participants and raise some of the areas which may prove relevant for their diary collection process. The interim method of data collection was individualised according to the choices and capacities of the participant. However, by having similar questions and focus points through the semi structured interviews dovetailing the process ensured that the material could be compared to each other and that evaluation could take place between the perceptions which the participants presented at the start of the process in comparison to the end. It offered participants the option to reflect upon their own

experience of the research process and evaluate if and how involvement and reflection on issues of disability may have affected their experiences. There were of course strengths and weaknesses in employing this method of data collection. Some of the strengths which it offered were for me to access historical information (Creswell, 2003), to capture some complex opinions and views (Arksey, 2004), and to explore the rationale and build a relationship with each person (Bryman, 2001). The weaknesses of using interviews, such as not all participants are equally articulate or comfortable with the interview process (Creswell, 2003), the degree to which rapport between the participant and researcher may affect the outcomes of the interview (Bryman, 2001) and the need for a skilful approach by the researcher themselves (Pole and Lampard, 2002) did not for me negate the value of the approach. In order for the research to be effective in examining change over time, each participant was keeping diaries for six months, and so two interviews were by no means the only opportunity offered to seek insight into their experiences. In any event the nature of the research (on-going contact and diary method) meant that it was essential that the relationship between myself and the participants was a continuing one.

It would have been disingenuous to represent my role to be that of external and distant researcher, as considered above in the section entitled designing the research. I also recorded my own thoughts in a reflective diary throughout the data

collection process which will be discussed in greater detail within the analysis and an example of an entry supplied (Page 359).

The prompt questions which I employed for each were very similar to each other in content (see appendices 5, 6 and 7). I chose to use semi-structured interviews rather than structured ones as I recognised the individual nature of the participants, their experiences and levels of understanding of the areas for discussion. For similar reasons I decided that the interviews should not be entirely unstructured, to ensure that the data collected was related to the areas which were of relevance to the research (Arksey, 2004).

The participants produced very different forms of data depending upon their individual choices of diary keeping and some of those involved were naturally more conversational in style the others (see Chapter 8.1 for a comparison of data types). I sought a way to capture the frequency of the entries supplied in table form, which will be introduced in Chapter Five and developed case studies which enabled comparisons between participants, whilst recalling and seeking to capture their individual nature.

#### **4.7 RESEARCH QUESTION THREE**

Particularly in light of the intensively individualised process of diary collection outlined above, and the relative scarcity of the use of diaries as a data collection method over such a time period (Alazewksi, 2006; Day and Thatcher, 2009) the final research question was developed. As each diary collection method was individualised and yielded such varying material and data, the rationale for including this as a research question recognised that employing such methods would therefore affect the data yielded and the results of the research. The final research question therefore asks **'How do the methodological choices made within this research influence its outcomes?'**

#### **4.8 ETHICAL CONSIDERATIONS**

The ethical considerations relating to research are far more than processes which need completing in order to undertake field work (Macintyre, 2010). They also include much of the thinking highlighted above, including seeking to make the research participatory, situating myself within the research and making choices in relation to what personal information I shared with participants. I was also aware of the importance in undertaking effective formal ethical processes. Naturally I contacted the relevant local authorities and undertook their governance processes to ensure the safety of the participants. I also undertook the research governance

framework for the Institute in which I work and University wide indemnity before undertaking research. I circulated an invitation and information letter, highlighting key points, anonymity, time commitments, and their right to withdraw and complain and request additional information (Creswell, 2003: 64-67). This documentation can be seen as appendix 2. All participants were required to sign (or for those not able to write, verbally agree, to their involvement which was recorded after the details of the form had been read out to them) consent forms. All information was also available on audio tape and large print for those who required or preferred such formats.

However I was also aware that in addition to ensuring confidentiality and that the participants were fully informed before giving their consent, that what I was asking people to do was a major commitment, in terms of time, effort and the request to focus on areas which may not have been comfortable for them. I endeavoured as much as practical to reassure participants that they were entirely in control of what they chose to talk about. All participants also chose their own pseudonym, saw and were able to comment upon and shape their pen portraits and examples of how their data may be used within the research.

I was concerned that participants may feel vulnerable in discussing personal issues despite my attempts to keep them in control of the process; however as will be discussed in the findings, all participants who completed the research said it had been beneficial for them. Although I could not remunerate the participants and was

aware of many of the debates surrounding participant remuneration (Russell et al, 2000), I made sure there was no cost to them involved in taking part. For instance, I visited them where and when required, providing prepaid envelopes, equipment such as recording devices and tapes where necessary, and rang the participants to avoid expense to them.

I wanted the participants to be able to be involved in the use and dissemination of the findings of the research within their local areas, if they so chose. A number of the participants expressed interest and plans to use the research to attempt to influence their own regional areas and future experiences.

I spoke about anonymity and did so in detail with those who wished to discuss it. One participant was concerned of the possible repercussions of recognition, and so we worked together closely to change sufficient details to make that person harder to identify and ensure that they remained comfortable with how they were represented. Conversely there remains a concern that if sufficient details are altered the representation of the data and people involved in the research are so far removed from reality that the work ceases to have credibility (Plummer, 2006:217). I have endeavoured to work closely with the participants to avoid this happening, whilst also securing their anonymity.

## 4.9 INTRODUCING THE PARTICIPANTS

**\* Please note all the names provided are pseudonyms chosen by the participants themselves.**

The participants who agreed to take part in the research will be considered in detail within the following chapter. I recognise that a brief overview cannot effectively represent either themselves or their experiences. However, I hope that it will assist the reader in learning more about those involved and understanding some of the challenges they encountered.

Name (Pseudonym)	Age	Nature of Impairments
David	56	Epilepsy (recent change in circumstances resulted in seeking to access new social structures) (non-visible impairment)
Edward	74	Recent loss of sight
Flavia	24	Post-Traumatic Stress Disorder and head injury (non-visible impairments)
Fred	46	Fibromyalgia (Non visible impairment)
Maria and Hermione	42 and 16	Mother and daughter (rare and debilitating pain condition resulting in daughter becoming a full time wheel chair user within the last year)
Mrs Haynes	62	Stroke (affecting mobility)
Patrick	65	Stroke (affecting substantial loss of speech)
Richard	58	Limited sight and hearing (substantial increase in impairments)
Susan	48	Severe Repetitive Strain Injury RSI (non-visible impairment)

*Table 2 - Overview of the participants who began the Research*

Whilst I have described the visible and invisible elements of impairment as evident, I am aware that this is not always the case and what one person sees as manifest may not be recognised in the same way for another person (Lingsom, 2008). I have based these divisions therefore on a combination of my own impressions and the discussions that I had with the participants regarding their own impairments and whether they felt them to be manifest.

#### **4.10 CHAPTER SUMMARY**

I have selected and illustrated a method of ontological realism and epistemological relativism.

I have demonstrated here how the three research questions have been established from the nature of the research I sought to undertake and the literature which I have reviewed in previous chapters. These are:

1. Which factors affect the expectations of, and services received by the participants?
2. How are self-perception and identity affected by encountering disability and the resultant treatment?
3. How do the methodological choices made within this research influence its outcomes?



I have located the ontological and epistemological considerations I have undertaken: illustrating foundationalist and anti-foundationalist perspectives ontologically and evaluating interpretivist and positivist epistemologies. I explored the relationship between the macro and micro and the challenges of seeking to incorporate a dualistic philosophy towards the social sciences before identifying critical realism as the relevant approach to my research. Critical realism has been considered in relation to disability, situating the researcher within the research and the implications of the above choices and the effect on this research. I have demonstrated how I took ownership of this research, developing the research questions. I situated myself within the research and then showed how I had designed the piece, and considered how my understanding of the social model of disability impacted upon my practice. The process of recruitment and overview of the participants taking part in a discussion of the pilot study and the ethical considerations which I incorporated are also presented here. This demonstrates the practical elements of the methods employed within this research. Finally within this chapter I have introduced the reader to the participants and illustrated how the decisions made by the participants regarding what methods of diary they employed shaped the data yielded. I have also demonstrated what decisions I made to the research regarding keeping in contact and using data through mediated processes. The next chapter will begin by outlining how the analysis process was developed, before analysing the first set of themes.

## **CHAPTER FIVE – INTRODUCING THE DATA**

### **5.1 INTRODUCTION**

The previous chapters have illustrated the literature, discussions and ideas which have shaped the research process up until the time that the analysis took place. Research questions were introduced and the methods and analysis process. Here the participants are illustrated in greater detail, the data is presented and the process of analysis introduced. Four case studies are developed, demonstrating the themes and research questions explored within this research, and these themes then applied to the remaining participants who completed the research. The intent is to get a sense of the individuals and an insight into their approaches and circumstances before detailed analysis occurs in Chapters Six and Seven.

### **5.2 OVERVIEW OF DATA**

Some of the themes yielded greater complexity than others. In order to provide an overview of these divisions, a pictorial breakdown of the analysis provides an overview of the themes selected and a breakdown of the sub-sections undertaken. This will be found at the start of each theme.

Four of the participants whose individual experiences within the six month data appeared particularly pertinent in terms of this research will be outlined in order to begin to explore how the research questions raised in this thesis and the themes considered throughout were relevant to those involved, then return to the remaining participants and consider how their experiences also inform the findings of this research.

The participants considered in detail are David, Fred, Marie and Richard. These were selected as they demonstrated a range of interesting similarities and differences which allow broader comparisons on the data. For example, David and Fred come from the same geographic region (A), while Marie and Richard come from another region (B). Both regions in terms of population size and diversity can be seen as comparable to each other, with populations estimated at 600,00 at the time the research was undertaken. **David and Fred's impairments may be viewed as invisible, (I) while Marie's daughter Hermione and Richard had impairments which were evident and visible (V) to other people they met.** While all those considered here undertook one to one interviews at the start and the end of the six month data collection period, the data collection method for two of the participants, Fred and Richard remained static throughout the intervening period, while the methods changed for Marie and David.

<b>Name</b>	<b>Region</b>	<b>Gender</b>	<b>DP or Carer</b>	<b>Visibility of Impairment(s)</b>	<b>Data Collection Method</b>
<b>David</b>	<b>A</b>	<b>M</b>	<b>DP</b>	<b>I</b>	<b>Changed</b>
<b>Fred</b>	<b>A</b>	<b>M</b>	<b>DP</b>	<b>I</b>	<b>Static</b>
<b>Marie</b>	<b>B</b>	<b>F</b>	<b>Mother &amp; Carer</b>	<b>V</b>	<b>Changed</b>
<b>Richard</b>	<b>B</b>	<b>M</b>	<b>DP</b>	<b>V</b>	<b>Static</b>

*Table 3: Comparison - Participants Selected for Case Study*

What also influenced the decision to select the above participants, were the evident transitions which they had all encountered within the research period and how closely those case studies could be used to answer the research questions. Marie was the only woman considered in detail at this stage and was the only carer submitting data within the process. There is a danger therefore of the perspectives of disabled women therefore not being adequately recognised within this thesis, particularly as Hermione and Mrs Haynes did not submit any data after the initial interview stage. Initially equal numbers of male and female participants were recruited and while a larger number of carers were sought, no other volunteers who met the criteria were found.

The decision, therefore, to only include one of the female participants from the three who completed the research was as a direct result of the nature of the experiences encountered within the data collection period. If the research were to be undertaken again, a more balanced number of participants in terms of gender may be preferable but the nature of research in practice is that often uneven distributions occur (Devine and Heath, 2009).

Initially these participants will be introduced by an outline of their data collection input, followed by a pen portrait, which has been developed and adapted via discussion between the participants and myself to ensure that it effectively captured their experiences and represented them in a way which felt accurate. A time line will then be presented, describing events within the data collection period. The points taken from the time line are all based directly upon statements and focus given by the individual participant.

The remainder of the pen portraits of the participants who continued with the research and a synopsis of the key points encountered in the data collection period can be found later in this chapter on page (174).

**FRED**

Initial Interview →	Month 1				Month 2				Month 3				Month 4				Month 5				Month 6				Final Interview ←
	WK 1	WK 2	WK 3	WK 4	WK 5	WK 6	WK 7	WK 8	WK 9	WK 10	WK 11	WK 12	WK 13	WK 14	WK 15	WK 16	WK 17	WK 18	WK 19	WK 20	WK 21	WK 22	WK 23	WK 24	
Data Collection Entries	7	9	6	2	7	6	6	7	6	4	7	7	8	3	7	8	4	6	7	7	8	5	7	7	

**RICHARD**

Initial Interview →	Month 1				Month 2				Month 3				Month 4				Month 5				Month 6				Final Interview ←
	WK 1	WK 2	WK 3	WK 4	WK 5	WK 6	WK 7	WK 8	WK 9	WK 10	WK 11	WK 12	WK 13	WK 14	WK 15	WK 16	WK 17	WK 18	WK 19	WK 20	WK 21	WK 22	WK 23	WK 24	
Data Collection Entries	6	7	7	7	7	7	7	7	7	7	7	7	7	7	7	0	7	7	7	7	7	7	7	7	

**MARIE**

Initial Interview →	Month 1				Month 2				Month 3				Month 4				Month 5				Month 6				Final Interview ←
	WK 1	WK 2	WK 3	WK 4	WK 5	WK 6	WK 7	WK 8	WK 9	WK 10	WK 11	WK 12	WK 13	WK 14	WK 15	WK 16	WK 17	WK 18	WK 19	WK 20	WK 21	WK 22	WK 23	WK 24	
Data Collection Entries	3	2	1	0	2	2	5	6	6	4	3	6	4	3	5	6	3	6	3	4	5	4	3	3	

**DAVID**

Initial Interview →	Month 1				Month 2				Month 3				Month 4				Month 5				Month 6				Final Interview ←
	WK 1	WK 2	WK 3	WK 4	WK 5	WK 6	WK 7	WK 8	WK 9	WK 10	WK 11	WK 12	WK 13	WK 14	WK 15	WK 16	WK 17	WK 18	WK 19	WK 20	WK 21	WK 22	WK 23	WK 24	
Data Collection Entries	6	5	4	3	0	4	6	3	4	2	2	5	3	4	3	5	4	5	6	4	7	2	4	2	

Table 4: Data Collection Comparison

The tables above denote the number of separate points which the participants made during each month. While some months are more than four weeks in length, the months have been divided into four and the remaining days added into the fourth week so that direct comparisons can be made.

While these representations demonstrate the frequency and range of different points discussed, they cannot represent the depth to the data produced, which was hugely

variable, dependent upon the individual, their personal style of recording and what contact they had encountered in any given week. A graphic representation of points raised over the six months, is included for each of the first four participants.

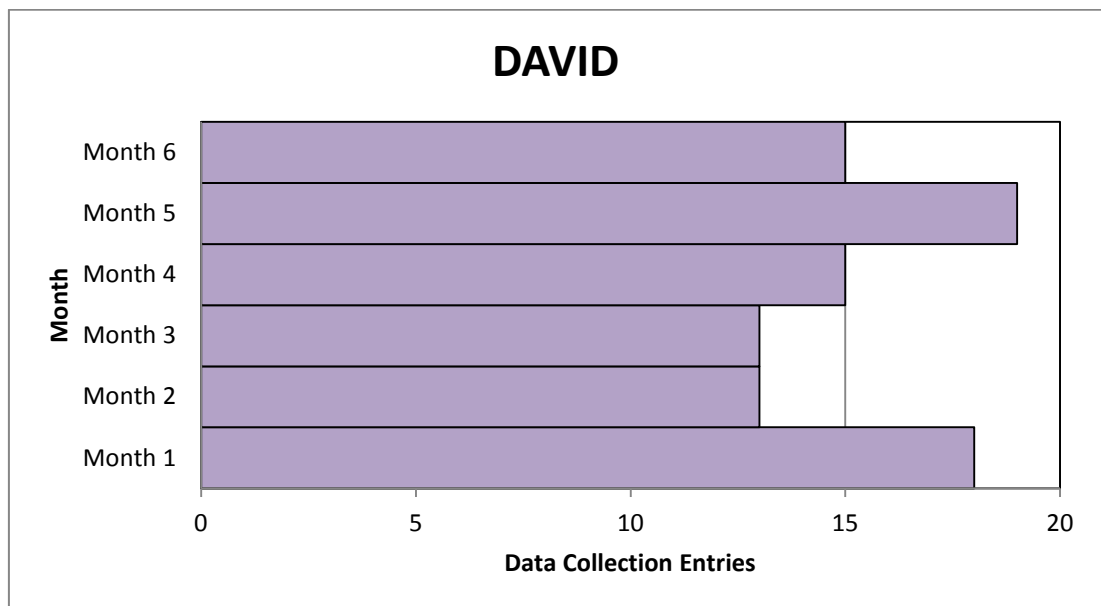
### **5.2.1 David Pen Portrait**

David is a man of 56; he is highly intelligent with a strong interest in Marxism and left wing politics. Grammar school educated, he worked for thirty years in administrative roles before stopping work around twelve years ago as a result of the pressure of work having an adverse impact on his epilepsy. He is currently in receipt of Incapacity Benefit and some private funds.

David decided to go to university at the age of 50, having taken up further education after leaving work and greatly enjoying the process of learning. However a **disagreement with the University's interpretation of guidelines relating to disability affected him greatly. This '*professionalisation*'** of disability as he described it, led to him being more aware of being disabled and treated differently than he had ever encountered previously. It had affected him greatly and altered how he felt **perceived by others and also saw himself. David's approach towards his epilepsy is to** generally not discuss it unless forced to.

David has a rich sense of humour and is highly articulate. When the research began he lived in relative isolation living in the outskirts of a city, reliant on public transport and experienced little in the way of social activities. Nor has David chosen to become involved with any disabled people groups. He has some funds as a result of an inheritance, which has meant he can afford his own home; he therefore sees his situation as much better than many other disabled people. By the end of the research period David had moved locations and was living closer to family members and had developed a much stronger support system.

### 5.2.2. David Time Line and Case Study



*Illustration 1 Data Collection Frequency Graph: DAVID*



Initial Interview - *"I don't like to be the victim. I don't like to be defined by a medical condition."*

Month One - Plans to move to new town closer to family members.

- Queried whether I as a researcher would believe his experiences and the ways he had been treated as a result of epilepsy.
- Taking part in the research has begun a *'voyage of self-discovery'* although expressed frustration that diary emails to researcher having been lost or accidentally deleted. (Discussed in greater detail at page 302)

Month Two - Decided to handwrite the majority of data for remainder of the six month period.

- Described himself as having little to complain about owing to his advantages: house in a quiet area and spare cash.

Month Three - Reflecting on work opportunities offered after his recent graduation. Education has helped him **see through the labels and see disability as a 'social construction'**. **"people with money and power and self-esteem have no need to let an impairment rule their life, or even regard themselves as disabled."**

- David decided to turn down a work opportunity out of concern about the pressure of deadlines and the stress which could adversely affect his epilepsy again.

- David is currently spending time with his sister sorting out purchases for new home.

Month Four - Received a letter stating he would be required to attend an Incapacity Benefit review, he was very concerned, and felt there was such limited information on the form. For instance not being told when or where the review would take place the length or the nature of the interview, this resulted in David feeling anxious and **describing himself as 'on edge'**.

- David tried to contact the Department of Work and Pensions, as he was concerned that information may have been sent to the wrong address, but was unable to get through. He wished he had the confidence to challenge those in authority, in relation to benefits, so that he could get through on the phone and then know what to say.

Month Five - Reflecting on how he feels epilepsy is viewed now compared to 30 years ago, David feels it is a more marginalised position.

- In dealing with solicitor in relation to his house purchase and moving, he stated he had the confidence to challenge and chase the agencies, involved **because he had financial resources and his sister's** support.
- David had difficulty in opening a bank account to transfer monies in relation to his upcoming move. He was repeatedly asked to provide a driving licence, and **felt when he was eventually forced to explain that the reason he didn't have**

such ID, was as a result of epilepsy that he felt pitied and criticised. (Expanded further on page 316).

- David was reflecting on his reaction to the events one week earlier when he had disclosed his epilepsy. "*The more I write about it the more I feel I can understand her reaction.*" He believed that the woman in the bank wanted him to be ashamed of his disability and that was why he had been told not to mention epilepsy, but just refer to having a *'disabled condition'*.

Month Six - David has moved into his new home, and is waiting in for people to attend to set up services, such as the internet and phone connections. He had not been successful in his negotiations, so his sister had contacted the relevant parties and arranged everything. The family support he had received alleviated hardships.

- Registered with new GP with very little fuss: which he found quite surprising.
- David has tried to get a bus pass: in the previous areas he had lived people with epilepsy were entitled to the pass. The first person he spoke to in relation this, began speaking to him slowly and as David put it *"IN CAPITAL LETTERS"*, once he said he was looking for information regarding disability passes. When he eventually found the correct department he was advised that in this area people were only **allowed concessionary passes if they were 'leg disabled'** David disliked this phrase, wondering whether by such a categorisation he would be described as *'brain disabled.'*
- Reflecting upon the importance of support mechanisms, before he had moved to the new area close to his family, David recognised that he had relied upon the

Socialist Workers Party. He felt that he would never have been able to challenge and react to the oppression he had encountered without their support (see page 297.)

Final Interview David felt he was now more aware of disability and felt a little more positive about discussing the subject because *"there's somebody at the other end that needs this information"*.

- He no longer feels that he needs to apologise, or his disability be viewed as *'unmentionable'* He recognises that there is a great deal of fear regarding speaking about disability generally.
- In terms of practical steps David decided to get his first passport ever in order to end possible problems with regards to appropriate ID in the future.

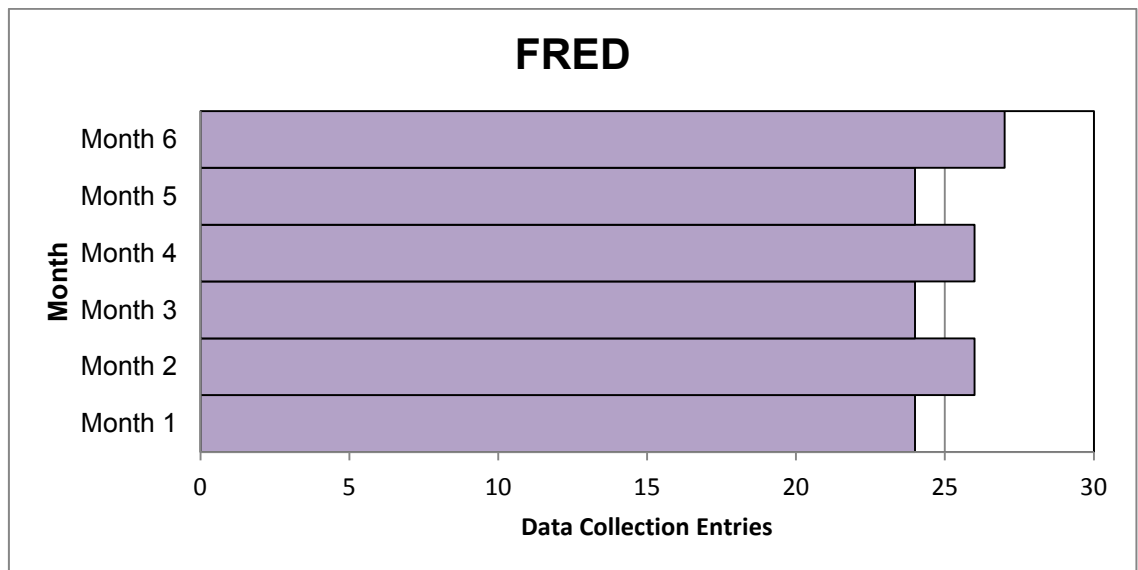
### **5.2.3 Fred Pen Portrait**

Fred is a quiet thoughtful man in his late forties, he has lived all his life in a northern city and came from a large family. Married for over 25 years and working for the same company for a similar amount of time, he has one adult child and grandchild. Having left school with no qualifications, Fred developed skills and confidence throughout his working life, working as a factory operative, training officer and convenor before his impairment prevented him from continuing to work.

Fred began to experience problems with his joints by the mid-eighties, for around twenty years Fred experienced significant pain and cramps, the duration and intensity of such attacks increasing over time. He repeatedly visited his GP. surgery and was tested for a wide variety of conditions and variously diagnosed with and treated for, a range of causes. Around two years ago, the intermittent condition became a permanent one. Eventually Fred was referred to a pain management clinic before receiving a diagnosis of fibromyalgia. At the clinic he was provided with details of self-help groups, courses and leaflets to explain his condition to his employers. Arising from this contact Fred attended a pain management course which **helped him to see his situation in a more *'positive light'*.**

Fred has now been forced to take ill health retirement from work and at the start of the research project was seeking to access benefits and relevant impairment and disability information for the first time in his life. He feels that his condition has been dismissed by health care professionals because his impairment is not visible. Fred is generally an optimistic person with a down to earth sense of humour and who believes in helping other people, but is becoming increasingly frustrated and despondent as a result of his experiences.

## 5.2.4 Fred Time Line and Case Study



*Illustration 2: Data Collection Frequency Graph FRED*

Initial Interview - Fred is just beginning to need to access services, support and information on a much more significant level than previously.

- He has been signed off work for many weeks and is not able to return owing to his condition.
- Beyond the on-going pain, one of the biggest battles Fred feels he has encountered so far is being believed over the last thirty years until his condition was finally correctly identified.
- He recently joined a self-help group and also recognises the importance of family support.

- Fred remains quite shocked and daunted by the lack of support, information and help he has encountered to date.

Month One – Repeated difficulties in contacting the benefits agency, numbers permanently engaged or not answered.

- Fred also contacted the legal department of the Union affiliated with his employment; one of their representatives is willing to help him.
- Fred discovered the expert patient programme and immediately signed up, within a few weeks the people running the course offered to train Fred to help run future courses.
- Fred is dealing with on-going physical pain, tiredness and lack of mobility, he does swim when he feels physically able and tries to remain positive through family and social activities when possible to take his mind off the challenges he is encountering.

Month Two - Fred continues to refer to his on-going pain and the difficulties in accessing services support and information.

- For instance, there is confusion between the DSS and his employer regarding the end of statutory sick pay, he is very concerned that he may be without money for at least a week as he cannot contact anyone to resolve the situation.

- Repeatedly Fred rings agencies, when he eventually gets through he is told that his issue requires input from a supervisor, but as their number was engaged. He was unable to speak to anyone who could help him.
- Looking for leaflets and information anywhere he could, Fred described his experiences as having hit a brick wall.
- He finds the Expert Patient Programme course very tiring, but also valuable.
- The paperwork he eventually received from the Benefits Agency was inaccurate and did not reflect his circumstances as he had explained to them.

Month Three - Fred refers to his long term difficulties with pain and exhaustion which appear to run parallel with his attempts to get answers from the agencies intended to offer support.

- He repeatedly rings agencies, there were also strikes and bank holidays which resulted in Fred again being in danger of receiving no money at all for a few weeks.
- Eventually his employers find a way to provide financial support in the interim.
- With the help of his representative from the Union, Fred now applies for Disability Living Allowance, as well as Incapacity Benefit and an Ill Health Retirement Pension.
- His contact with the job centre later in the month informs him that they are working four weeks behind and have not yet begun to look at his claim; they



describe a complex process whereby the claim needs to go to several different geographic locations in order to be completed.

- After making repeated enquires the agency agree to rush the claim through and that he can apply for an emergency payment and someone will ring him within four hours to discuss how this can work.
- No one ever contacts Fred in relation to this payment. He relies upon his **wife's wages and a small amount that they had previously saved to keep afloat** until the claim can be completed.
- He receives a form from the DLA confirming receipt of his claim but warning him to expect delays in processing it. Later in the month he is informed that his Incapacity Benefit Claim has been successful and receives a series of letters from the department which appear to contradict each other, which have been sent by the same department on the same date.
- Fred is informed that his DLA claim has been refused. When he queries why this should be the case he is informed that his GP described his condition as **'mild to moderate'**.
- Fred ends the month feeling very worried about his future and that he is continually fighting to be believed.

Month Four - Fred continues to battle with the systems relating to DLA and finds getting information incredibly hard. He is regularly told that information giving is not part of the role of the person he is talking to.

- He becomes increasingly depressed due to delays and financial worries. When he relays this information to the DLA department he is told that depression is a new symptom and so cannot be considered in relation to the current claim, **which was not Fred's intention.**
- He is still awaiting a decision regarding his works pension.
- He is discharged from the pain management clinic as they do not feel they can offer him any further assistance, but state he can return whenever he requires.
- When Fred tries to gain access to GP he finds it impossible to see the same doctor more than once.
- He discovers that the GP who wrote the assessment regarding DLA had never treated Fred in relation to fibromyalgia at all. He also feels that the pain **consultant's report has been misunderstood. Fred believes that** the GP does not believe Fred or recognise the condition and assumes because Fred walks into the surgery without apparent need for support that there is nothing wrong with him.
- His Incapacity Benefit Claim used an independent Doctor to assess his condition and he discovers that he has been successful in that claim.

Month Five - After regular battles to try and see a GP, Fred finally gets an appointment and asks the GP to refer him back to the pain management clinic, as the stress he is under is exacerbating his condition.

- He also asks for help coming to terms with disability as he is experiencing significant pain alongside depression relating to his financial worries. He is told it is too soon for him to return and is given anti-depressants.
- At the end of the month Fred is able to see another GP, this time it is a locum who allows him plenty of time, listens carefully and agrees to refer him back to the pain management team.
- He reflects on people passing judgement on disabled people and seeing them as *'scroungers'*.
- Fred receives a date for his appeal hearing in relation to DLA, but is concerned as the location is inaccessible.
- He is very relieved that the Union representative will be there to support him, as with the significant pain and large amount of pain killers he is using, he **wouldn't be able to articulate himself properly without that support.**

Month Six - Fred continues to report continual pain, he is offered more support by the pain management clinic and the specialist there agrees to write a testimony statement in support of his DLA claim. She expresses frustration and disappointment about the attitude encountered by the GPs surgery.

- Fred wants a medical assessment to take place, as his condition is creating further new problems every day.
- He wants those involved in making decisions around disability in his case to recognise how fully the condition is affecting his life.

- Money is becoming increasingly tight and family social activities are rare but appear to help Fred relax and feel more able to cope.
- An occupational therapist visits him and discusses aids and adaptations.
- Fred feels that he now needs to acknowledge the depth of the problems he is encountering and use whatever help is available.
- He is informed that he is on a waiting list to see a psychiatrist, which is expected to be at least four months long.
- Fred believes that his company may be close to making a decision regarding his pension.
- He also begins his role as an Expert Patient Programme tutor, which he finds tiring but very rewarding.

Final Interview – being involved in the research Fred reflected had helped him stay on track and led him to be even more determined, though in any event he was certain his wife would not have allowed him to give in.

- His attitude towards disability before this time had assumed that if people needed help they could get it, and he was shocked to discover this was not the case.
- Fred believed that if people were given the help they required when they needed it, the approach would pay for itself in relation to people with long term conditions.

- By the end of the data collection period, Fred had received DLA upon appeal and his ill health pension had been granted.
- He sees himself as starting to come to terms with disability, "*though I still see myself as a normal person*".
- His attitude towards the agencies with which he had negotiated was that a person simply could not assume that anyone you spoke to would do what they had said they would.
- The services Fred has received from the pain management team, the Union representative and the occupational therapist were valued, while the GP provision was not.
- He believed that if he had received help earlier he may have been able to return to work at some point but for example waiting six weeks for physiotherapy had meant that was not likely to happen.
- For Fred the most shocking thing about the whole experience had been people's predominantly negative attitudes.

*\* I have made the decision to include the Marie and Hermione outline as one pen portrait, as after the initial meeting Hermione did not have direct contact with me to negotiate her own description and definition. However Marie and Hermione looked at the description together and agreed the representation.*

### **5.2.5 Marie and Hermione – Pen Portrait**

Marie is a cheerful practical woman in her late forties, she lives with her husband and daughter Hermione aged sixteen. **The family's older son also lives at home when not** away at University. The family live in a comfortable, well cared for home in the south of England, though originally come from a different region. Around three years ago Hermione began to develop significant pain. After approximately a year of being on waiting lists, and seeing **a range of both NHS and private specialists, Hermione's pain** became more severe and the family were referred to an NHS pain management team. Throughout the last two years the pain management team have worked with Hermione and her family; including the use of physiotherapy, counselling and employing a range of medical treatments with limited results, **Hermione's symptoms** have increased over time rather than reduced. The condition has now been identified as a rare pain related syndrome with an uncertain prognosis.

Marie gave up work as a legal secretary to support her daughter on a full time basis. Hermione has little opportunity to move freely about her home or, for example, access a bathroom independently. She currently uses a wheelchair with her legs extended in front of her and has pain and limited movement of both her arms and legs.

Hermione attended a private school prior to developing her condition, but experienced what the family saw as bullying and a lack of support, which resulted in the family withdrawing Hermione from the school. Marie found a suitable state school, but the Local Authority refused to fund additional support which Hermione would require. **The state school negotiated on the family's behalf, but a lengthy battle including formal appeal process ensued to get full funding in relation to Hermione's needs. The school were successful** and Hermione moved to a state school with specialist provision which offers a source of support and information which the family had not encountered before and which they all appreciate. Marie and her husband have also appealed against Local Authority decisions regarding **Hermione's needs, for example**, in providing transport to education. The family have been successful in each appeal and tribunal they have attended, though found the process intimidating. Hermione is currently in receipt of both care and mobility elements of the Disability Living Allowance.

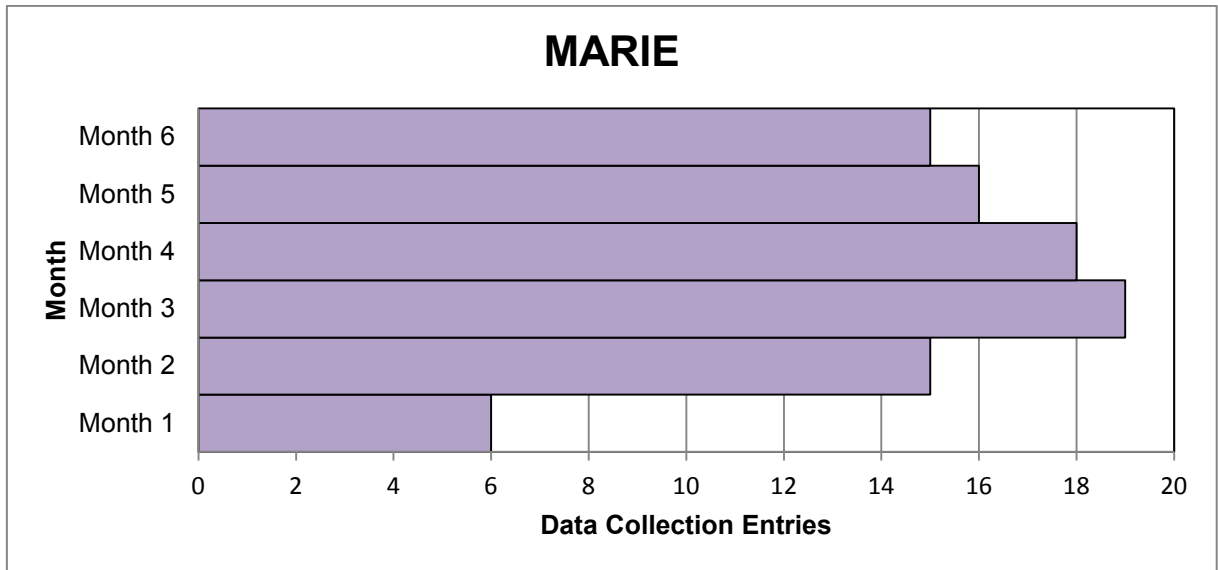
During the treatments the family sought to remain positive about the future in spite of the psychological pressures they have experienced. By the end of the research period the family had been advised that they have exhausted all current medical options and are looking to develop an independent life for Hermione, which will now involve wheelchair use for the foreseeable future.

Hermione is doing well at her new school, despite her on-going pain and the evident stress she has experienced. While hospital treatments resulted in many enforced absences, she did well at GCSE level and is an intelligent young woman determined to embark on a successful professional career. She has within the last year undertaken the hobby of sailing and is greatly enjoying the experience. She has also sought out advice regarding adaptive technology so she can learn to drive and the family were finding out about such technology at the end of the research process.

#### **5.2.6. Marie Time Line and Case Study**

*\*I have included this case study purely from the perspective of Marie, rather than included that of her daughter Hermione, as Marie retained contact with me throughout the research period, sent diary entries and a final interview. I was therefore in a stronger position to explore Marie's feelings and perceptions throughout this period rather than her daughter's.*





*Illustration 3: Data Collection Frequency Graph MARIE*

First Interview - **Marie described how Hermione's syndrome is not well-known**, it results in pain in multiple sites and throughout her body, there is no prognosis.

- The family are working closely with a pain team at a regional hospital.
- There was great difficulty originally three years ago getting a diagnosis, owing to this the family paid for a private consultant, but still there were extensive waiting lists for physiotherapy and pain management.
- Again the family paid for private services in the interim as their daughter was in substantial pain.
- Hermione was at this stage encountering bullying at the private school she attended "*because nobody could see what was wrong*".

- Marie experienced a great deal of guilt as she felt responsible for the decisions made regarding getting appropriate help for her daughter and she did not know how to access the appropriate help, **feeling unfamiliar with 'the system'**.
- Doctors had also urged Marie to believe that her daughter will get better telling her *"You must believe this you have got to believe she will get better"* and suggested that if she did not communicate this belief to her daughter it may adversely affect her condition.
- Marie and Hermione now claim Carers Allowance and DLA, however when a friend first told Marie of the benefits *"I was so upset that she had...how could she think that my daughter was disabled?"*.
- On-going battles have included trying to access support and services for a condition which is so rare people had not heard of it and so dismissed requests for support, such as blue badge parking, links to support groups and so on.
- When eventually Marie sought to access sport activities for her daughter, who had previously really enjoyed such pastimes, the only option she found was one in which all disabled young people were included in one group, including disabled people with autism and downs syndrome, but Marie felt Hermione did not have the same requirements *"there was always a sharp intake of breath when I would say her needs are different from a child with downs."*
- While a social worker did assess the family and complete a large report, she told Marie that no help was available as they had *"run out of money"*.

- Marie was currently challenging a decision made with the local council not to provide Hermione with transport to access her school, which will be going to appeal, which made Marie quite nervous of the processes to follow and reflecting that the "*trouble was you need energy to fight these things.*"
- The physical caring which Marie was undertaking included throughout the night and three years of "*battling for support*" had affected her.

Month One - Hermione was very unwell during this period and Marie described spending a great deal of time with medics, a decision which had been previously agreed with the consultants had not taken place. Phone calls, emails and the stress exacerbating her daughters condition made it a very difficult time for the family.

- Marie was also in contact with the Patient Advisory Liaison Service (PALS) and parents of other young people with debilitating conditions to try and discover what their rights were for challenging the medical delays and lack of treatment.
- The appeal regarding Hermione being refused transport to sixth form college was undertaken, whilst it was very formal and intimidating. Her husband spoke mainly on their behalf and although they were successful, Marie felt the whole process was a huge waste of time and resources and that many people may not have been able to articulate their situation under such pressure.

Month Two - As Hermione is sixteen she was able to take over control of her DLA, however as she was unable to write the DSS stated someone would have to assess her mental capacity before that would be permitted, Marie expressed frustration **"I feel quite irritated by the narrow mindedness of the DSS"**.

- Hermione had begun sailing in an adapted boat, arranged through the contact a teacher at her school had. Hermione really enjoyed the activity and Marie described the help given **"the kindness of all these people in giving their time and support is very humbling"**.
- **Hermione's condition was worsening and Marie felt that the consultant** on the medical team was speaking to Hermione in a very critical and unhelpful **manner and "could not understand why she was not getting better"** suggesting that if the next intervention failed they would look at bending her legs permanently and Hermione would be spending the rest of her life in a wheel chair **"The fact that Hermione has a condition that is not given funding by the NHS is not her fault, she is still a person who needs help and support – not blame and guilt"**.

After this month, Marie found it very difficult to keep a diary on a regular basis: her daughter was extremely unwell and in and out of hospital and their computer was affected by a virus which lost some data which she had prepared for the research. While keeping in contact with Marie, we agreed that the only way in which she felt she could continue to be involved was if she spoke to me on the phone at least every

two weeks, that we record the conversation, and that her descriptions of event could be used as diaries. I will reflect in Chapter Seven how such events and methodological decisions shaped the research as outlined in research question three.

Month Three - Marie outlined her belief that in light of the appeals and fighting necessary at each stage in their seeking support for Hermione, that the authorities *"will say no until you can prove we have to do it"*.

- Marie noticed that being in a wheelchair is a social barrier and that she now **recognises a** *"huge culture of discrimination which only people who have crossed the boundary or care for someone who has crossed that boundary can recognise."*
- The pain management team has changed and the support which was there **previously is no longer available** *"there seems no sense of cohesion any more"*.
- The Mobility Advice and Vehicle Information System have helped in terms of an adaptive car and the whole family continues to value the school a great deal.
- Hermione continues with sailing whenever possible and values the freedom it offers her.

- Despite her pain, disruption and extensive stays in hospital, Hermione succeeded in seven GCSEs, four As and three Bs and Marie's **pride in her** daughter was evident.

Month Four - The medical team appear to have become even more fragmented and less able to communicate with each other.

- Marie would try and force the issue, but feels entirely powerless and believes that if she is seen as "*belligerent and pushy*" they could lose the limited support which they are currently accessing. In a case where there is no formal **funding for a condition the need to be liked and affected by other people's** judgements are substantial and '*daunting*'.
- The family went on holiday on a cruise with a number of disabled people and their families. The disabled people were around five per cent of the customers on board, they had a range of different ages and experiences, many of them had also acquired impairments, it was a really positive experience for the **whole family and had evidently increased Hermione's confidence and hopes** for her future.

Month Five - More difficulties with the medical team and changes in personnel had meant that it was even harder to access information regarding treatment.

- Differences in procedure meant that two of the consultants did not have access to the hospital where they were consulting once a month and had to have someone working with them all day and allowing them access when they did work at the centre.
- Marie was now of the opinion that if she did not drive things along her daughter would not get the support she needed. *“From my experiences with the NHS now the one who pushes and shouts loudest gets the most”.*
- Attempts to get help from social services had not been successful, the information they had sent her when she rang to ask about what may be available was inaccurate and out of date by several years.
- **The school and external activities remained the highlight of Hermione’s** experiences and Marie views this as fantastic.
- The transport to school is now allowing her daughter to become more independent and the adaptive aids accessed by the school are helping a great deal.
- A formal letter addressed to Hermione from the DSS had been sent which threatened to take away her benefit unless appropriate proof of identity was submitted in the next week. When Marie contacted the agency to query this **she was told that there had been a “small mix up” and the information they** required was already on record.

- The pain management team finally acknowledged that they do not feel any further intervention will help Hermione and that she is likely to be a wheelchair user for the rest of her life.
- Marie is therefore focussing upon accessing the life skills training that her daughter will need and find ways to look forward.

Month Six – Marie is seeking to access adaptations to the house and information about a whole range of resources such as wheelchair training and strengthening independence. Currently in order to bathe or move up or down stairs, Hermione has to be helped by her parents which means her daughter often uses a commode and remains downstairs.

- Marie has sought access to a counselling and psychology service which Hermione had used a little previously, in light of the new final prognosis. However, **as the pain management team appears to have 'dissolved'**, no one has returned her calls or told her how to access such services.
- Hermione has lost a great deal of weight and the endless delays, treatment and decisions have clearly affected her adversely.
- It was rare for Marie to talk about herself a great deal and her discussion had always focussed upon her daughter. At this stage, however, Marie spoke of not quite knowing how she was, that she felt quite shut away and while she was normally able to express herself she felt quite numb; *"but with a growing acceptance that my daughter is never going to be the girl **she was**".*



- **Marie felt guilty and worried; she didn't know whether they should accept the decisions of the medical team or continue to fight and was unclear which would be best for Hermione.**

Final Interview - Marie reflected that the days were beginning to get a little clearer **and that the family had entered into a normality which hadn't been there a year ago.**

- Both Marie and Hermione were now involved in activities independent from each other and as a result she can **see her daughter's self-esteem** has risen, although there are many more battles to follow.
- Marie felt that the medical team really had failed to recognise the challenges which disabled people face.
- Hermione had passed her driving test and had a licence early as a result of her disability, which had led to some greater freedom.
- The family are talking about Hermione going away to University and Hermione has stated that apart from holidays she would not plan to return home to live afterwards, though Marie and her husband are still planning to move so that they have accessible accommodation when their daughter does want to visit.
- Hermione is now accessing psychological support for the changes she is dealing with, through a GP who has begun to get involved in recognition of **Hermione's weight loss and is fighting to help the family.**

- Marie felt that she was less conscious of people staring at Hermione now, **that some people's attitudes had changed and the focus was at times on** them being mother and daughter, rather than disabled person and carer.

### **5.2.6. Richard Pen Portrait**

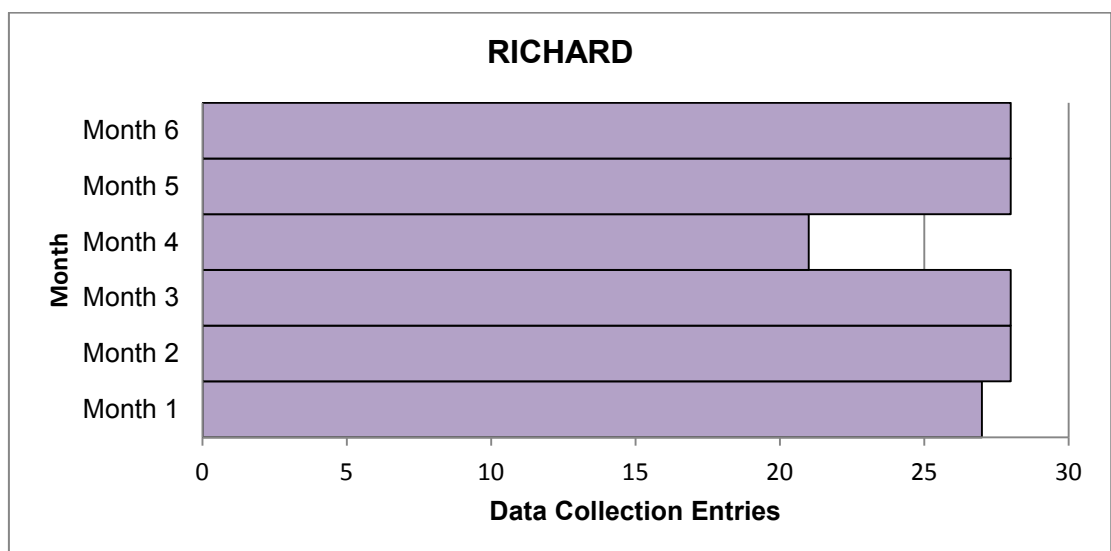
Richard is a man of 58 coming from the south of England, initially from a rural area. Having had rubella as a child Richard developed a visual impairment and hearing issues, and his hearing difficulties were identified around the age of 12. In 1999 Richard was diagnosed as diabetic. In the last 3 or 4 years, his sight has become much more impaired and he now calculates his sight at around 1 or 2 %. This means individuals can only be identified as shadows unless they are within inches of his face, even at this proximity their images are not clear. He now, therefore, deals with combined challenges of significant dual impairment loss.

He has a quiet determination about whatever he undertakes, is house proud, cares for himself and seeks to find practical solutions to whatever problems he faces. Richard has a good memory and is skilled in seeking out and using technology which can help him. He is lonely and isolated at times, yet he faces this calmly, rarely complains and continues to try and improve his circumstances. Richard keeps himself

busy and has a range of interests, including further education, the Internet, and amateur radio.

Trying to find a location which suited him, since his sight has reduced, Richard has moved three times in the last six years, seeking an area which both offers appropriate support and where he does not feel that local people are aggressive towards disabled people. The last move Richard made was back to a larger costal city as the isolation and discrimination he had found living in more rural areas became intolerable, for example where some of the people, particularly around pubs had been hostile towards him.

### 5.2.7 Richard Time Line and Case Study



*Illustration 4: Data Collection Frequency Graph RICHARD*

## First Interview

- **Glaucoma four years ago caused a huge change in Richards's life experiences** affecting his independence, social activities and ability to communicate with other people.
- The attitudes of people generally he feels are his biggest barriers and that *"people are often frightened as they don't know how to deal with it"*. In particular
- Richard feels that the people he encounters can understand a disability on its own, *"but they can't stand both"* i.e. both a visual and aural impairment together.
- Disability for Richard is a *"label which has been forced upon me"*.
- When seeking to access help, Richard is skilled at problem solving and persisting until he gets results.
- For instance he described having returned to the geographic region in which he now lives and contacting local government agencies identifying what help was available, he described **seeking to speak to the right person as** *"pass the parcel"* but once he had got through he was able to get some help within a week.
- In the past Richard has been involved in self-help groups, but he feels that they mainly cater for people with physical impairments and such *organisations*

*"don't fit with sensory 'handicap' "* and understanding communication in larger groups is very difficult.

- The annual University courses he attend with other sensory impaired people have been some of his fondest memories, he likes to learn and is particularly fond of science.
- The University are planning within the next year to integrate the people with sensory impairments with a group of sighted and hearing people and Richard feels *"that's so intimidating for us"*.
- Richard is quite clear that for him the biggest challenge are people's attitudes. On the occasions he finds someone willing to work with him and help him, he recognises and values that input, such as the estate agent who helped him buy his flat, who he feels went out of her way to help him and he trusts a great deal.
- **He is** *"not surprised, but disappointed that people in the street see disability and imply it's your own fault"*.

#### Month One

- Richard spent time visiting local organisations and agencies, such as the library seeking out resources and information about what services were available.
- However, many of the opportunities he found were not suitable and focussed predominantly on people with physical impairments.

- He described this time as quiet and often lonely.
- He sees his support worker once a week which is greatly valued.
- Once during the month he visited his family who live in a different city, which gave him the opportunity to socialise a little.
- Richard goes out quite often seeking social contact, for example he goes to a local pub now occasionally, but owing to the noise and volume of people he cannot always hear and communicate effectively.
- He continues to seek to change the approach of the local University in closing courses for people with sensory impairment.

Month Two -Repeated attempts were required to get through to the DWP regarding the need for a letter to visit the dentist. Richard rang repeatedly and was out on hold for a great deal of time before finally getting through to speak to someone, though the issue is not fully resolved.

- He finds Dial-a-Ride to be a really valuable service when he can access it, but that sometimes can be limited as demand outstrips resources.
- A local charity is working with him to help him also find safer routes for independent public transport travel.
- Owing to his diabetes being very unstable at present he has to have district nurses visit twice each day.
- On more than one occasion they have not noted his impairments, and become angry when he has not heard the door and told him he has inconvenienced

them. He believes that if they were aware and simply rang the doorbell more than once and waited for him to get to the door, there would not be such problems.

Month Three – Richard described himself as feeling very isolated during this time.

- He visited his family in another city once and rated the support provision available through the train service.
- Beyond which however he has rarely gone out and has missed telephone calls more than once.
- Richard decides to seek out further technological aids to help him hear the phone and door more easily if possible.
- Protests are planned regarding the University closure of the courses they value next month and this is central in his thought process at the moment.

Month Four - The dentist states he requires a letter supporting Richards assertion that he is on income support each time he attends the surgery, which is proving very hard for him to access via the DWP.

- The mobility training has proved useful and he also now often uses dial a ride when the service is available.
- He has been invited to take part in a local action group for people with dual sensory impairment and is particularly keen that they should push through

disability awareness training for secondary school children as “*they should be made to realise we’re not all witches and we don’t bite!*”

- Now his computer is up and running, he has internet access and is using software to help with communication, which he feels is a real breakthrough. He is now able to access Google and a wide range of websites for the first time and so is able to access much more information.
- The demonstration regarding the University course closure went ahead.

Month Five: Again Richard reported much isolation in this month.

- At a meeting of the forum regarding blindness and hearing loss the group discussed improving services and local provision. He was able to tell many people at the group about aids and adaptations available which he uses and they had no idea existed.
- The media attention regarding the University course closure appears to have had some success and meetings and discussion will take place about how the courses may be maintained in some form.

Month Six: Previously permission had been given for Richard to put an antenna above the flats he lives on in order to access his hobby (Amateur Radio). However the aggressive adult son of the woman living in a flat above him, pushed his way into



**Richard's home and demanded that the aerial** be taken down for health reasons.

Richard felt badly shaken by this abusive behaviour.

- Richard has been offered direct payments, he is excited about the possibility of lessening his isolation, but nervous about how practically this can happen. For instance interviewing people and employing them while having sensory deprivation.

Final Interview: Reflecting back Richard recognised he was slightly better established in his new home than he had been when the data collection period began.

- He was still in negotiation regarding taking down his aerial although he had been given permission to put it up in the first place. He did not feel it possible to fight, as he felt that the attitude and aggression he had encountered showed no understanding of the challenges he encounters in communicating.
- The direct payment appears to be moving forward, while Richard hates the label he received along with the audio correspondence regarding the service. He dislikes the term *deaf / blind* as a *"blunt crude description"*. Much of the information appears to be aimed at people with learning difficulties and he found this material very vague.

- **As Richard's diabetes** has stabilised and he no longer has district nurses visiting, his relationship with health services had improved and he felt generally that he was being well treated by the NHS.
- However Richard does not believe that public attitudes to disability have changed a great deal in the last six months and in terms of accessing information such as in relation to policy changes "*we're so far down the other end of the telescope, you know we're right off the radar*" and so does not get appropriate information in an accessible format.
- He would very much like to find wider methods of dissemination of policy material and information generally.

### **5.2.8 Situating the Research Questions within the Analysis**

The first research question within this thesis is concerned with identifying what factors affect the expectations of, and services received by, the participants. As demonstrated in Chapter Four this question seeks to recognise the external factors which people encounter, such as the nature of the impairment(s), the areas in which they live and so on. Such factors and in particular the structurally imposed barriers which were encountered, will be outlined initially here and considered in detail in Chapter Six. The literature reviewed within this work and methodology applied, has illustrated the importance of structure and agency in shaping the individual experiences of people, particularly when negotiating change, encountering

impairments and facing disability. The second part of this research question therefore considers the individual or micro actions and responses, to the circumstances and barriers which they met to understand the interplay between the structures and agency. This will be evaluated in greater detail in Chapter Seven.

As considered in Chapter Three, people have unique attitudes towards their own identity and that at the point of encountering or acquiring impairment, is a crucial time in how people may negotiate with external structures while seeking to respond to possible internal dichotomies brought about by their change in circumstances. The second research question therefore asks *'how are self-perception and identity affected by encountering disability and the treatment participants experience as a result?'* **This will be further answered in both Chapters Six and Seven, the first part of the question discussed in Six and the latter part in Seven.**

The final research question, which looks explicitly at how the use of diaries and the methodological choices made within this research influence its outcomes, will be considered in detail within Chapter Seven. This is in recognition that the individual options and methods selected by the participants influenced the outcomes, but the singular way the researcher developed the methodology facilitated a greater awareness and opportunity for reflection for all involved, thereby widening the opportunities for agency at the micro level of engagement.

### 5.2.9 Themes Within the Analysis

While it would be simplistic to present the themes or research questions as only applying to macro, micro or the interplay between the two, it is helpful to situate at what level the theme may be initially encountered. For instance Chapter Two recognised the external discourses of disability and how these may impact upon individuals. While such discourses may be seen as operating primarily at a macro level; through the responses which people encounter when acquiring impairment and resultant disability, it is also their own reactions at a micro level towards such impairment(s) and disabling structures and what factors affect the negotiation between the macro and micro which may also effect the experiences and outcomes at an individual level. The analysis will further demonstrate how three themes proved **relevant to the participants' experiences and answering the research questions**, namely:

<b>Theme One</b>	<b>Structural and external barriers</b>	<b>Macro level</b>
<b>Theme Two</b>	<b>Exercise of individual agency</b>	<b>Interplay between Macro and Micro levels</b>
<b>Theme Three</b>	<b>Negotiation of 'new' identity</b>	<b>Micro level</b>

*Table 5: Themes of Structure, Agency and Identity*

## **5.3 THE REMAINING PARTICIPANTS**

The remaining participants are presented here through pen portraits and a description of the key challenges perceived through the information they provided within the data collection period. The tabular representation of their contact points can be found in appendix 11. All participants who continued with the research throughout the data collection period will be included within the analysis and discussions within the following two chapters.

### **5.3.1 Edward**

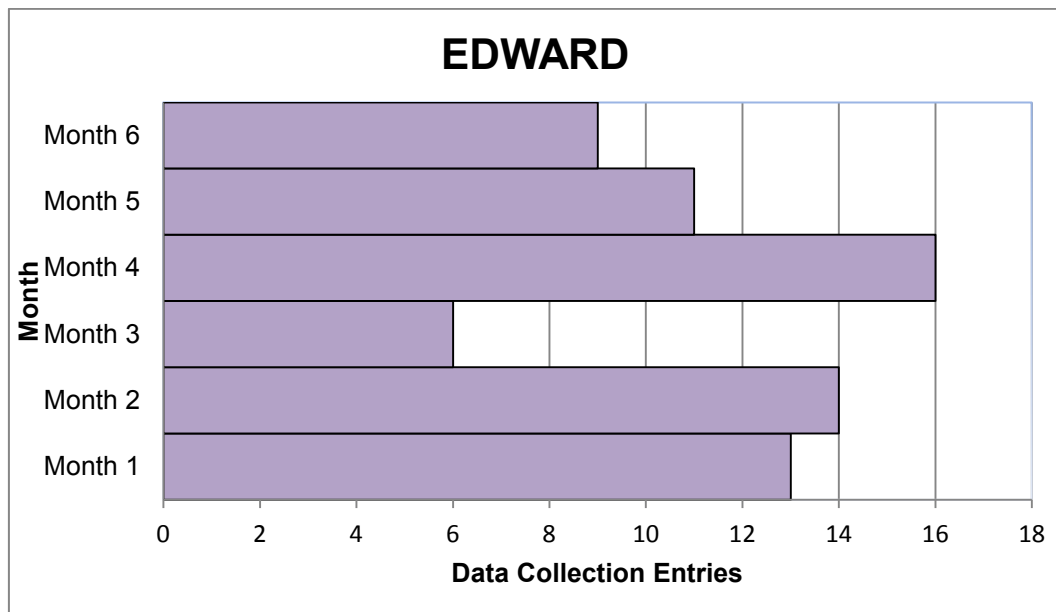
**Edward is a tall intelligent articulate man in his late 70's.** Before retirement Edward had been a lecturer at a technical college. He lives in a village with his wife and has two adult children and grandchildren. He began to experience a loss of vision around seven years ago. Age-related macular degeneration (AMD) resulted in substantial loss of vision within one year.

Edward was approached to be registered as blind at the hospital once the permanence of his vision loss was assessed. He was given information at the time and when he agreed to be registered the local branch of a national charity got in touch and they offered him support and further information.

The loss of vision has affected his life considerably; for example, he is now unable to drive, cannot cross roads alone, and finds day to day tasks such as shopping and banking difficult without the support of his wife. He finds this loss of autonomy quite a challenge, as he has been an independent person. Edward has been determined to continue to live a rich and active life, and has for example learnt to play a musical instrument since his loss of vision. He has also found out about and uses a wide range of aids to help him; including text magnifiers, talking cassettes and in relation to his computer, speech related software, scanners, and coloured letters on his keyboard. He has accessed Attendance Allowance, which makes it easier to pay for many of the specialist aids and adaptations which he uses.

Edward is involved in a wide range of groups and activities, in particular a local access group, which provides both support and a campaigning platform from which to seek to get his voice heard about the experiences of disabled people within his area.

### 5.3.2 Edward Case Study Synopsis



*Illustration 5: Data Collection Frequency Graph EDWARD*

Edward focussed predominantly on writing about what aids and adaptations could be developed to aid people with visual impairments. His diary entries mainly referred to situations where he felt practical steps could be made to improve circumstances, such as central information points, lowered pavements and accessible buildings. His biggest frustration appeared to be loss of independence. He valued being involved in pressure groups and organisations seeking to apply collective action in order to shape changes in the treatment of disabled people. There was little reflection in his diary entries, but a focus on what could be changed rather than what had occurred.

**Only in one entry entitled "How I learnt to accept the situation",** Edward stated that

he felt "the main factors involved with my coming to terms with my disability was the

*help given to me (and still get) by very concerned people" together with the care and support of his wife and in his determination to make a new life for himself. He firmly believes that having a positive attitude towards life will result in other people wanting to help, rather than disabled people who may bemoan their situation.*

### **5.3.3 Flavia**

Flavia is a lively articulate woman of 25. She experienced a road traffic accident four and a half years prior to the start of the data collection period, which resulted in head injury and post-traumatic stress disorder (PTSD). She continues to seek support, information and provision particularly to help her overcome the PTSD.

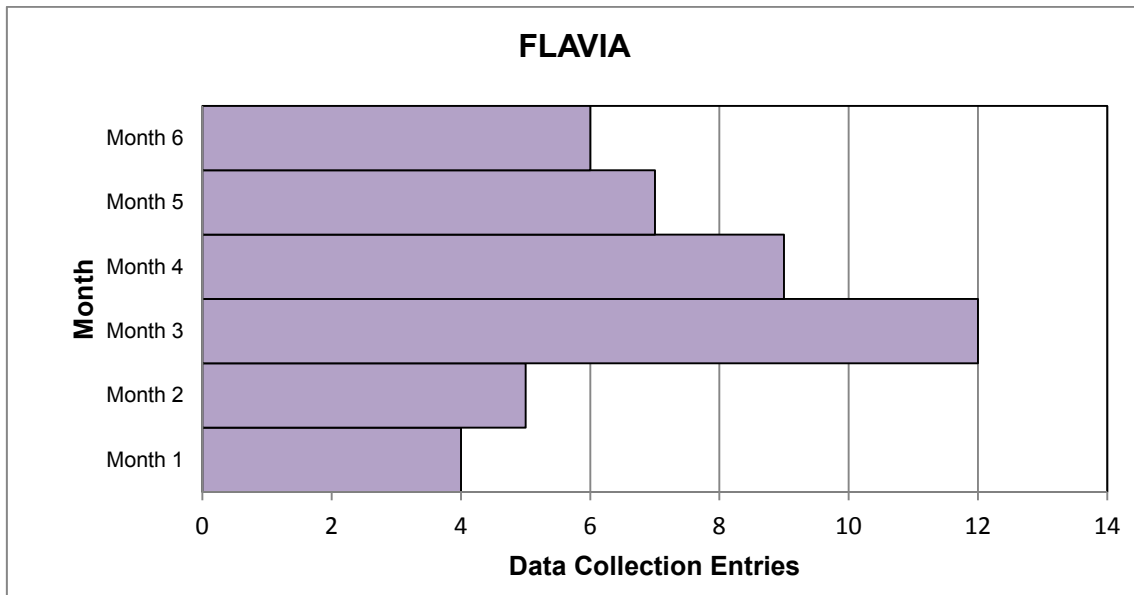
Despite her experiences Flavia has continued to try and complete a degree in photography at a technical college of further and higher education allied to a university. Initially beginning study in another region, she moved areas after the accident in order to be closer to her mother and in what appeared to her to be a more positive environment. She faces on-going battles to have her condition recognised and supported, both through health care provision, social care and college sources, mainly without success. She was, for instance, at the time of the



data collection paying for her counselling services and psychotherapy as she has been unable to find such help outside the private markets.

In March 2006 Flavia was mugged at a local cash machine, which exacerbated the condition. Flavia lives alone in a small well-maintained house in an industrial city and cares for two noisy and affectionate cats. Her mother lives around fifteen miles away and offers support at times. Flavia experiences very high states of anxiety, exhaustion, panic attacks and sleeplessness; she has great difficulty in finding ways **for her brain to 'switch off'**. Flavia is in a precarious financial position, feeling unable to work for long periods of time and not thriving within the educational environment. She has sought to access benefit provision within the research period, without success. Despite all setbacks and failures to find support she remains determined to get the provision she needs to overcome her current situation.

### 5.3.4 Flavia Case Study Synopsis



*Illustration 6: Data Collection Frequency Graph FLAVIA*

Flavia began sending very detailed and extensive diary entries, however these appeared to be muddled at times repeating the same information, while at others making reference to issues she had never mentioned before with insufficient content to grasp the points she made. As she became more stressed and in light of various losses of her internet access at home, Flavia reported more of her experiences on the phone and in a personal reflective diary which she had kept throughout the period and agreed to allow me access to and copy. The overwhelming barriers for her related to accessing services, provision and information, particularly in light of her conditions being little understood by other people and the difficulty in getting people to understand the nature of her conditions and being believed. These

challenges occurred at University, government agencies and in the NHS where Flavia had to deal with symptoms, confusion and a lack of support alongside professionals telling her to *"pull herself together"*. She appeared to have found less support and recognition or understanding of her impairments than any of the other participants involved in the research and found it hardest to articulate her experiences.

### **5.3.5 Susan**

Susan is a friendly talkative woman in her late forties; she lives with her husband in an industrial city in the South of England and has five adult children. Around twelve years ago she developed Tenosynovitis, commonly known as 'teno' and aligned with RSI (Repetitive Strain Injury) she believes as a result of poor work practices at her main place of employment at the time.

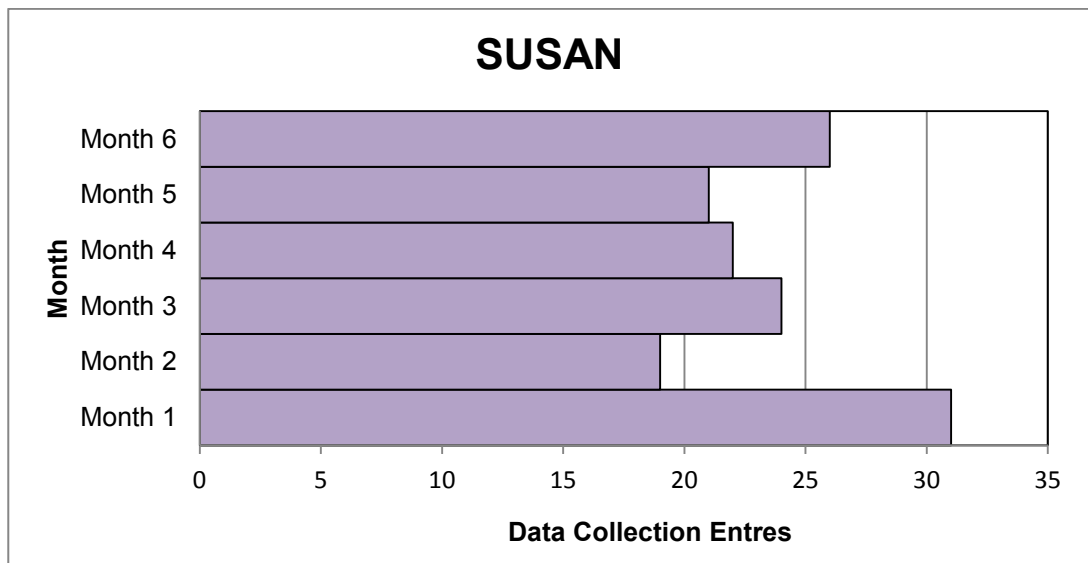
**Susan's symptoms began as 'excruciating pain'**. Currently she has intermittent bouts of pain and loss of movement, she becomes tired very easily and cannot undertake many daily activities, such as opening heavy doors, turning traditional taps, or carry goods with any weight. Over time Susan has used a wide variety of methods to help manage her teno; she has a close working relationship with her GP, through which she has accessed occupational health, counselling services, and acupuncture

intermittently. She pays for further treatments privately, for instance regularly using toning tables to ease muscular tension.

A voluntary role with a small local organisation eventually developed into paid employment from which Susan has learned a wide range of skills. This means she can support, represent and advise other disabled people as well as herself and has been involved in many support groups, consultation activities and advisory roles. She has a strong social network of friends and family. Susan also places great value on **complimentary therapies, including guided meditations and healing CD's**. She uses **these approaches almost daily to *'inspire and sustain her'***.

A year before the start of the data collection period, Susan referred herself to the Expert Patient Programme, (EPP). It gave her perspective and encouraged her to think more deeply about certain aspects of living with her impairment and reinforced her confidence to be assertive and positive about her future.

### 5.3.6 Susan Case Study Synopsis



*Illustration 7: Data Collection Frequency Graph SUSAN*

Susan used both tapes and email diary entries in addition to the interim telephone contact with the researcher. She sent by far the largest amount of material than any other participants. The diaries appeared to allow her to reflect both on previous and current circumstances. She used complimentary therapies, guided meditation, toning tables, GP resources and support groups to help her deal with the pain and limitations she encountered. Instances which were particular barriers to Susan during the data collection period were mainly about a lack of understanding or belief in the effects of her teno and circumstances where agencies, including her employers, agreed to undertake certain actions and then failed to do so. When Susan fell and was told to use crutches, the medical team could not recognise that this meant in

was not possible for her to do so in light of her RSI. Undertaking an Expert Patient Programme was greatly valued by Susan. Although her condition (at that time) had first occurred eleven years ago, the course facilitated in her a new understanding and acceptance of her impairments, combined with a greater sense of assertiveness in discussing her needs with other people.

### **5.3.7 Patrick**

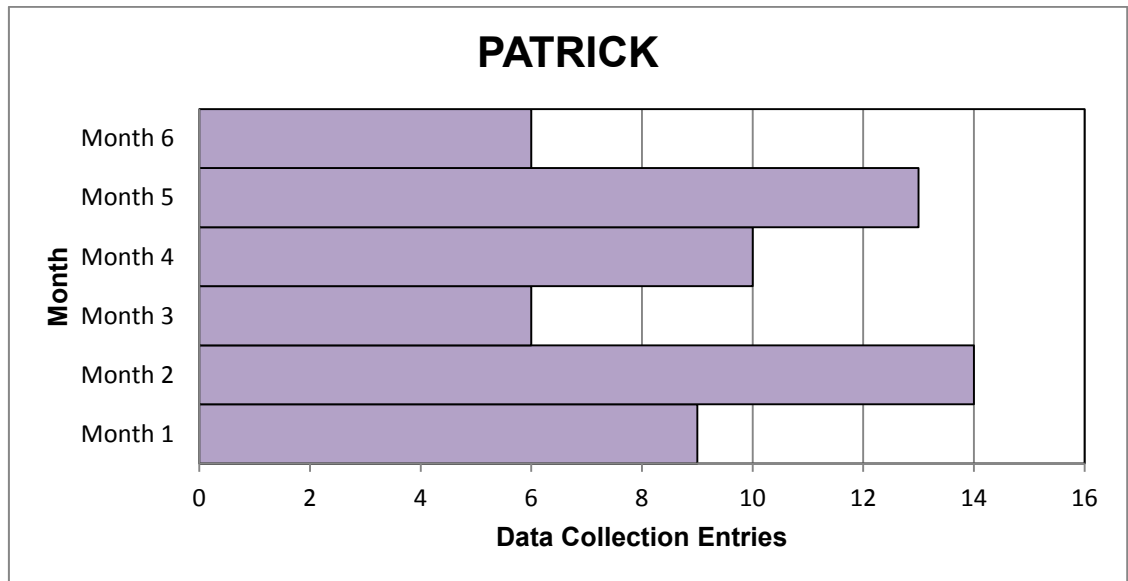
Patrick is a tall good-humoured man in his mid-sixties, he experienced a stroke six years ago which substantially affected his life. He continues to have difficulties in relation to speech and communication. Patrick is a retired policeman and prior to his stroke was physically fit and had been involved in a wide range of community and sporting activities including teaching rugby. After his stroke Patrick was diagnosed with a brain tumour, which was operated on successfully two years prior to the data collection period.

Patrick lives with his wife, Molly, one adult son with learning difficulties and a very lively mongrel dog. There are numerous children and grandchildren and their extended families are dispersed geographically but keep in regular contact with them.

Molly supports him intensively and used her previous employment experiences in helping him improve his speech and mobility. Patrick has a very resolute attitude and this determination has led to substantial improvements in his abilities, for example, to walk without aids, drive again and express himself more fully. He has also used complimentary therapy in the form of the Bowen technique, which he feels has substantially helped his improvement.

**Although Patrick's speech remains hard to understand for people who have not met** him before, his energy, warmth and humour are evident. Both Patrick and Molly have become active in support groups, consultation processes and awareness campaigns in relation to strokes. Although it was necessary for Patrick and Molly to downsize their home after the stroke, and his wife gave up work in order to support him, they remain positive and forward looking people. Patrick is in receipt of Incapacity Benefit, National Insurance Credits and Disability Living Allowance (DLA). In relation to the DLA, Patrick and Molly appealed the decisions of the Department of Work and Pensions twice before being able to agree the level of benefit.

### 5.3.8 Patrick Case Study Synopsis



*Illustration 8: Data Collection Frequency Graph PATRICK*

Patrick used diaries to illustrate the activities he undertook such as physical treatment and therapy, developing a greater sense of independence and being involved in groups seeking to improve understanding and awareness regarding strokes. He was well aware of other people's often negative attitudes and reactions towards him, but this has not negated his determination to improve as much as possible and help and support others in similar situations.



## **5.4 REPRESENTING PARTICIPANTS WHO CHOSE NOT TO CONTINUE WITH THE RESEARCH**

Two people became involved in the research and then decided that they did not want to continue. Therefore as will be considered within the analysis section, eight out of ten participants described themselves as pleased that they had taken part in the research and that their involvement was a positive for them. However two of participants did not take part in the research after the initial interview: Hermione and Mrs Haynes. The reasons which motivated these participants to initially agree to involvement, then change their minds and decide that they did not want to continue cannot be established. In terms of Mrs Haynes, no reason was ever given. In respect of Hermione, her mother, Marie explained how she interpreted Hermione's decision to not take part; however this cannot be seen as the participant's decision herself.

Mrs Haynes was contacted when no data was sent and messages left. She did not answer telephone calls or letters. I visited the retirement home once to make sure she was not unwell. She was not in. I then received a telephone message from her saying that data would be sent shortly, however no data was ever received. It had always been made clear that any participant had a right to leave the research project at any time. Having identified that Mrs Haynes was not experiencing ill health and

therefore her non-contact had been a personal choice (she had already agreed at our initial meeting and previous telephone conversations that she was happy for me to use the data supplied) I made sure both by letter and telephone that this was still the case in relation to the data she had already contributed. In light of this, the data provided from her initial interview will only be used sparingly to compare and contrast with other participants at the initial stage; however no consideration of her experiences over time will be possible. Her pen portrait is placed within the appendices, see appendix 12, and was the only one where the participant was not asked to comment or given the opportunity to alter the way they were presented in the text.

Marie had agreed to take part in the research and felt that Hermione may also want to do so. I spoke to Hermione about this, and suggested this as an option if she wished to do so. Marie asked Hermione if she was willing to talk to me after I had visited and undertaken the initial interview with Marie. Hermione agreed to speak to me and confirmed to me that she was happy to do so, however as we spoke she appeared quiet and withdrawn throughout the meeting. Hermione listened to the process as I explained it to her, I then asked her to think about this and let me know if she was interested or had any other questions after the day I met her. I was also aware that Hermione was in on-going discomfort and pain and was going through major changes arising from sudden acquired impairment which had occurred during **puberty. Marie's contributions gave an insight into the challenges which a family**

encountered when a young person suddenly became disabled and their attempts to facilitate independence for a young woman maturing into adulthood, whilst negotiating with a sudden, distressing and unexpected debilitating condition. Throughout my initial outline of the research, one aim was to include those parents of children of a much younger age than Hermione. However no such people expressed an interest in becoming involved in the research, despite targeted recruitment processes.

## **5.5 INITIAL FINDINGS OF RESEARCH**

**5.5.1 Research Question One:** What factors affect the expectations of, and services received by the participants?

The experiences of, and services received by the participants varied greatly depending on many factors. The variables upon which the expectations and services were dependant included the nature of an individual's impairment, their personal support mechanisms, and what barriers and / or professional support they encountered throughout the process.

The barriers which participants encountered affected the expectations and services received and naturally participants encountered different barriers at different times; for instance many practical barriers regularly affected Richard, while attitudinal

barriers were evident particularly for participants with invisible impairments. However the single barrier encountered by all participants most often was that they did not know where to look for help or information when it was needed.

**5.5.2 Research Question Two:** How are self-perception and identity affected by encountering disability and the resultant treatment?

**People's self-**perception and the language of self-reflection that they employed, particularly relating to insecurity, were very much influenced by how the participants perceived they were being treated, both by the system and by others. This, in turn, affected how much they were willing to challenge that treatment. In terms of self-perception and identity the approach they encountered and reaction of individuals appeared to have a greater impact than the unsympathetic system itself. The most crucial barriers therefore in relation to research question two are those defined as **attitudinal barriers, those of 'professional and cultural' barriers and of 'status and legitimacy'.**

It was not experiencing impairment(s) alone that caused participants to be insecure about how they were viewed or their rights, but the way they were perceived that they were spoken about, judged and constrained by others, particularly health professionals and agents of external structures. For instance, those with invisible **impairments often had battles being '*believed*'** or treated appropriately. For example,

David felt the manner in which he was treated by the Disability Office at his University has a hugely negative impact upon him.

For many participants then the challenge they encountered was the need to be seen as individuals with a range of needs and roles, which need to be considered holistically, rather than an isolated set of symptoms or impairment. Impairment and **disability are only part of what can contribute to a person's identity and for some** participants it was not part of the way they defined themselves. Many other aspects including their age, gender, ethnicity, sexuality and life experiences are likely to also shape their identity. However the way they felt they were treated by others often affected participants own sense of themselves.

**5.5.3 Research Question Three:** How do the methodological choices made within this research influence its outcome?

As considered in Chapter Four, at the beginning and the end of the six-month data collection process a semi-structured interview took place, which was individualised for each participant. However the responsive and adaptive use of diary collection methods did lead to some very different ways of working, which must be noted as the use of different diary methods in turn may lead to different types of data. **Analysing different types of data can lead to a broader insight into participant's** perceptions; however it also required the researcher to reflect carefully on different

styles of articulating experiences. The most essential element therefore was that the method was right for the individual participant and that it allowed them to tell their own story and describe their experiences as they chose.

The participants' intentions as to the way they would record their experiences and thoughts in diary form did not always end the period of data collection in the same way as they began. A breakdown of this follows.

<b>Name</b>	<b>Diary Data Collection Method at the Start of Research</b>	<b>Diary Data Collection Method at the End of Research</b>
<b>David</b>	Email	Letter
<b>Edward</b>	Letter	Letter
<b>Flavia</b>	Email	Telephone
<b>Fred</b>	Audio Tape	Audio Tape
<b>Hermione</b>	Did not send any *	N/A
<b>Marie</b>	Email	Telephone
<b>Mrs Haynes</b>	Did not send any *	N/A
<b>Susan</b>	Audio Tape and Email	Audio Tape and Email
<b>Patrick</b>	Email	Email
<b>Richard</b>	Audio Tape	Audio Tape

*Table 6: Breakdown of Diary Collection Methods*

\* This will be considered in detail later in Chapter Seven.

Working with participants over a six-month period and using a tool which encouraged articulation of experiences and reflection, clearly influenced the outcomes of the research. The diary system and length of time of involvement within the research have, as shown, shaped the nature of the data received, in terms of depth and reflexivity. It is also useful to note that seven of the ten participants expressed an interest in the dissemination of the research. Participants stated that they wished to use the findings as a tool with which to raise awareness within their own geographical locations. The process of reflection employed throughout the research has facilitated in some of the participants a desire to become more politically active and aware. This involvement can be viewed as an empowerment tool with which to widen participation and result in more active and informed groups. As they can use or disregard the research as they choose, participants are left in control about how much they extend their involvement within dissemination of this research.

## **5.6 CONCLUSION**

I have introduced the reader to the participants and illustrated how the decisions made by the participants regarding what methods of diary they employed shaped the data yielded. I have also demonstrated the key decisions I made in the research. The initial findings which have been introduced in Chapter Five have indicated that the

point at which a person initially experiences impairment is not automatically the greatest challenge that they encounter. It can be months, or for instance in the case of David, many years after acquiring impairment that they find their identity and/or rights in relation to disability contested. Identity transition therefore continues for a great deal of time for some people. It is no doubt that the barriers and macro structures encountered can engender a sense of hopelessness but in terms of agency and seeing other options open to them, factors were determined by far more than just the nature of the barriers themselves. External barriers and a sense of powerlessness can be the triggers for an identity crisis, instigating self-doubt. Chapters Six and Seven will consider the transition in identity and how these may come about, what are the determinants to engender change and challenge and what elements can aid participants in accessing the relevant services, support and help and strengthen their sense of identity.



## **CHAPTER SIX – BARRIER THEMES ANALYSIS**

### **6.1 INTRODUCTION**

The data is analysed to identify the some of the many barriers which participants encountered in four main areas here: structural, procedural, financial and practical. Recognition is also given to the fact that the barriers can also be reversed: participants also cited situations where they were helped by other people in areas which may have otherwise been seen as barriers.

A barrier within this context refers to something which prevents a participant from accessing services, support or information relevant to their circumstances. The concept of barriers, as a method, has been used to illustrate the social model of disability since its inception, as discussed within the literature review section. It offers disabled people an opportunity to move the perception of disability from a purely personal tragedy to an external location imposed from a society which has not taken into account disabled **people's needs in its own development.** The use of barriers when developing themes for analysis therefore fitted well into my framework for understanding disability and offered a useful basis with which to explore the experiences of the participants. Hudson and Hardy (2002) had developed the tool explicitly in relation to barriers, see appendix 9. These had to be adapted to effectively respond to the different experiences the participants may encounter. However, it was used as a base from which to interrogate the data, a comparable

example of the subdivisions which I made from this material is available at appendix 9 and 10.

## **6.2 ANALYSIS PROCESS**

Thematic analysis was undertaken manually in order to have a full familiarisation with the data. Thematic analysis is primarily a process of interpreting and understanding data (Matthews and Ross, 2010:373). Although the analysis was based upon my own interpretation of that data, this did not negate my critical realist approach. The critical realist position I adopted within this research shaped the way in which I analysed the data as it led me to seek a system which analysed both the macro structural elements and the micro individual aspects.

I sought initially to encapsulate the structures with which participants negotiated and **so adapted Hudson and Hardy's** barriers model as a first stage. However, the original subdivisions did not reflect the experiences of the participants, or what areas they could be expected to know, and so were adapted. For example, one of the original divisions which Hudson and Hardy applied was that of "*differences in budgetary cycles and accounting procedures*" (Hudson and Hardy, 2002:241). However, as this research was conducted from the perspective of the participants, who if they were successful at accessing support and services would be recipients, were unlikely to be

aware of the differences in cycles and accounting processes. This is demonstrated within the analysis itself.

The second set of themes for analysis, were primarily derived from themes which I identified from the data which the participants raised within their entries. This analysis also includes the barriers of *'professional and cultural assumptions'* and *'legitimacy'*, I chose to place these within the later chapter, in recognition of the degree to which these areas analyse the later research questions: these are found in Chapter Seven and focus more upon research questions two and three. The two step approach recognises the importance of individual perspectives as well as the external structures considered above.

Some of the themes yielded greater complexity than others. In order to provide an overview of the more complex divisions, a pictorial breakdown of the analysis provides an overview of the themes selected and a breakdown of the sub-sections undertaken. This will be found at the start of each theme.

### **6.3 THE BARRIER THEMES**

It was not possible to capture every facet of **the participants' experiences**. As discussed the volume of data arising from this research was extensive: over 3000,000 words, and instead this was shaped into meaningful sections which could

be applied and developed into findings. In order that these can be reflected upon and so that the reader is fully informed, the origin of each quotation is indicated next to the quote, including the nature of the diary method where appropriate and how long within the research period the statements were made.

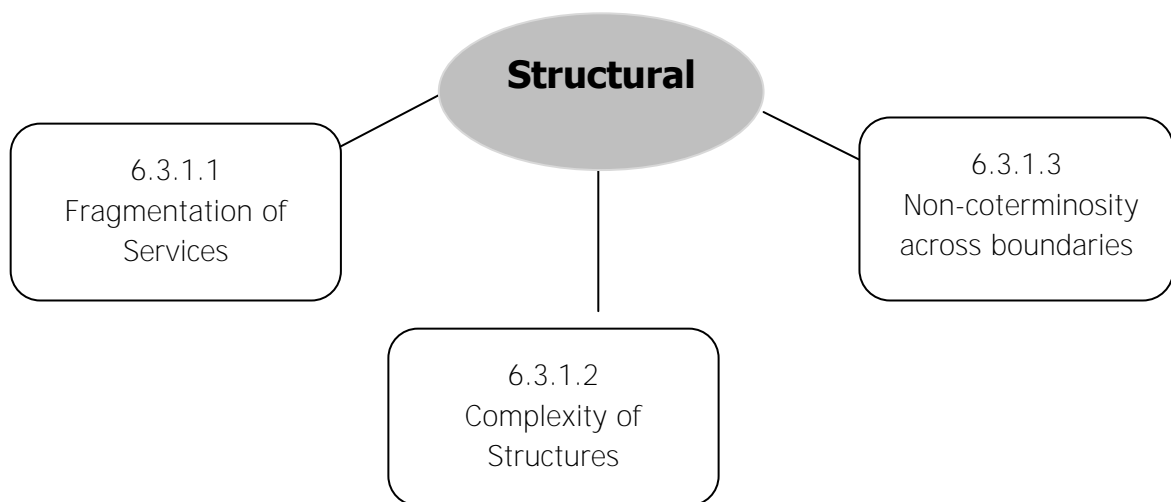
The first four themes of analysis considered below are those of barriers originally derived from Hudson and Hardy (2002): structural, procedural, financial, and practical. The final theme considered here - practical barriers was developed directly from the research. It was included these within the barriers sections in order to give as holistic approach as possible towards the barriers participants encountered.

**The research question that this analysis explicitly sought to explore asked 'What factors affected the expectations of, and services received by the participants?'** While this question was also partially answered in the following chapter, in relation to expectations its analysis began here, in the form of barriers encountered. The themes analysed are described as barriers, rather than factors, as predominantly these were how the participants perceived them. For instance, participants described their frustration at processes which they could **not work their way round, 'giving up'** on trying to access certain services or trying repeatedly to contact government agencies without success. They had clearly perceived barriers to access and participation, my adaptation of the Hudson and Hardy framework was developed to account for barriers operating in different sectors and at different levels. However

within this research the reverse could also be true: at points when barriers are traversed, access to help, information and resources become attainable. Within the distillation of the analysis and findings in Chapter Eight I will be exploring why barriers were perceived or encountered in the way they were.

The additional themes explored later within the analysis will incorporate other factors affecting the expectations and service received, for example the support mechanisms that a participant had available to them. The themes developed directly from the data also explore the intersection between impairment and other aspects of identity.

### **6.3.1 Structural**



*Illustration 9 – Breakdown of Structural Barriers*

Within this research, structural barriers relate to the ways in which an organisation, service or system is structured. Government structures were not set up with intentional structural complexity: systems are developed and adapted over time, through legislative and policy edicts, challenges to policies through the courts, amendments arising from legal process, changes in policy and international directives. Consider, for example, the system for Disability Living Allowance (DLA) in place at the point to research was undertaken in 2006. It was a benefit which six of the participants, either already claimed or attempted to claim during the analysis period. DLA, since its inception in 1992 has been adapted and revised almost constantly, with interpretations and understandings of needs and disability altering often in response to legal challenges about the existing definitions (UK Parliament Standing Committee, 2002).

The three key structural problems that participants encountered are those of fragmentation of services, complexity and non-coterminosity across boundaries (illustration four, while these had been developed from the Hudson and Hardy, 2002) other areas did not apply and so were not included.

### **6.3.1.1 Fragmentation of Services**

This sub-theme acknowledges that there is no comprehensive system of governance, support or provision available to everyone at every stage in their lives; indeed that it would not be possible for such a level of comprehensibility to exist. However the fragmentation both within and between services did cause a range of barriers for participants. Fragmentations between services were for me easier to comprehend initially; each service has its own rules, expectations, agenda and role specific requirements, which are often at odds with other services. Although successive governments speak about joined up governance - it remains an on-going challenge to actually ensure that a seamless relationship occurs between these services. In terms of fragmentation *within* services, the complexity of legislation, directives and requirements result in sections within a specific service being separated out and dealt with individually; see for example the detailed example in respect of Fred and the Incapacity Benefit claim outlined below.

<b>Structural</b>	<b>Barrier</b>	<b>Support</b>
Edward	Two tier authority structure (b)	Hospital and T.S.O. (b)
Richard	Social Services (w)	Social Services and T.S.O. (b)
David	University sections (w)	Mobility Advice and Vehicle Information Service (MAVIS) (w)
Marie and Hermione	Health Service structures (w)	
Patrick	PCT and City Council (b)	PCT and Social Services (b)
Flavia	Housing Benefit and Council Tax Benefit (b) Two Universities (b)	None cited
Mrs Haynes	NHS and Social Services (b)	None cited
Fred	Incapacity Benefit (w)	None cited
Susan	None cited	None cited

*Table 7: Structural Fragmentation Barriers and Support Encountered by Participants*

Key: (w) barriers or support *within* services and organisations  
(b) barriers or support *between* services and organisations.

Examples of fragmentation that occurred between services were described by participants and explored by myself during the analysis process. For instance, Flavia hoped to get Housing Benefit and Council Tax departments to work together, by sharing information. She submitted forms to the Council Tax Department, but they were unable to confirm this or show the evidence of income to the Housing Department. Although the departments did share information, she was led to understand that there was only a one-way flow of information: the Housing Benefit team could relay information to the Council Tax department, but the Council Tax department could not relay information back owing to the structure of the



organisations. This fragmentation of responsibility and the apparently single direction authority to pass on information caused Flavia worry and frustration, which she felt exacerbated her stress disorder and made her fearful of the consequences of failing to produce the correct information to one department, when she had supplied it to another.

However, fragmentation also occurred within services, for example, when Fred had to wait for his Incapacity Benefit claim to be processed between different sections of the same department. The example will be considered in some detail, firstly because Fred, as discussed in the methodology section, was the participant closest to the immediate point at which impairment and disability brought about a dramatic change in his life when seeking to negotiate government structures. Secondly, his experience is an exemplar of the protracted and complex structural barriers arising from a fragmentation of services. It is possible from this instance to reflect on all the key elements highlighted above from this one narrative. Finally, a further reason for the importance of this example is that it relates to ensuring the participant had access to basic income. Without his savings and his **wife's income the structural barriers Fred** faced could have resulted in circumstances of abject poverty and hunger, owing to structural barriers resulting from how departments are organised.

**In Fred's case his application for Incapacity Benefit was collected within one section** and initially processed, then transferred to another section within the same building

before being transferred to another city for completion. The decision was then relayed back to the initial department which Fred had initially applied to.

***"I took my forms down to job centre plus, handed them into a young man, he put my name and my national insurance number on the front envelope and said somebody in that department today will check through it and ensure that everything that is required is included. Then these will be passed on to yet another department in the city and they'll process it from there and they'll be in touch with me in due course."***

(Fred, Audio Diary, 1 of 6)

Throughout this time Fred was left without money, information or a contact point and felt frustrated and powerless. The claim was delayed; Fred rang up to enquire what had happened and how he could apply for an emergency payment. He was told the centre were working four weeks behind and that his claim had not even been looked at and that further elements of processing the claim required it to be sent to another department.

***"She says, as you know we process it here and it's got to go to Morley Street and they've got to process it and arrange for the payment to be put into my bank."***

(Fred, Audio Entry, 1.5 of 6)

Fred was not aware of the process, having received no printed or detailed verbal explanation of the process, nor does it appear likely that any claimant new to the system would know sufficient details of the process which a claim must be put through. This illustrates a combination of barriers incorporating both the complexity of the structures which the process of benefit claiming incorporates and a cultural /

professional barrier which will be explored in the following chapter, in the assumption that claimants know or should know the processes which claims go through. This experience demonstrates an opaqueness faced by people seeking to navigate access to benefits and / or services. When asking what he was to do for money while the claim was dealt with, Fred was told that the claim would be looked at the next day. Fred therefore rang another department, which had sent his claim form out initially, **and a woman told him that an emergency payment could be made, "That she would get in touch with them and somebody should contact you within four hours" (ibid).** No one got in touch with Fred and he had no form of recourse, as he had not been given any details of the person who would be looking at his application for emergency payment, or whom he had been speaking to earlier. There was no sense of accountability or opportunity for him to follow this up.

*"I still feel it's very disappointing, disillusioning the way they run that and can knowingly leave someone who's informed them that I've had no money for two weeks, in my opinion beggars belief."*

(ibid)

The complexity of the system prevented any individual person being able to take responsibility for the difficulty Fred faced or work with him directly to resolve the situation. Much has been written about the need for accountability when dealing with complex multi-layered forms of organisation. King acknowledges that the 'crisis' in accountability may arise because the systems in which they operate are so complex **it is not possible to 'strip them down' (King, 2007:89).**

The relative difficulty people encountered with fragmentation varied substantially based upon their previous understanding of the structures in which they operated. For example, Susan had experience and understanding of the structural barriers and was able to follow the appropriate procedures which meant she requested receipts for emails she sent out, retained copies, identified supervisors of the individuals she sought answers from, and then copied letters to the supervisors. This meant that while she remained frustrated when she received unsatisfactory responses, she was able to challenge these and undertake a professional approach to engagement based upon her deeper understanding of the structures than other participants had at this stage. This is likely to be due to the fact that Susan had been negotiating with structures in relation to her impairments for a longer time than the other participants, and as discussed later in the analysis, had accessed a variety of support mechanisms offering her insight into such structures.

#### **6.4.1.2 Complexity of Structures**

Ostensibly complexity appears to be very similar to the fragmentation of services outlined above and the two do have many commonalities. The distinction made here is that fragmentation relates primarily towards schisms between services or sectors of a service causing barriers for participants. Complexity, in this context, refers to structures where gaps may or may not exist. However the complexity of the structures as it was perceived by the recipients, meant that it was not possible to

know, further demonstrating the complexity and opaqueness inherent. In such circumstances the complexity alone appeared to have caused such challenges for the participants that they are unable to grasp the entirety of the circumstances that they were encountering.

This complexity, both between and within organisations, led to barriers for participants who were unable to understand the structures with which they were faced. For instance, Richard, who has limited sight and partial hearing, was extremely concerned about the direct payments system which he understood compulsorily required him to search out his own support workers, interview, check for references and deal with the finances in relation to them. This caused him great anxiety, worrying about how he could deal with recruitment issues when he could not see well enough to read documents without the support worker. He felt this would put him in a position of great vulnerability having to select and interview people in his own home and require him to have immense trust in individuals before knowing them personally.

*"I've been thinking about this social services project where they just pay me the money and I have to go out and buy the services myself. I do not think this is the right way to be going, it depends on the disability you have."*

(Richard, Audio Entry, 5 of 6)

The structural complexity of the direct payment system had not been fully explained to him and there appeared to be no flexibility in relation to the provision for people with communication difficulties such as Richard.

***"I do feel that they are getting out of the responsibility by just handing over the cash and there are a lot of questions I would like to ask about how this thing is administered."***

(ibid)

It will be discussed in detail at a later stage, but there was no accessible information available for Richard with sufficient detail for him to understand the system fully. However even if the material had been available in an appropriate format for Richard, this suggests he was being asked to take on a professional role for which he had no desire to assume responsibility.

On an individual level the fact that no information was available to Richard in a format he could use left him fearful of what he perceived as organisational changes over which he felt he had no control. On the one hand he saw direct payments as an opportunity to gain more independence and a much desired social life. On the other, the complexity attached to the process and lack of appropriate information relating to this lead to significant challenges (Richard, Audio Entry, 5.5 of 6).

Complexity barriers for the participants also occurred between services, for instance Flavia returned to her original University after her road traffic accident, which had an Independent Access Centre attached to it. Flavia was explicitly told that the access centre was independent from the University, however when she decided to move University to be closer to her Mother and other support networks, the complexity of the two University systems and the independent access centre meant that support provision broke down.

*"I was supposed to get this support from University X. It took over a year and a half to sort all that out because University Y kept saying it was X's job, X kept saying oh no that's Y's job. It was making things much harder for me. I didn't have the equipment to support me with my course. And then I was having to take the time out to go and sort other things out."*

(Initial Interview, Flavia)

This debate about responsibility left the participant unable to look anywhere for definitive advice which she could rely on. Instead Flavia was forced to spend a great deal of time moving from one organisation to another trying to find out whose responsibility her support provision should be.

### **6.3.1.3 Non-coterminosity across boundaries**

The first two structural barriers considered above were evident both with and between organisations and services. However the third area applied to the data was specifically concerned with the 'alignment' of boundaries between such entities. The ability of statutory organisations to align their boundaries into a neat 'fit', with no overlap or gap between the responsibilities of two separate entities is not an easy task. Throughout the research more 'gaps' in boundaries were experienced rather than two entities having ambiguity and any desire for control over the same area (as may be expected in a time of cash limitations, directives and outcome focussed goals prevalent in governance structures). Non-coterminosity is a difficult theme to identify; the data from the participants could not be reported in this way and the

complexity and lack of information regarding the structures illustrated above, did not permit participants at the receiving end of information or services to fully understand what the barriers were. Nevertheless it was an area which in my interpretation did challenge the participants.

The most comprehensive example of non-coterminosity related to the experiences encountered by Mrs Haynes. This instance also illustrated how regularly more than one barrier combined to build even further obstacles for the participants to encounter. Here we see non-coterminosity aligned with a lack of personal support (a theme which will be explored later within the analysis), the amalgamation of both barriers resulted in a barrier which Mrs Haynes was not able to overcome and as such her wishes were not acknowledged and no attempt made to mediate the focus of the structures and the force of the macro with the desires of the individual, or insight into the micro experience.

Mrs Haynes had no family to oversee her welfare when she experienced a stroke at the age of 58, as a result she was heavily reliant upon NHS and Social Services. She felt pushed into making decisions about her housing situation, with each agency looking after its own interests rather than anyone looking after hers. As a single person living in rented accommodation which required her to walk down a flight of stairs in order to access the flat, Mrs Haynes was told unequivocally that she would not be able to return to her home. While this may be true she felt that the NHS



wanted the bed space and Social Services in her eyes wanted to place her in the first retirement home they showed her without exploring any other options. Here the legislation offers a disincentive to Local Authorities in delaying the process of a patient leaving hospital care: the Community Care (Delayed Discharges Act etc) 2003 levies a financial penalty on Social Service Departments relating to all people who will require social assistance after their release.

Referring to the time immediately after her stroke, Mrs Haynes spoke of not being **'mentally strong enough' to deal with the choices and** information which she had to face. Mrs Haynes had no family or friends to support her through the process and felt heavily pressurised into making the decision to enter a retirement home, which was far from her wishes.

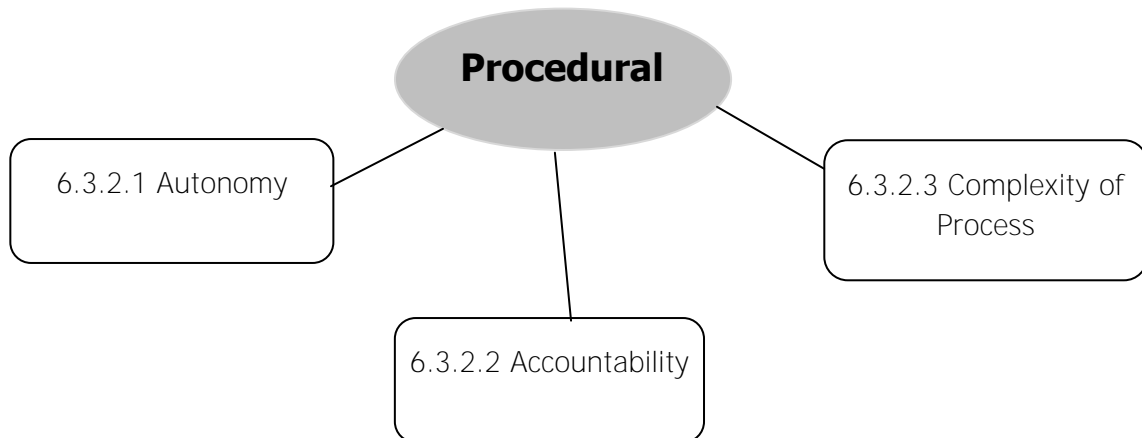
*"Because your mind is blocked. Once that de-fuzzes I call it, which it has. They can say right you can go home. The other thing is, if they're going to take a roof off your head, you want it done in writing, not just verbally at the side of your bed and you should get a receipt. You should have a person who was different to the physios, the doctors, the social services: an independent person."*

(Mrs Haynes, Initial Interview)

A number of items and monies had disappeared during the time she had been transferred from hospital to the retirement home in which she had been placed after her stroke. Items including clothing, cheques, a bed and a new carpet, for which she **had paid a cheque to 'a woman from social services'**, were never found and there was no responsive contact point for her to approach about these concerns. This lack

of cohesion about services and gaps in provision related more to areas where no agency had responsibility rather than any lack of funding limiting the provision. This non-coterminosity left Mrs Haynes feeling frustrated, ignored and '*kept in the dark*'. Mrs Haynes felt that, if she had been given support from an independent person at this time and more physiotherapy, it might have been possible for her to return home, in time, with appropriate adaptations to the property. Many participants spoke of the support they accessed from friends and family in times of confusion, stress and vulnerability, which is considered in more detail within the analysis of the support mechanisms themes. In terms of costs to the state to recognise and support Mrs Haynes desires to return home, it may have required further outlay of monies in the short term, but evidence suggests it would have lessened long-term service requirements and may have reduced the likelihood of requiring long-term admission to institutional care (Green et al, 2005). There was no overseeing body in a position to recognise this and take control or give Mrs Haynes more options, and neither of the statutory bodies concerned, either Health or Social Services, were authorised or apparently able to take on this role.

### 6.3.2 Procedural



*Illustration 10 - Breakdown of Procedural Barriers*

This theme into three areas: autonomy, accountability and complexity. The first two are closely related, but in these circumstances a distinction is made between autonomy and accountability.

Autonomy is a phrase applied where it appeared to the participants that the level of power which agencies held meant it was not possible to challenge their actions: i.e. this related to the autonomy of the organisation. In relation to the accountability sub-theme, the data suggested much more that the individual holding professional responsibility could not be identified and participants were left struggling to know what the procedures were and who to turn to.

### 6.3.2.1 Autonomy

Many statutory and government structures appeared to participants to be relatively autonomous. For example, Fred was extremely worried when administrative delays meant he did not receive Incapacity Benefit when it was due as a result of delays owing to staff shortages. As a result of his concerns Fred asked what could be done **and was told 'nothing'**. Eventually, after persisting and ringing several different contact numbers he finally spoke to someone in a different county. As highlighted earlier an emergency payment was agreed by an official, and he was informed that he would receive a phone call within the next hour. However, no one ever contacted Fred in relation to this: he was left without any money over the weekend and had been given no contact details or names of any of the people he had spoken to, or who was due to contact him in order to challenge why the agency had not acted as they had agreed to. This left him feeling

*"That getting help and advice from the NHS, the DSS and that it's bloody virtually impossible."*

(Fred, Audio Entry, 2 of 6)

While he wanted and intended to complain about this experience, he felt the system for doing so was far from evident; *"God knows how these people work"* (ibid).

Flavia was left in a dire financial position and extremely frustrated at her lack of redress over procedures when attending her local Benefits Agency. She was told that

she could not receive Income Support and could not have an emergency payment until next week *“as the person that does those is off today.”* (Flavia, Telephone Contact, 5 of 6). Flavia asked if she could complain about this decision and was told *“No I told you no one like that is in until Monday”* (ibid). When Flavia persisted and said even if she had to wait until Monday she wanted to know what the complaints procedure was she was told that she *“didn’t have the right to complain”* (ibid). The difficulty with claiming benefits notwithstanding, it was the lack of transparency over the procedures which resulted in her anger, as Flavia saw it. The department appeared to Flavia to be asserting that they were free to make any decisions they chose without the claimant having any right to redress.

When seeking to access support and services provided by the local authority in relation to her daughter, Marie found the procedures in place intimidating and unclear. For instance, when requesting that transport services should be made available for Hermione to get to school, her request was refused and the appeal **system not explained to her in a written form at all. Hermione’s school had already** previously negotiated with the Local Authority regarding funding for her place. In relation to the transport to school Marie persevered and asked about the process and why the appeal system had not been followed.

*“I phoned the council re Hermione’s appeal, and it seems to be cock up rather than conspiracy that they have not sent any information back to us.”*

(Marie, Email Entry, 0.5 of 6)

Eventually the tribunal took place and Marie and her husband attended. They were not advised that they could have anyone there to represent them and encountered a large room, with a panel of Councillors, legal representation for the panel, a clerk and a council officer arguing for the council policy.

*"This appeal took place in a large formal room with the parties sitting in positions as if in a court of law. The format was for me quite intimidating."*

(Marie, Telephone Entry, 4 of 6)

At the end of the data collection period Marie reflected that every service and resource which she had sought to access for Hermione had resulted in the matter going to an appeal or tribunal, this she ascribed to an intentional policy on the part of the council.

*"I saw something about that the other week, I can't remember where it was, and it said that it's actually their standard policy, not just..(pause) was it in some Panorama that it was on, it is standard policy to refuse in the hope that most people won't come back ."*

(Marie, Final Interview).

The possibility of refusing services to which participants may be entitled as a procedural policy will be explored in more detail within the financial barriers section on page 220. However it is highlighted initially here to demonstrate the way in which barriers overlap with each other, making accessing appropriate support a much harder process for the participants.

### **6.3.2.2 Accountability**

The data often illustrated difficulties in accountability, and indeed there is crossover between accountability and autonomy. However the challenges relating to accountability often appeared to be linked to a lack of information or opportunity on the part of the participants to see how they could challenge decisions enforced upon them. While autonomy and accountability have much in common, the distinction which is being made here is the level of intent attached to the procedural barrier. I am arguing that the autonomy highlighted above related primarily to agencies intentionally presenting themselves as autonomous in the way they have responded to participants.

Although Richard rarely complained about the procedures relating to services that he received, he did express frustration regarding the gaps within provision (which will be considered in detail later). He was not given information regarding procedures; this resulted in limited forms of redress. For instance Richard did not know who sent his support worker, whom he rated very highly. He received no information in an accessible format and was presented with a person who attended regularly. However he had no way of knowing which organisation she came from and he spoke of being unclear as to whether she was sent by the local Social services or the local Third Sector Organisation for the Blind. This meant that if she had not attended at any

time, or he had any problems with the service, Richard would not have known whom to contact in relation to this, the procedures were therefore obscure.

*"So, I think the government could explore ways of delivering information to us in other ways you know, because the press isn't much good to us if you can't read it."*

(Richard, Final Interview)

There is a marked distinction here between policy and practice; part three of the DDA 1995 refers to disabled people receiving information and services in a way which is accessible to them. Even though the services Richard was using were specifically as a result of his dual sensory impairment, he did not receive information in relation to services in any accessible format.

Mrs Haynes described her accommodation within a retirement home in very negative terms, describing how monies and private possessions had gone missing but there were no processes or forms of redress available to the tenants, particularly as there had been no permanent warden at the home in over two years. Mrs Haynes had complained about the losses and continues to do so, but described the process as *"Just a blank, it's like putting your hand through air"* (Initial Interview). This resulted in her feeling and describing herself as *"very cynical"* about her home environment and wanting other people to know and understand how isolating and negative the conditions there were.



Susan experienced substantial difficulties when a place of work within a Local Authority was refurbished. She had sent reports and information requesting that the building should be accessible to herself and other disabled people prior to the adaptations taking place; these included outlining how such accessibility could be achieved. Susan has also attended meetings and received assertions, both verbally and in writing that these concerns would be addressed: despite all these efforts the completed building was inaccessible and inappropriately designed. However the process was complex and there was a range of individuals involved. Susan, as previously considered had a good range of skills and experience in challenging such procedures and was fairly confident in her approach. She recognised that this gave her an advantage over most people: *"I know where to go or try to find out where to go, whereas a lot of people won't have that"* (Susan, Email Entry, 5 of 6).

It took three months and over twenty-five emails to local authority officials for changes to occur. Further adaptations were then made to the work environment to ensure that she could work without being disabled by her surroundings. While some emails were never acknowledged, some of the emails she received she also felt were intimidatory: *"he bullied me"* (ibid). There was no transparent process through which she could find out who was accountable for the building refurbishments or challenge it, as the complexity of the procedure and range of the people involved proved extremely stressful and frustrating for Susan.

The relationship between accountability and autonomy is a close one; in many cases the third area to be considered within procedural barriers also appeared alongside the other two. The complexity of procedures therefore was not always so evident in isolation, but was often an inherent part of the difficulties participants encountered.

### **6.3.2.3 Complexity of Process**

The differences in protocol and information systems between agencies and departments caused challenges and frustrations. These often related to gaining access to information and services, specifically in participants understanding the processes that they were required to undertake or the relative complexity of attempting to do so.

Marie experienced many difficulties with the medical team working with Hermione, and staff changes resulted in a lack of transparency about who was responsible for each aspect of care. Referral letters from the GP had gone astray and specialists could not **be contacted, as it was no specific person's responsibility. Two consultants involved in Hermione's care did not have permission to move freely throughout the building in which she was being treated; this was an issue of complexity of system, which did not marry with each other.**

*“We’ve got this weird set up with the two new consultants coming in, who don’t actually have access rights to the children’s hospital, so everything has to go through a third consultant.”*

(Marie, Final Interview)

Fred repeatedly spoke in his diaries and at both interviews about the complex, laborious and lengthy systems relating to claiming Disability Living Allowance and Incapacity Benefit. At one point he received two letters from the same department posted on the same day with conflicting information within them. The range of complex paperwork he received also led to frustration and some appeared unnecessary to him.

*“This morning one letter telling me that my incapacity payments were due under the non-taxation rule, so applying my tax code to my benefit I am now due to pay 0.00p and this means my benefit drops down from £70.05 to £70.05; a really useful letter, I’m glad they let me know that.”*

(Fred, Audio Entry, 3 of 6).

For Flavia, the relationship between Income Support and Council Tax Benefit appeared to be clear, but in actuality was anything but. She handed in documents to the Income Support Section, who informed her that they would retain the documents and pass the relevant information on to the Council Tax Benefit Department. However, when she received a letter stating that she was in arrears with her Council Tax, she contacted the Income Support Department who stated that they had forwarded the information which they were supposed to and did not intend therefore **to take any further action in relation to this. Only with Flavia’s insistence and upon a personal visit to their office, did they provide her with a copy of the information for**

her to take, herself, to the Council Tax Department. When she took the information in, she was told that as this was not an authorised copy it could not be used. Consequentially, Flavia had to return to the Income Support Department and eventually was given an assurance that someone would contact the Council Tax Department. Flavia sent me an email shortly after the end of the research period and informed me that this matter had been resolved after the end of the research period.

As has been illustrated the participants encountered extensive challenges in accessing information, services, treatments and benefits through procedural barriers. Indeed they rarely felt armed with sufficient knowledge or information to be able to contest what had happened to them. Even when they did have additional knowledge (such as Susan), the procedures remained complex and difficult to negotiate. On the few occasions when participants felt someone had gone out of their way to help them comprehend systems or assist them, they acknowledged this help and appeared grateful, but did not see this as a usual practice amongst the agencies they encountered. However, by the end of the data collection method, seven of the ten **participants used the term 'cynical' to describe their attitude to seeking services, information or help:**

*"But I'm also much more cynical I think than I was, about what can actually be done in terms of, you know, accessing stuff without major wars, major fights, major stress."*

(Marie, Final Interview)

If participants were approaching the negotiating with government agencies as something they were cynical about, this could have negative impacts on the on-going relationship between individual and state in the future. This will be considered **explicitly within the findings chapter in relation to the 'Process of Disillusionment'** (page 327).

### **6.2.3 Financial Barriers**

Financial issues came into play regularly within the research. In this context the barriers have been divided into three sections, the impact of which in their most extreme forms may result on poverty: financial concerns arising from disability, fragmented services and the possibility of complex procedures being used to limit access to services and benefits.

### **6.2.3.1 Financial Barrier Overview**

It was clear that limitations of funding were a significant barrier, both in terms of the perceived low level of benefits available and, more commonly within the research relating to services and provision not being available. All participants within the research period believed that limitations in funding impacted negatively on them in terms of service provision, this will be considered in the area entitled fragmented services. However, a general overview of the direct financial effects of impairment and disability follows.

**Financial Worries the Participants Encountered as a Result of Impairment and Disability**

<b>Participant</b>	<b>Employment Status Prior to Onset of Impairment and Disability</b>	<b>Employment Status after Onset of Impairment and Disability</b>	<b>Financial Implications</b>
<b>David</b>	Full time employment	Not employed	Incapacity Benefit and Private Income
<b>Edward</b>	Retired	Retired	None evident; accessed attendance allowance
<b>Flavia</b>	Part-time	No employment	Loss of part-time income to support studies resulted in substantial financial hardship
<b>Fred</b>	Full time employment	No employment	Financial Hardship, Incapacity Benefit and DLA.
<b>Hermione</b>	Not employed, full time pupil	Not employed full time pupil	No immediate implications evident; costs covered by Marie and her husband – DLA.
<b>Marie</b>	Full-time employment	Not employed	<b>Carers Allowance 'a bit of a joke', substantial loss of income</b>
<b>Mrs Haynes</b>	Full time employment	No employment	Incapacity Benefit, followed by State pension and attendance allowance
<b>Patrick</b>	Part-time employment and pension	No employment	DLA.
<b>Richard</b>	Not employed	Not employed	N/A
<b>Susan</b>	Employed full time – two part-time jobs	One part-time job (one day a week initially)	Loss of income and Pension credits

*Table 8: Financial Worries the Participants' Encountered as a Result of Impairment and Disability*

The above table illustrates a substantial loss of income for the majority; only two participants, Edward and Hermione, were apparently financially better off as a result of their impairments. This, however, does not take into account the increase in expenditure and emotional costs of disability, or the fact that Hermione was at **school and the costs borne by her parents, as illustrated by Marie's substantial loss** of income.

The financial effects of acquiring or an increase in impairment often resulted in less obvious barriers for the participants. For instance, although Richard was unable to work and had been on Income Support equivalence for Incapacity Benefit for many years as a result of his long term sight and hearing loss, the increased impairment resulted in him being less independent or mobile than he had been previously. For instance, in the past he had been able to ride a pushbike and therefore move relatively easily around the area in which he lived. As his impairments substantially increased, Richard felt ever more isolated and unable to alleviate his loneliness, as going any substantial distance now required a support worker or taxi in order to ensure that he felt safe. The same amount of money in relation to Income Support (Incapacity Replacement) and Disability Living Allowance was available to Richard, but his needs had increased dramatically; he could not feel confident in being able to catch buses as this often required two buses situated at different stops for example. There was little in the way of support or social structures in his immediate area and travelling into the city centre and out again to access suitable activities was not something Richard could undertake often. For instance, a return trip by taxi to an



impairment-related support group would cost £24; this was therefore not something he could consider on a regular basis. Such costs were not available, although direct payments were being introduced by the end of the research period, which may have altered these circumstances.

A table alone does not take into account the emotional aspects of accessing financial support from the state. Fred was extremely stressed and concerned about his loss of income until his works pension, Incapacity Benefit and Disability Living Allowance claims were established. In his case the worries about his financial insecurity and feelings of being powerless to influence these factors had a huge effect on him. This coincided with, and from his perception resulted in, significant depression and mental health issues which he directly ascribed to the uncertainty of his position.

*“It’s just so unfair because it just totally changes your life and it isn’t just about money, but like, originally when I was getting Incapacity Benefit, if right from the beginning got that Disability Living Allowance, it’d just have made my life a lot less stressful and then I wouldn’t have ended up being treated for depression and things like that. ....And it isn’t just for the financial cost, it’s how much of that person’s life has he lost, or she lost, for having to go through all this.”*

(Fred, Final Interview)

The example further demonstrates how the financial concerns caused a greater range of barriers and challenges for the participants than purely that of economic concern.

For some participants, including Fred, work was of primary importance, in terms of contact with others, routine, structure and personal identity. Mrs Haynes, felt that her life as she had known it and her independence had ended when she had a stroke, and she presented the loss of work as the most obvious manifestation.

*"So I can't work and I can't get about as much as I could so you've just got to adapt. You might just say you've had two lives. One were able bodied and one's disable bodied."*

(Mrs Haynes, Initial Interview)

These examples from the data illustrate the complexity with which financial barriers **intertwine with other barriers and thereby limit participants' opportunities to** maintain a range of elements, activities and variety of aspects of their own identity. For instance Mrs Haynes and Richard were socially isolated but the financial circumstances they encountered greatly exacerbated the situation. The associated tensions and complexities of replacing income, through claiming benefits also caused stress and confusion, for instance for Fred and Flavia. This resulted in participants needing to deal with financial concerns in addition to the impairment related **circumstances and the other barriers considered here. The 'fragmented services'** evaluated within the structural criteria above often illustrated gaps within provision, where no resources or services were available at all.

Mrs Haynes described her needs: isolated in a retirement home with no accessible form of transport, support workers or social groups within the immediate area. This isolation she saw primarily as a result of funding difficulties, where the services

which may ease her segregation were non-existent: "*there just wasn't anything available at all*" (Initial Interview). In this brief description, it is evident to see how widespread financial barriers may become, for instance, incorporating factors of personal finance, economic responsibility, financial stability and availability of funding for resources.

Edward believed that the six months which it took for Social Services to begin working with him when he first became registered as partially sighted was very poor. This will be discussed in greater detail within the area of professional and cultural barriers. In relation to the fragmented services there appeared to be no recognition that these aids would be crucial at the point someone became partially sighted and were attempting to readjust, rather than being provided with the resources six months later. **This was a case of Edward's private funds being necessary in the face of provision not being timely.**

Both Susan and Patrick paid privately for complementary therapies in order to improve their conditions and believed the results of such therapies had helped them considerably. These private costs affected their financial situations adversely, but the benefits to the conditions of both meant that these were seen as essential expenses. Patrick explained how an arm which had been curled up had become much more **flexible, indeed both his speech and mobility increased dramatically. Patrick's wife Molly** also described the substantial improvement in his speech as a result of using the Bowen technique.

*“It’s a really gentle therapy and I couldn’t believe it but it’s definitely, certainly made a difference to Patrick and his speech.”*

(Initial Interview, Molly [Patrick’s Wife])

Susan ascribed a substantial proportion of her improvement to the range of therapies which she used. Her GP also appeared to approve of her use of such therapies, taking details of some she used and referring other patients to them (Audio Entry, 4.5 of 6).

Susan was well aware that very few such therapies were available under the NHS and that she could only access services she believed genuinely eased her symptoms by paying for them privately. Although her GP encouraged the use of complimentary therapies, he was not able to offer such resources to his patients, indeed he did offer acupuncture, but stopped offering the service towards the end of the research period. According to Susan this service was terminated because he was *“told by someone outside the practice that funding was cut and he had to stop the service”* (Interim telephone contact, 5 of 6). If Susan’s understanding is correct, this appears to be at odds with the policies at that time. For instance Commissioning a Patient lead NHS 2006, refers to clinicians having a leading role in what services are provided locally (DoH, 2007).

#### **6.3.4.2 Funding limitations a matter of Procedure?**

There were many situations that the participants encountered where resources were not available and they expressed frustration. However, these were often voiced as limitations of the systems. For instance, Fred referred to the DLA process, the difficulty of accessing the system and high ratio of people, as he perceived it, that were required to use the appeals process in order to be successful in their claims. These were rarely specifically ascribed to limitations of funding, as participants appeared to focus upon the failures of the system as a whole. The following illustrations are in relation to the points when participants perceived the barriers they encountered were due to funding limitations.

Marie reflected in an emailed diary entry that she and her husband had recognised that every time they had approached the Local Authority for anything for Hermione which involved any costs to the Authority, they had been forced to go to the appeal stage to have the needs met.

*"On all three occasions they have initially refused our request for help only granting it on appeal."*

(Email Entry, 1 of 6)

**As was highlighted earlier, Marie's cynicism grew and by the time the final interview occurred, Marie had watched a television programme which she believed confirmed her perspective that refusing legitimate claims for help was a standard government policy, both local and nationally, as a money saving exercise (ibid). This view of**

using procedural processes, rejecting claims and forcing applicants to undertake an appeal process as an attempt to save money, created a substantial barrier and distrust towards government structures over time.

Mrs Haynes still had mobility issues relating to her stroke over three and a half years afterwards. She does not have full use of one arm and hand, but it is her mobility which bothers her particularly, not being able to walk unaided or for long distances while living in an isolated retirement home. She has repeatedly asked for further physiotherapy but had received none in the last two years.

*"Last time I were asking for physiotherapy they did a bit and they said **that's it. I said 'why?' 'We've run out of money'** and I thought **'well that's your problem not mine.'**"*

(Mrs Haynes, Initial Interview)

**Patrick's speech therapy ended and he and Molly worked alone in improving his speech.** They applied for further speech therapy to keep the improvements continuing, however the speech therapy was again ended much more prematurely than Patrick would have liked, the official reason given was limited funding.

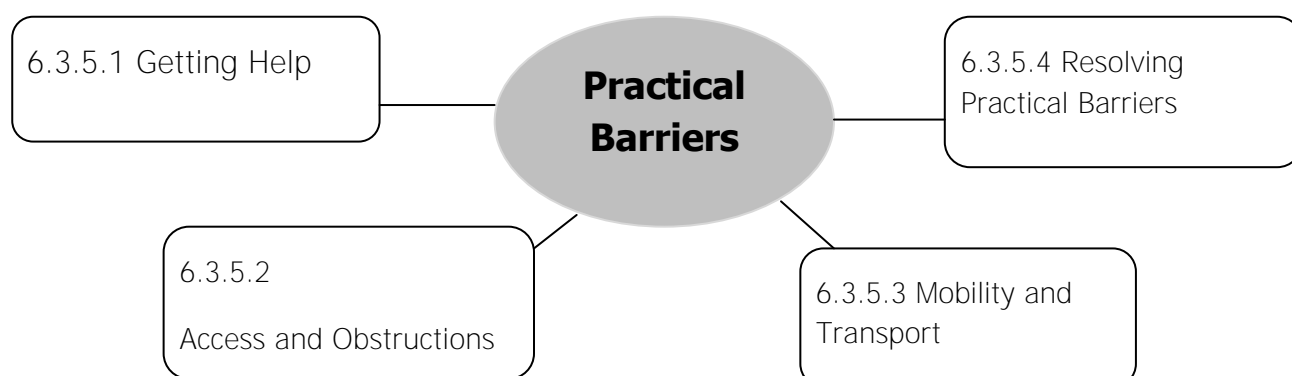
Flavia found no support mechanisms available at all, despite extensive searching. For example she investigated resources on the Internet, at the information shop for **young people, and finally contacting domestic violence organisations as she couldn't** find anything specifically relating to Post Traumatic Stress Disorder. Some groups refused her access to their services without referral from her GP. Some organisations she found had been shut down or people had agreed to ring her back and never did

so. In fact ,Flavia felt extremely frustrated by the apparent lack of support for people in her situation and felt this was about money and there being nothing offered (Initial Interview).

The funding limitations which the participants encountered were met with extreme frustration, but it was the obdurate procedures, attitudinal barriers and isolating nature of their experiences accompanying financial barriers, which as illustrated, caused more frustration and resentment. The fragmented services evaluated within the structural criteria above often illustrated gaps within provision, where no resources or services were available at all.

A further set of themes which participants identified arose from directly from the data collected: that of practical barriers. However, it is positioned within this chapter in order that the barriers and conversely the opportunity of amelioration of those barriers are placed alongside each other.

### 6.3.5 Practical Barriers



*Illustration 11 – Breakdown of Practical Barriers*

There are many barriers which participants encountered throughout the research period which affected their day to day experiences, however in relation to this research I am focussing specifically on the barriers which affected access to services, support and information. This analysis therefore also incorporates the access issues which people face within their daily routines. In light of this distinction the practical barriers have been divided into the following subsections, getting help, access and obstructions and finally transport and getting around.

#### 6.3.5.1 Getting Help

The most immediate challenge which participants encountered was knowing who to go to for help and how to access information, benefits and support. In some ways this can be seen as integral to the thesis as a whole, however it is explicitly



considered here to demonstrate to practical nature of the search for appropriate direction, if the participants were to negotiate government structures. Fred, Marie and Hermione, Mrs Haynes, Patrick and Molly and Flavia all cited notknowing where to go for help as a barrier they frequently encountered. For instance in a telephone entry, three months into the six-month data collection period, Flavia reflected on her head injury. She had raised this issue when undertaking psychological tests when seeking help regarding her impairments. Flavia was told that there were definite signs of head injury – but no one had told her what to do about this, where to go or the nature of the way she was affected; *“As usual I feel the greatest battle is knowing where to look for support and information”* (Telephone Entry, 3 of 6).

A related challenge experienced was when participants thought they had the correct details of the people to contact but that they simply could not get through.

*“So there were this number on this government thing and I rung it up, you ring up and they give you a number. You have to give your name, address and everything and they give you a number and say ‘you keep this number’. So I went through all this, got this number and I waited and waited and I waited and in the end, I waited over 20 minutes or so. I tried it again next day, just the same thing.”*

(Fred, Initial Interview)

From Richard’s perspective with dual sensory impairments, finding out numbers to contact services was even harder; there was little in the way of material that he could access as he was unable to read printed text. He had walked to the local library; having initially asked passers-by for directions and there found contact details for the local ring-and-ride in the hope of accessing transport. The library had

found him the number and had written it down for him. However, upon returning home Richard then had to wait until he had a visitor who was able to read the number out loud in order for him to programme it into his talking phone and so be able to use it in the future (Richard, Initial Interview).

Knowing where to look for help and how to access such resources appeared to be skills that could be developed over time; the use of support mechanisms as a source of access to information discussed below illustrates this. Consider for instance Susan, who had arguably the widest access to sources of information, through her extensive support networks and her paid and voluntary roles.

*Joy: In terms of help do you feel that you get the help that you need?*

*Susan: Erm, yes because I ask for it. If I didn't have the support network that I had then it would be a completely different matter wouldn't it?*  
(Susan, Initial Interview)

Even in such circumstances access to certain elements of information seemed somewhat arbitrary. For instance, **Susan only heard about and accessed the 'Warm Front' scheme because someone canvassed door to door.**

*"If they hadn't turned up on my doorstep I wouldn't have known where to go and how to ask about that apparently because I get DLA, I was **entitled to it.**"*  
(Initial Interview)

If someone as well informed as Susan only found out about certain of her entitlements by chance, it was clear throughout the research that many other participants were frustrated and overwhelmed in seeking to access to information.

*“It all seems that it’s all on you to.... and to me it feels like I’m begging and I’m not that type of person so there are things that I do need help with as I am at the moment I don’t know when that is and if I can get the help.”*

(Fred, Initial Interview)

At the start of the research period, Fred was receiving statutory sick pay and was employed by the company he had worked for, for over 25 years. However by the end of the research period he had been retired due to ill health. At this point Fred was in receipt a pension from his previous employers, received Disability Living Allowance, had completed an Expert Patient Programme and was involved in running future similar courses for others when his health permitted. It was particularly evident at the early stages of his impairments becoming more substantial that the negotiation with macro structures was extensive, but that Fred did not know what to do. He jokingly suggested that one way he had thought of accessing information was to go down to the pub and listen to other people talking and take a note of the agencies they mentioned in order to look them up later (ibid).

It can be seen that Fred moved from a position of knowing nothing about how to access support, information and benefits through a period of struggle and frustration to one where he had achieved some level of understanding of what was available to him and established himself in his new role. This was not necessarily the case for all participants. For instance, Flavia had not found a greater range of support mechanisms, information or resources by the end of the research period than she had at the beginning.

Richard had experienced limited sight and hearing since he was very young. Three years prior to the start of the research his vision deteriorated substantially, yet Richard described discovering resources which were useful for him accidentally.

*“I got those from Any Counties’ services for the blind. They’ve got a shop in the city I was living in. So it’s everything that talks, including microwaves. Now I don’t know if some sighted friends of mine knew about it because they had a relative with poor sight and I didn’t know about it until they told me. No government agents or local sources. Because nobody talks you see; it’s this barrier again.”*

(Richard, Initial Interview)

It does not appear, therefore, that the amount of time that someone requires support or experiences impairments equates directly to how easy it is for them to access what they need. The practical barrier of getting help then was something that every participant experienced, though precisely who accessed what help and how will be considered in the conclusions of this analysis.

### **6.3.5.2 Access and Obstructions**

Within the context of this research, there is a distinction between access and obstructions; when referring to access therefore this will relate to non-physical barriers that are practical while obstructions will refer specifically to physical barriers.

### 6.3.5.3. Access

In addition to the general practical barrier of knowing where to get help, attempts to access support, services and information had varying barriers dependent upon the nature of the impairments.

For instance, Hermione was permitted to apply for her driving licence at 16 in light of her impairments. Her mother Marie described the first step was getting a provisional licence, but the system did not recognise that some people may be slower at responding to the questions than others.

*"We did try earlier this afternoon to apply online but we kept being kicked out of the system as we were too slow – the website by the government clearly is not particularly **disabled friendly!**"*

(Email Entry, 1 of 6)

When attempting to contact other people, Edward expressed frustration that cordless phones had become much smaller.

*"The old phone ceased to function and I had to buy a new one. All the new models were designed around the mobile phone system. They were much **smaller and had a tiny screen.**"*

(Edward, Letter Entry, 1.5 of 6)

Current designs therefore had effectively become less accessible for Edward than **before and meant that without his wife's support it was much harder for him to** contact other people. Eventually Edward purchased a specialist phone with larger buttons, specifically intended for people with limited vision. But the options available

to him were significantly limited as manufacturers altered the range of options and sizes they had available to purchase, effectively moving Edward from mainstream purchases into a much narrower specialist field.

Increasing complexity in banking systems caused challenges for Richard, who used a telephone banking system. Although he ascribed this as a way of reducing fraud, the complexity and number of questions his bank asked him to complete in order to undertake telephone-banking rose. It was only through complaining, relying on his memory and searching out understanding contact points had Richard been able to continue to access banking services.

*“Mother’s maiden name, no problem. Date of birth, no problem. Then they start asking me questions, about, what part of the month do you pay a direct debit? Because I can’t see with the bank account details in front of me, I can’t tell them. I had such a row in the end they gave me an 0800 number which takes you to somebody in the bank with a sympathetic attitude. I had to go through hell to get that sorted out.”*

(Richard, Initial Interview)

Having resolved this challenge, Richard was currently encountering an increasing reliance on using the international banking number **that was “About twice as long as the card number and harder to memorise” (Richard, Final Interview).**

Edward is also a visually impaired person for whom banking services were hard to access. He described challenges in using chip and pin and cash machines, recognising it would be virtually impossible to use such services without the support of his wife (Letter Entry, 1.5 of 6 and 2 of 6).

One regular barrier raised by both Richard and Edward was accessing up to date information.

*"No because people who can see all the time, they just sit, you know 'oh, I'll read that,' there's a bit in the paper and they'll read it and they'll remember it, but you see we haven't got access to daily papers and what is read to us on tape are selected items you see."*

(Richard, Final Interview)

Talking books alone therefore have not successfully resolved the challenge of accessing information for visually impaired people.

*"Such a lot is missed and I fail to keep up-to-date with many topics. New advances in many things are missed and often when I learn about them they have been superseded by further models."*

(Edward, Letter Entry, 1.5 of 6)

This left the two participants feeling not fully informed of what was going on in the world and so less confident about engaging fully in many areas including the wider structures in society and changes to the world around them.

#### **6.3.5.4. Obstructions**

Physical obstructions affected seven of the ten participants. The specific area of transport and getting around will be considered in detail in the next section. The physical barriers causing obstructions however often involved a lack of thought of the consequences of structures rather than any specific intent.

Public Service buildings, including hospitals and Departments of Work and Pension buildings were inaccessible and the effects on people using those services not apparently acknowledged or considered. Fred outlined the process he faced when he had to attend an appeal meeting in relation to Disability Living Allowance. He was **given less than a week's notice of the appeal, which took place in a different city to the one he lived in.** He described how there was no parking within half a mile of the building and the bus station was a twenty-minute walk from the site. The paperwork did state that Fred could get a taxi and claim the cost if necessary, but from his perspective this was another process he would have to go through, which he found complex and new. As Fred has fibromyalgia and walking any distance could exhaust him and cause discomfort he felt that he *"didn't have a level playing field as others to begin with"* (Audio Entry, 5 of 6).

Marie described taking Hermione to hospital appointments at a children's hospital in the city where they live.

*"It's right in the centre you cannot park even if you've got a blue badge you cannot so you have to draw in, get Hermione out, get the wheelchair out and get Hermione to the hospital and up to the physio. Come back down and take the car back and park it then go back up."*

(Marie, Initial Interview)

The pressure and complexity of even accessing the buildings then caused stress and anxiety for the participants.



Other physical structures and obstructions which the participants encountered were not government or service related buildings, but nevertheless suggested, that **disabled people's needs had not been fully considered. Edward acknowledged that** changes had occurred within since the DDA, but that by no means all buildings appeared to have made adaptations or made circumstances easier. For instance he points out that steps which are not painted a contrasting colour at the edges are very difficult to see and that doors which can open inward or outwards make it hard to know how to open the door, or avoid being hit by another person opening the door from the other side (Edward, Letter Entry, 5.5 of 6).

Susan encountered similar problems where doors, which required pulling, meant she was unable to access buildings, particularly petrol stations without her husband to help with the doors. She felt this was particularly frustrating when the petrol station she was attempting to enter was part of a large international supermarket chain (Susan, Audio Entry, 1.5 of 6).

The facilities to make a building accessible did not automatically result in the freedom or end of barriers which have been the intention. For instance, Marie described how Hermione attended an end of school prom at a local hotel. Although the hotel had a wheelchair lift, it needed a member of staff to operate this, particularly as the function room was a split-level with stairs in the centre. The tables and chairs had also been placed too close together which meant manoeuvring around them was very hard for Hermione. Although she had looked forward to her

prom a great deal, these factors meant that her evening was not the success she had hoped.

*"This meant that Hermione was quite isolated as the company flowed between the two levels and she could not move without help; she felt that **the staff viewed her as a bit of a nuisance.**"*

(Marie, Email Entry, 1.5 of 6)

Without a willingness to engage in the values behind the Disability Discrimination Act, the legislation alone will not be sufficient; this will be explored in greater detail within the findings of the analysis.

General obstructions in the streets were particular challenges for the two participants who had visual impairments: Edward and Richard.

*"There are obstructions which have and are appearing on pavements. Refuse collection bins which are left out for days, sign boards outside shops which **reduce the width of the pavement.**"*

(Edward, Letter Entry, 4 of 6)

However even attempts to challenge such practices were not always successful. For instance, Richard noticed that in a street close to his home, he had great difficulty in walking along the path as a shop owner had covered the pavement with obstructions in the form of goods and advertisements. Richard challenged the man explaining the difficulties he had encountered as a result of this (Audio Entry, 4 of 6). The shopkeeper had apologised and moved the obstructions out of the way; however he had put the items back out again shortly afterwards.

*"As far as I know they're back out, yeah. I mean I know they rent part of the pavement, but that's only half the pavement, like where a greengrocer will put his groceries, but this one they're putting them right across and they're putting a rubbish bin on the end, so in other words they're taking up... anybody would have to come up to them, turn right, go around and then back around to carry on. To me that is obstructing a public right of way."*

(Richard, Final Interview)

Richard reflected, therefore, that he felt unable to do anything about the situation as having looked up the company on the Internet he had identified it as a franchise store, with little apparent control by the parent company.

Marie also reflected that the only single accessible changing room in the local private gym which she and Hermione attended was often used by families without disabilities and was also used as a storage area.

*"It is also full of extra chairs and baby changing facilities which means that a wheelchair user could not use this on their own as the furniture has to be moved in order to allow the **wheelchair entrance.**"*

(Marie, Email Entry, 05. of 6)

Marie had pointed out these difficulties to the gym manager on more than one **occasion, who was very polite but the circumstances did not improve.** Marie's frustration was evident.

*"It seems unfair that the facilities available to us are of secondary standard to those available to other users."*

(ibid)

It appears that there was lack of redress open to participants when they met such obstructions.

### 6.3.5.3 Mobility and Transport

Getting around and being mobile was something which every participant discussed within their interviews and within the diary process. Without effective means of transportation participants encountered isolation and were unable to engage with a wide range of activities or negotiate structures. The table below demonstrates the challenges which participants encountered in relation to mobility and transport.

<b>Name</b>	<b>Mobility and Transport Issues</b>
Fred	<ul style="list-style-type: none"> <li>• Accessibility of DWP appeal building.</li> <li>• Slow pace of walking owing to pain.</li> </ul>
Susan	<ul style="list-style-type: none"> <li>• Automatic Car essential.</li> <li>• Using buses alone not possible; jerking and getting on and off.</li> <li>• Accessing garages for petrol without support e.g. doors.</li> </ul>
Edward	<ul style="list-style-type: none"> <li>• Being alone outside home challenges;               <ol style="list-style-type: none"> <li>I. Reading road signs,</li> <li>II. Avoiding obstacles,</li> <li>III. Using buses,</li> <li>V. Seeing where things are</li> <li>VI Shopping and banking.</li> </ol> </li> </ul>
Patrick	<ul style="list-style-type: none"> <li>• Not confident in using buses – challenges in communicating with drivers and speed of movement.</li> <li>• Getting driving licence back huge change in movement, independence and confidence.</li> </ul>
Marie and Hermione	<ul style="list-style-type: none"> <li>• Appeals process necessary to get educational transport for Hermione.</li> <li>• Hermione reliant on Marie for social and health related mobility</li> <li>• Seeking adapted car and driving licence for</li> </ul>

	Hermione; I. Cost implications substantial II. Intended independence greatly valued. III. Access around many buildings limited owing to insufficient facilities for wheelchair users.
Richard	<ul style="list-style-type: none"> <li>• Obstacles.</li> <li>• Unable to access resources for visually impaired people as journey involved two buses and complex change in centre of city.</li> <li>• Taxi too expensive for regular use.</li> <li>• Ring and ride used when available, but limited access.</li> <li>• Use of specialist services at train stations when going out of town. Two train operators praised.</li> <li>• Overall significant isolation</li> </ul>
Mrs Haynes	<ul style="list-style-type: none"> <li>• Limited mobility in walking</li> <li>• Isolated nature of area of retirement home</li> <li>• <b>Reliant on taxi's to access town centre;</b> cost implications</li> <li>• Result isolation.</li> </ul>
David	<ul style="list-style-type: none"> <li>• Reliant on bus services and lifts</li> <li>• Noted loss of free bus pass when he moved areas.</li> </ul>
Flavia	<ul style="list-style-type: none"> <li>• Loss of confidence in travelling by car after road traffic accident</li> <li>• Nerves and anxiety related to her condition often meant hesitant about leaving home at all.</li> </ul>

*Table 9 – Mobility and Transport Issues*

Every participant therefore experienced some limitations to the opportunities open to them relating to their impairments, but it was practical barriers relating to transport which often prevented people from resolving these challenges.

For example, **Richard's dual sensory impairments may have limited his opportunities** to access resources, but a lack of provision of affordable and effective transport for him resulted in the isolation he repeatedly referred to in his audio diaries. Susan encountered pain and limited movement in her hands and arms, but the lack of

automatic or sliding doors was the factor which prevented her being able to independently get petrol for her car.

**Not all participants' experiences were directly related to the process of getting around; nevertheless the impact of limiting factors affected their ability to do so. For instance, while Flavia's impairments and experiences may have made her nervous to leave her home, from her perspective it was the inability to access effective treatment which made it harder for her to overcome this. She sought cognitive behavioural therapy because she believed it would "stop this closing in on me and like learn how to not be a hermit" (Flavia, Initial Interview).**

In contrast to the limitations participants experienced, when Patrick got his driving licence back in the fourth month of data collection, the positive effect it had for him was substantial.

*Patrick: I feel more up to date*

*Joy: Right*

*Patrick: Yeh, I don't know, erm*

*Molly: What would have made that difference in you Patrick? Now what's made you feel more up to date?*

*P: Getting me driving licence back has done that.*

(Patrick, Final Interview)

He was able to travel to areas he had not been able to go to when alone before, became more involved in bowling, was able to take his dog to the seaside and generally felt better informed as a result of his increased mobility. This demonstrates

how purely considering the **aspects of a person's life through the lens of macro** structures fails to capture some of the areas of particular importance for the participants themselves. The resolution, therefore, of practical barriers can offer real improvements in day-to-day life.

#### **6.4.5.7 Resolving Practical Barriers**

There were occasions when resolutions were found for issues that could have been **practical barriers for participants, as indicated by Patrick's example above.** These were often acknowledged, for example Susan was pleased to note that her local tax office doors had been replaced and were now automatic. This meant for her an immediate challenge of entering the building was removed (Susan, Audio Entry, 2 of 6).

When Richard finally got his Internet connection linked to a freedom box specifically designed for blind people, he was able to use the Internet and access a range of resources and ways of communicating with other people which previously had not been open to him. While this could not remove all the isolation and loneliness which Richard repeatedly reported in his diaries, it gave him opportunities which had not been available before.

*"It has its own screen reader with several voices and has proven to be quite a **success. I've been able to use Google for the first time in my life and have been surfing a lot of websites which I was never able to use before.**"*

(Richard, Audio Entry, 3.5 of 6)

However it was not practical barriers or employing technology and ways of traversing these alone, which created this resolution. It was also the individual determination shown by Richard. He repeatedly tried to install such systems and get his connection accessible. This took over three months and involved him ringing advice lines, asking friends, paying taxi fares on one occasion and using ring and ride on another to get across the city he lived in to visit the third sector organisation which offered technological equipment for sale in relation to visual impairment.

Throughout the research and analysis it is possible to see that the challenges and often the resolutions to these challenges were as a combined result of factors. The way in which Richard overcame this practical barrier in communication, for example, was by the technology being accessible, him having heard about it and having the personal determination to overcome this challenge.

Similarly when Hermione reached the age of 16 and was legally entitled to manage her own Disability Living Allowance, with the support of her mother Marie, Hermione opened a bank account. The immediate practical barrier which Hermione encountered was that as she could not write as it would not be possible for her to sign a cheque or complete appropriate forms and therefore there was a query as to how she could manage her account. The bank clerk was unsure how to deal with this and undertook to contact head office. He did not display cultural assumptions **about Hermione's capacity because she had impairments. Marie reflected positively on the bank clerk's attitude as well as the practical** resolution offered by the bank.



*"He covered his and our embarrassment by saying, "I'm sure there's a way as this must happen all the time." which made us feel much more "normal". There is, he phoned us back this afternoon to say that they would give her a stamp to use as a signature."*

(Marie, Email Entry, 0.5 of 6)

The practical barrier could also have been one of cultural and professional barriers, **as discussed earlier in that section; the government department began, in Marie's** perception, with the assumption that as Hermione could not write she did not have the mental capacity to deal with her own finances. However, the practical barrier of not being able to sign papers was resolved here and the attitude of the bank staff to finding a resolution meant the problem was overcome quickly and effectively.

One of the support mechanisms which Edward has utilised, which will be discussed within Chapter Seven, is that of joining an access group. The practical barrier for visually impaired people when accessing pavement edges is something which he mentioned more than once throughout the research. When the Local Authority **appeared to have responded to the access group's requests and distinguished** between the street and the pavement, Edward was pleased:

*"I felt quite proud the other day that finally there are some steps that we've got the edges painted."*

(Edwards, Final Interview)

The practical barrier of moving from a pavement and into a road had been resolved. The resolution was not complex, but Edward felt this would not have been overcome if it were not for the access group (ibid). In this case a practical barrier was

overcome because of the access group and way in which people with impairments in that area collected together to get their voices heard.

## **6.4 CHAPTER SUMMARY**

This chapter has explored some complex themes of analysis, in light of this I have provided a brief summary of key points of each theme separately that I feel are particularly salient to this research.

### **6.4.1 Structural Barriers**

The fragmentation of services and particularly the opaque systems which participants encountered caused immense frustration for the participants. For example the expectation that people applying for benefits would know how the system worked, which Fred encountered assumed a level of specialist knowledge which the participants were unable to acquire immediately. The structural barriers which participants encountered were more often the effects of unintentional responses of an unwieldy system.

### **6.4.2 Procedural Barriers**

Similarly to structural barriers, a lack of transparency and highly complex systems combined with unintentional effects was commonplace. Many statutory and

government structures appeared to participants to be relatively autonomous. Whether or not this was the case, the lack of information explaining processes for redress or further possibilities for the participants to seek out proved a barrier for many.

### **6.4.3 Financial Barriers**

The financial worries people encountered can be characterised as a feeling of helplessness and a lack of information being available as to any other options which may be possible. This, in turn, led to a feeling of helplessness and a sense that the government structures delivered their judgements with a sense of finality which could not be challenged. The fear of being destitute, losing their home or not having sufficient food were at times very real for two of the participants: Fred and Flavia, but at some point in the six month period of research a further four mentioned finances as an issue of concern.

### **6.4.4 Practical Barriers**

The range of practical barriers encountered within the research was wide and participants with physical and sensory impairments tended to encounter practical barriers more frequently. Practical barriers relating to transport issues were something that affected everyone. There appear some practical resolutions which were relatively easy to solve, such as painting a pavement edge, others such as the

inaccessible nature of public service buildings and a lack of parking around them does not appear as easy to respond to. Repeatedly it appears that knowing who to contact, how to contact them and what options of resolution are open, are relevant motifs for participants throughout the research.

Practical barriers were understood and responded to more frequently and immediately if the individual was seen in person and if their impairment was visible. Very often however practical difficulties were specific to the impairment(s) the participant had and therefore needed explanation and possibly negotiation if the barrier was to be overcome. Consider, for example, **Susan's difficulties with using crutches**.

#### **6.4.4 Conclusion**

Having demonstrated the macro barriers which were encountered, this chapter has clearly set out many of the barriers and challenges which participants faced. The barriers outlined to date demonstrate some of the factors which shape the services and provision which individuals encounter. The themes which arose directly from the data and discussions with the participants throughout the research period will be considered in greater detail in the next chapter, alongside the effects of such barriers and the ideas of agency and identity transition.

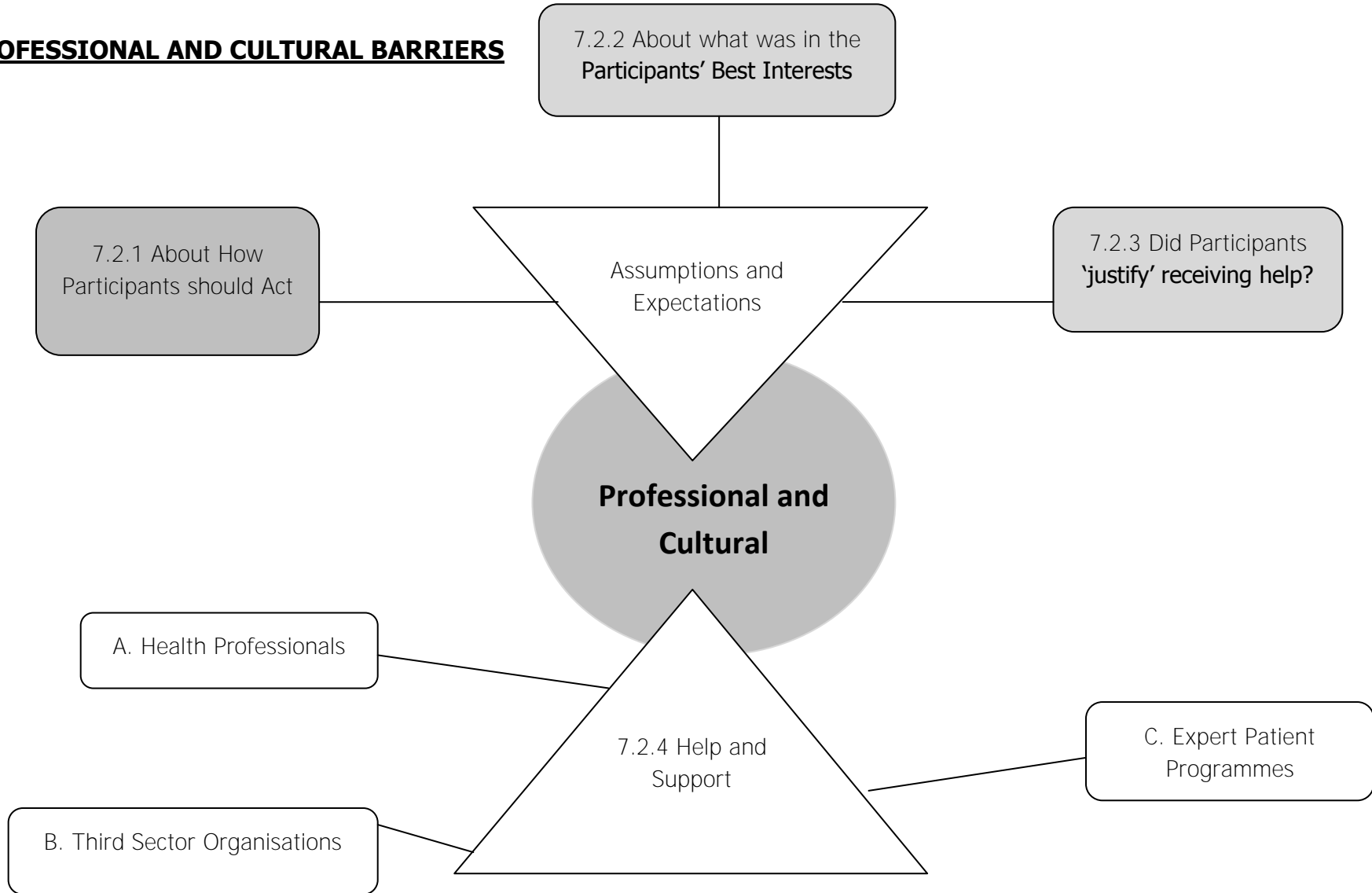
## **CHAPTER SEVEN ANALYSIS – INDUCTIVE ANALYSIS**

### **7.1 INTRODUCTION**

The second group of themes for analysis relate to primarily the research question: 'how are self-perception and identity affected by encountering disability and the resultant treatment?'. They also partially answer research question one, by illustrating some of the ways in which **participants'** expectations of service provision may be shaped. This analysis was developed directly from the data itself and relates to attitudes towards the participants, (as experienced and reported by them) through issues such as professional and cultural barriers, legitimacy, and support mechanisms. These themes were developed through considering the initial research questions and by observations of the data as it came through from the participants throughout the data collection period and by reviewing the data at the point of transcription. They were also developed between the participants and myself as the researcher, which allowed us to reflect on their experiences and the data which was arising. For example, the importance of support mechanisms to participants was highlighted to through our discussions and reflections upon the data. It was something which Susan focussed upon substantially in her initial interview and throughout the collection process. In light of this the researcher looked in detail for data relating to support mechanisms with all participants, and was able to see what a huge impact this area had on an **individual's** experiences and perceptions. Later in this chapter, exploration how agency and identity were experienced by the

participants will occur. However the chapter will begin by exploring attitudes towards disability and disabled people through professional and cultural barriers and ideas regarding legitimacy.

## **7.2 PROFESSIONAL AND CULTURAL BARRIERS**



*Illustration 12 – Breakdown of Professional and Cultural Barriers and Support*

Professional and cultural barriers were themes which were frequently experienced and raised by participants. Within this analysis the sub themes relate to two areas, as visually represented above. The first I developed from Hudson and Hardy's (2002) original framework to incorporate a range of 'assumptions and expectations' in respect of participants' behaviour and intent, in this context these assumptions and expectations related to the relationship between professionals and participants.

The second set of sub-themes within this research referred to specific 'help and support from professionals', for as demonstrated below ,while professionals and health professionals in particular were most commonly cited barriers, they were also significant sources of support and recognised as such. This element of analysis was therefore inductive and deductive. The two breakdowns can be compared to each other in appendices 9 and 10.



## Professional and Cultural Barriers and Support Cited

Name	Types of P & C Barriers Encountered	Types of P & C Support Encountered
David	Disability Advisors at University	GP
Edward	Social Services	Third Sector Organisation
Flavia	GP and surgery, psychologist, Disability advisors and lecturers at University	Paid therapist, NHS Direct, Local Education Authority
Fred	GP and surgery, Some consultants, benefits staff	Expert Patient programme, one consultant
Mrs Haynes	Hospital staff, Local Authority including social services,	
Maria & Hermione	Local Authority education department, Private School, Private Gym, Some medical staff, GP initially.	State School, Some medical staff, Third Sector Organisations.
Patrick	Initially hospital staff, consultant	Some Local Authority staff and medical staff at later stages after his stroke.
Richard	District Nurses. Dental surgery, Third Sector Organisation	Third Sector Organisation
Susan	Some Local Authority Staff	GP, Expert Patient Programme, Third Sector Organisations

*Table 10 – Professional and Cultural Barriers and Support Cited*

The differences in ideologies and values and differing views about service user interests and roles here are explored through the assumptions made relating to participants and are divided into three: how participants should act, what is in the **best interests of participants and whether participants were seen to 'deserve'** helping. Not all professional and cultural involvement resulted in barriers, some

quite the reverse, i.e. were extremely helpful and were recognised and commented about in such terms. In light of this an exploration of the professional and cultural 'support' participants received follows the consideration of the barriers. The support can be seen almost as the reverse of the assumptions and expectations highlighted below; they related to engaging directly with the participants, listening to their concerns in a non-judgmental manner and seeking to enter into genuine partnerships.

## **7.2. Professional and Cultural Assumptions and Expectations**

### **7.2.1 About how participants should act.**

#### A. Health Professionals

Richard has very limited sight and vision, during the research period his diabetes required monitoring as his blood sugar levels were high. He did not have any equipment which meant he could not monitor his own blood levels and had to rely upon district nurses to conduct tests. The district nurses did not give him a time of day at which they were likely to attend. Nor, despite regular requests from Richard, would they recognise that owing to his hearing limitations he required the door entry system buzzer to be pressed long and hard to ensure he could hear it. Instead when he spoke to the practice manager he was told that he should '*wait by the door*' throughout the day, '*they would come when they were ready*'. Richard found this insulting and that it meant he was expected to wait passively.

*"I can't just sit in and wait quietly, I have my own life to lead and so this is a real bone of contention. It's frustrating on one hand; I would do it myself if I could instead of sitting around waiting and waiting. It's behaving in a paternalistic way saying that this is a medical issue so do as you're told."*

(Richard, Audio Entry, 5 of 6)

Richard also noted that his blood sugar had gone down compared to three weeks ago, the nurses hadn't said anything in relation to this, but had reduced the frequency of their visits without warning. If Richard had been waiting by the door as advocated by the practice manager he would have been waiting for their arrival for over a week.

Approaching her general practice, Flavia regularly requested Cognitive Behavioural Therapy, but was repeatedly refused this request and offered anti-depressant medication instead. Flavia challenged their decision.

*"I said, "I've done my research on post-traumatic stress disorder. CBT is a recommended therapy. I've never been given the right care that's recommended by the NHS from the NHS, for my PTSD, and I don't think it's right!"*

(Flavia, Telephone Entry, 5.5 of 6)

Her willingness to confront her GPs often resulted in a strained relationship, where **Flavia's behaviour was seen as a challenge**. The relationships between the participant and G.Ps had broken down and left Flavia feeling unsupported and unable to seek further help.

*"I've just had enough to deal with. I don't know, I'm reluctant to go and ask for help because of the way that I have been treated and when I've tried to go and ask for help because I just seem to end up feeling worse."*

(Final Interview, 2006)

During the research period Susan fell over and injured her foot and ankle. She went to the hospital and was advised to use crutches. Susan explained that this would not be possible as she had tenosynovitis. Later in the consultation, the doctor again mentioned the use of crutches and Susan reiterated "*Look I honestly am not going to be able to manage them*" (Audio Entry 4.5 of 6). A few days later upon returning to the hospital to see a consultant regarding her ankle, he again raised the questions of the crutches.

*"He says 'I see you're not using the crutches?' So I said 'no, I have bilateral teno, which means I'm not able to use the crutches because it hurts my wrists' and then I said 'and I see that hasn't been noted on there'"*

(ibid)

Although Susan recorded that the doctor smiled at her comment, he did not verbally respond to her statement.

*"Because it's okay for them to be, you know, trying to reprimand you, but the thing is you've actually told them something and given them a reason why and they don't even document it."*

(ibid)

She felt that challenging his expectation of patient behaviour this way was not how she was expected to behave.

The illustrations given so far within the subsection of 'how participants should act' have looked at the assumptions and expectations of medical staff, though participants also experienced such barriers in other aspects of their lives; agents of government structures and Universities.

#### B. Agents of Governance Structures

A local branch of a third sector organisation contacted Edward shortly after the permanence of his loss of vision was confirmed. He registered his sight loss and sought out aids and adaptations, purchasing those which he thought would be helpful. A member of staff from Social Services visited Edward at home approximately six months after he had registered as partially sighted. The member of staff, "*intimated that I shouldn't have bought things until Social Services could provide it*" (Letter Entry, 5 of 6). Edward expressed surprise that the Social Services representative did not recognise that in his situation the help and support would be required within the first month, rather than six months later (ibid). The suggestion that the participants should rely upon Social Services rather than seek to help themselves until budgets and waiting lists allowed for such provision again can be seen to place the service user in a passive situation by the culture of the professional.

Marie discovered that at 16, Hermione was entitled to take care of her own finances. The bank provided a stamp with Hermione's signature to facilitate this,

however in relation to the disability benefits she was in receipt of, the D.S.S. had a different perspective.

*"Yesterday we got a phone call from the DSS saying that because she cannot write, she cannot look after her money and they will send someone out to assess her. This is blatantly discriminatory."*

(Marie, Email Entry, 1.5 of 6)

The assumption which the D.S.S. appeared to make, that anyone not able to write could not have the mental capacity to deal with their own finances, greatly frustrated both Marie and Hermione (ibid).

### C. Educational Institutions

Both Flavia and David experienced difficulties with the Universities they attended. Flavia began a degree in a medium sized town in the centre of England, but a road traffic accident resulted in Post-Traumatic Stress Disorder and a head injury, and so after recovery time she moved to a University at a larger institution closer to her original home city. Although Flavia liaised with the disability advisers and support mechanisms at both institutions, she felt this did not provide any support or understanding on the part of her lecturers.

*"If I go and see them and tell them "I'm struggling with this piece of work because I'm finding it hard to write things down and thinking properly and I'm finding it a bit difficult and I'm getting a bit lost with it." I've said that to them before and they say; "well that's you. That's not an educational issue," and it's like well it is, because it's my disability getting in the way and they say, "You've got to learn to live with it."*

(Flavia, Final Interview)

**From Flavia's perception** her lecturers did not recognise that her impairments resulted in additional needs and then looked at her performance purely in terms of the educational aspects.

David perceived the disability advisory staff at the University he attended as having developed an industry and earning their living through this role. David informed the University of his epilepsy; he had informed the local college he had previously attended without incident. However this University told him that it was policy that epileptic students should take their exams separately from others in **case they had "a fit" and upset the rest of the students. This had a huge effect on David's attitude to both his University and himself.**

*"After 39 years of epilepsy, I was at University before I was mocked and divided in such a fashion."*

(David, Initial Interview)

David reacted very negatively towards the University from this time on, speaking repeatedly about this to other students and staff, becoming angry and frustrated with the disability staff and at one point leaving the course for over a month.

When he was attending the course David was called into a meeting with two members of the supervisory staff of the disability advisors he had spoken to. He was not told the nature of the meeting or invited to bring any one with him, but was immediately challenged on how he had spoken to staff. One of the supervisory staff:

*"said straight away 'that wasn't a very nice thing you said to Flossie. I said hang on, hang on, hang on, what's all this about?'"*

(ibid)

David realised he was being reprimanded and was extremely angry about this; he **'didn't let them get away with it'** and later found the student disciplinary procedure, which described how he should have been informed of the nature of the meeting and entitled to bring someone with him for support. He reflected that he saw disability advisors as expecting specific forms of behaviour from disabled students, which did not include challenging policy or disability advisors actions.

*"It were somebody's job that I had to be kept disabled. I had to be kept in a baby like condition. That's it, they wanted us all children and we were their bread and butter."*

(ibid)

It may be argued that the University disability advisors sought to ensure fair provision for all their students, both those with impairments and those without. What is evident, however, is the marked difference between policy and practice in relation to the **intent of the Act and its interpretation in this situation**. David's anger and reaction may have exacerbated the situation, but the actions of his University illustrated specific expectations about how a disabled person should act in given circumstances. These expectations resulted in David feeling that **professionals were seeking to control him and make him childlike or 'infantilise'** him, which Kitwood (1990: 46) identified as a treatment often experienced by disabled people.



## **7.2.2 About what was in the participants' best interests.**

### A. Health Professionals

In a number of instances G.Ps acted as gatekeepers to participants in accessing specific services. This is acknowledged by many members of the medical profession as an essential role for GPs (Berney, 2005). However for the participants at times this role appears at odds with what they saw as their needs and a barrier was established relating to who should make the decisions and what **is in participants' best interests.**

Having waited to see the consultant for over a month regarding the pain Hermione was experiencing at the onset of her impairment, Marie described **contacting her daughter's** GP, repeatedly trying to convince him that this was serious and that the process needed to be speeded up. She **was told: "It's alright, it's nothing. Overanxious mother"** (Marie, Initial Interview).

Marie and her husband did not feel that the delay was in the best interests of their daughter and so paid for a private consultant who referred Hermione to an NHS hospital within 24 hours. Hermione was in hospital for a week at that time. However, the GP. **in acting as a gatekeeper had rejected Marie's assessment of her daughter's condition, believing that his opinion of the situation was the correct one.**

Even when a need for immediate treatment was recognised, disagreements as to the nature of the treatment were also common, with participants and GPs having different ideas about what was in their best interests.

Fred and Flavia both had invisible impairments, both went to see their GPs in seeking alternatives to anti-depressant medication; neither were successful. Fred had been referred previously to a pain clinic and found it very useful. He was discharged from that clinic as the consultant felt there was nothing more they could do for him at that stage. Fred was told by the consultants that if circumstances changed or he wanted any further help he could come back at any time. Fred felt he had explained fully to the GP how he felt and why he wanted to re-enter this treatment. However, the GP refused to allow him to return to see the consultant.

*"I wanted to go back and see the pain specialist, but he said 'no it's too early to refer you back there' and he's given me some anti-depressants. He seems to think that a few pills will calm me down and it'll help me. I've got no option but to go along with what he has to say."*

(Fred, Audio Entry, 1.5 of 6)

The offer of anti-depressants rather than a referral to a pain clinic frustrated Fred and he resolved to wait a month, see another GP at the surgery and try again to see the specialist, but that he would not take the tablets in the interim. Fred did not understand why doctors are not trained to help people come to terms with what he felt was the major loss inherent in long-term conditions. When he asks for helpful direction, he feels he was treated *"as if this is a heck of a lot to expect and instead tablets are doled out"* (ibid).

Flavia felt she was disregarded by her GP who failed to recognise her distress or understand (or even believe) in her condition:

*"I'd be laid in bed and suddenly it'd be like I'd get these really horrible feelings up and down my body. And I didn't know what it was, I got flash backs and the anxiety at the same time. I rang her on Monday and I was hysterical. I said I really, really need some help, can you please, please help me. She said oh Flavia; you're wasting my time again. Other people are really poorly and they need help. She said there's nothing I can do unless you're suicidal. I said alright I'm going to kill myself."*

(Flavia, Initial Interview)

One of the long-term results of the antagonism which developed between Flavia and her GP's surgery arose when seeing another GP: she asked for therapy, which was refused.

*"I went back to them to talk to them about cognitive behavioural therapy and he said do you work? And I said no. I'm a student and he said 'oh well in that case then I can offer you some anti-depressants.' It was like why, because they're cheaper?"*

(Flavia, Final interview)

Flavia by this stage did not believe that her doctors were looking after her best interests and that accessing any support or services was an ongoing battle in which she had to engage. Any possibility of a partnership between the GP surgery and herself had broken down.

At the point when Patrick first had his stroke, the consultant at the first hospital he was admitted to rejected Molly's suggestion that a CT scan was needed.

*"I said I understand he needs a CT scan, oh no, no he said, he's had a stroke we don't need to give him a CT scan and it's a Sunday, they don't open on a Sunday."*

(Molly, Patrick's Wife, Initial Interview)

Staff at the second hospital that Patrick was sent to, were 'horrified' (ibid) by the actions of the first consultant. It appeared to Patrick and Molly that the professional was not looking after Patrick's best interests, but 'taking shortcuts' (ibid) to lessen the immediate workload of the hospital. Patrick and Molly were keen to point out that they believed that the process for people experiencing strokes had improved dramatically in the area since that time.

The early stage of Fred's impairment saw him looking for medical support and understanding about his condition from a variety of sources. His long-term employers (at the start of the research) paid for him to see a pain specialist privately at a countywide clinic. In Fred's opinion the consultant had his own set of assumptions and was not willing to engage in dialogue with his patient.

*"He was a very arrogant, ignorant man. He kept interrupting me when I were trying to explain everything to him because I got the impression that within 30 seconds of him reading my letter from my own GP and him looking at me that he knew what the cause was and what were gonna work for me."*

(Fred, Initial Interview)

The treatment which this consultant advocated was not successful and when Fred returned and explained this, the private pain consultant referred him back to his GP and it was only at a later stage that Fred met Dr Steele who worked with him and he respected greatly. While it is not possible for every medical practitioner to

accurately diagnose and treat every condition at the first attempt, it was the assumptions which the consultant made about what would be most effective for **the patient, without ensuring he had understood Fred's perspective of what was** happening to his body, which Fred found so frustrating. This again caused a barrier between the participant and the medical specialist and a cynicism in Fred about the effectiveness of treatment.

## B. Educational Institutions

At University David found accessing computers to be difficult, he required a non-flickering screen, but no other requirements. His lecturers told him that they did not have a suitable machine available. In his final year the number of laptops available to the cohort was doubled. David informed one of his lecturers that if such laptops had been available throughout his course he would have had no difficulties. The lecturer was surprised and asked if David was able to use such equipment.

*"I said of course I can. Who told you I can't? Disability office have said you have to have a special computer. Told all the teaching staff I had to have a special computer. It's totally untrue."*

(David, Initial Interview)

David had not been told that the lecturers had been informed of these requirements, which were an inaccurate reflection of his needs. The assumption

made had caused David a practical barrier in not allowing him access to equipment earlier in his course.

*"Apparently whatever I needed, anything a computer, a laptop, anything it had to be a special one: got **through the disability office.**"*

(ibid)

This further reinforced his belief that the disability office was trying to make **distinctions as to a student's needs** on the basis of disability, leaving control exclusively to the disability staff.

Once Hermione was established in the state school which offered excellent **support and provision for pupils with limited mobility, she was, from Marie's perspective, much happier and appeared to be enjoying school.** There had previously been a formal appeal relating to funding for Hermione to attending this school with its specialist provision. Only after the successful appeal was funding and provision which Marie believed was adequate made available. However, Marie **was informed by Hermione's current school that they had been telephoned by another school, the Local Authority's preferred choice for Hermione's education. The preferred choice suggested that they had 'been contacted' by someone who wanted to know why Hermione could not be at their school.** This left Marie **worried and yet unable to explore the situation further as "this is all third party"** (Marie, Initial Interview). It was an instance where Marie became suspicious that the best interests of Hermione were not being promoted, and as the actions were taking place behind the scenes it was harder for her to challenge them.

Mrs Haynes, having had a stroke, was asked to decide while still recovering from her stroke where she should live in the future. The physiotherapist who organised the move told her that it would not be possible for Mrs Haynes to return to her previous home and that her only option would be to go into a retirement home. However, with hindsight the participant wondered if this really had been her only option and if the decisions made really had been in her best interests.

*"She said you can't go home, we've had a look at it you can't go home. I went with them I thought oh yeah fair enough so they brought me here and they said do you want to come here? So I thought I can't go home, I'll come here."*

(Mrs Haynes, Initial Interview)

Reflecting afterwards, Mrs Haynes wondered if needing the bed had something to do with rushing her into making a decision before she felt ready. The Community Care Delayed Discharges Act 2003 created financial incentives for speedy movement of patients, emphasising the need for quick decisions to be made in **relation to patients' possible future needs for community care (OPSI, 2003:5)**. The policy was adhered to, though from the perspective of the participant their wishes were not taken into consideration.

### **7.2.3 Did Participants 'justify' receiving help?**

This sub-theme appears at first sight contentious, but is intended to reflect how participants felt some professionals in positions of power perceived them. It has some similarities to the external attitudinal responses outlined in the status and

legitimacy section, indeed in the later stage of analysis certain elements will be distilled and this element will be considered in greater detail. The distinction made here is that the professional and cultural barriers refer to people who had a medical power and authority over the participants. The gatekeeper role for GPs, and the power to terminate treatment by specialists mean that the assumptions **and expectations made major differences to people's lives.** It was therefore important to participants whether or not they felt they were perceived as justifying help.

Fred had been going to see GPs regarding the pain and difficulties he was encountering, which he has later attributed to fibromyalgia since he was initially diagnosed in 1985.

*"They said it were a muscular skeletal problem and that it weren't gonna kill me and that I should just learn to live with it."*

(Fred, Initial Interview)

**In the intervening years Fred was told it was "all in the mind"** (Fred, Final Interview) that the pain was real, but was caused by the stress he was putting himself under. He was diagnosed with a wide variety of conditions and treated for these accordingly, including receiving physiotherapy for arthritis, which caused him considerable pain and later a pain specialist he saw discussed the frequent misdiagnosis that had occurred.



The report in relation to DLA. which one of the GPs at the local surgery had submitted without Fred's knowledge, as discussed within the status and legitimacy section, greatly affected Fred's attitude towards the practitioner.

*"I'm far from happy about and if I had the choice, I would personally sue that doctor, because in my view, he has personalised it. "*

(Final Interview)

This 'personalisation' as Fred perceived it resulted from this GP 'not believing' (ibid) in fibromyalgia. It left Fred not only wanting to change his GP surgery after more than 25 years, but also left him cynical towards the process overall.

*"I find it hard to believe that someone has given this medical opinion on me, when nobody's ever asked me about this and certainly nobody at my GP's surgery has talked to me in any detail about how my condition is currently affecting me."*

(Audio Entry, 1.5 of 6)

The DLA. form requires the signature of the applicant, in this case Fred, to consent to the GP writing a report: in respect of this, therefore, Fred could not claim that he had not given his permission. However it is evident that Fred had not realised that this meant the Doctor could write an opinion without discussing any element of the condition with his patient.

A similar sense of feeling judged as undeserving happened repeatedly to Flavia. One GP left her feeling highly criticised when she felt at a very vulnerable point.

*"I saw a doctor on the 28<sup>th</sup> November, a GP, for another sick note and he cut down my medication, he was quite arrogant, he said, "why do you come to me? Why don't you see the same doctor? Why do you see a different doctor every time?"*

(Flavia, Final Interview)

Although Flavia pointed out that she had sought to make an appointment to see the GP she had seen previously, she was bound by the appointment system of the surgery. She was left feeling nervous about returning to the practice, but feeling that she had no other options open to her (ibid).

The idea of 'deserving' help did not only apply to participants with invisible impairments. Two different sets of medical professionals questioned Hermione's commitment to getting well. Marie recorded that the physiotherapists within the first year of her condition arising suggested that her daughter **was a 'slacker'** (Marie, Initial Interview) who did not deserve help. From Marie's perspective they failed to take into account the nature of the condition and the individual they were working with.

*"They thought, I think that she was not doing her best. She was very private, these are huge changes to her body, she's in intense pain. She's very frightened and they were irritated and there was; she felt rightly or wrongly they undermined her."*

(Marie, Initial Interview)

The way these assumptions were communicated to the participants and the nature of the relationship between participants and professionals made it evident that there is a large amount of unequal power and no external authority open to the participants in these circumstances, therefore there was perceived to be no

sense of accountability for the actions of professionals. The policy intent of Patient and Public Involvement (PPI) under New Labour had emphasised better patient information with a patient centred focus and a range of strategies to ensure patients and users could be empowered. (Forster and Gabe, 2008:333). Again it is clear that there is a marked difference between policy and practice, here it appeared to relate to how health **professionals perceived Hermione's** behaviour and actions.

Marie recorded how a consultant who had been a valued and trusted ally for two **years appeared to have had a bad day and challenged Hermione's** apparent inability to get better.

*"It was a text book case of how not to speak to a client. She started by saying that the team were very tired after having treated H. for so long and that her physio was getting a hard time from the rest of her department for spending so much time with the chronic pain patients as there was no funding for them. She told Hermione that they could not understand why she was not getting better, but they were going to try one last treatment before they looked at offering her an operation that would bend her legs permanently and mean that she spend the rest of her **life in a wheelchair.**"*

(Marie, Email Entry, 1 of 6)

The frustration that Marie recorded as she and her husband had to sit and watch **their daughter being "verbally beaten" without any way of stopping what was** happening, caused great distress (ibid). This also led to a distancing in the relationship between patient, family and medical professionals which by the time the research period ended had not been resolved. While previously there had been a partnership between these parties, this perceived criticism with no right to

reply or form of redress in light of the power disparity between the parties effectively ended the partnership.

#### **7.2.4 Help and Support from Professionals**

##### A. Health professionals

Medical staff, including specialists, teams and GPs could make big differences in **people's experiences and expectations of support. For example**, twice within the three years since the onset of her condition Hermione had encountered great support from health **professionals, in her mother Marie's perceptions. These** according to Marie had made a huge difference to the way her daughter was able to positively respond to her treatment. Hermione bonded with an experienced physiotherapist who listened and responded to her patient and her mother.

*"So Hermione trusted her, I trusted her. We managed to start making little gains in de-sensing\* and we had help at home, and help at home in that they made suggestions about how we could bath her and all sorts of things like that."*

(Marie, Initial Interview)

*\* Hermione's condition meant that she was highly sensitive to any form of touch on affected areas, the process of de-sensing sought to allow Hermione to withstand people touching her when necessary.*

It was also in working with a team at the pain clinic that Marie felt the support and provision for treating Hermione holistically were very successful. This

unfortunately became particularly evident when someone Marie thought of as a key member of the team left and the team failed to work as well. At this time **while trying to 'keep people on side', Marie raised her concerns when speaking to** a psychologist on the team. Marie had always seen the woman being an integral part of the team and a person who was responsive to the insights and opinions of patients and their families.

*"I spoke to her about the change of consultant and that I didn't think the transfer had been that smooth. It was a gentle way of voicing my concerns you know, but the psychologist got quite prickly – 'well you'll have to bring it up with them'."*

(Telephone Entry, 3 of 6)

Marie reflected that the team had broken down, which then became a barrier for Hermione as they could no longer work together to ensure the best service for their patient. **The partnership team had worked effectively from Marie's** perspective for over 18 months. Marie indicated that previously, if her daughter had been very distressed and felt there was too much pain to cope with, then a discussion would have taken place between the team and Hermione and Marie and treatment would be suspended for a while. The shift in the culture of the team as Marie perceived it had meant that the vital support mechanism had gone; *"That line of communication is broken down now" (ibid).*

Fred saw the consultant at the NHS pain clinic as being extremely important to his welfare. He saw her as a support mechanism whom he rated extremely highly in comparison to every other form of support he had sought.

*“Only from Dr Steele, only at that level. Everything else I’ve applied for and asked for, I’ve had to justify it and fight for it. But everything she said I needed, she has arranged.”*

(Fred, Final Interview)

Fred saw a huge difference in the attitudes and perceptions of him, between Dr Steele and a number of his GPs for example. Dr Steele would work with him, believed in his condition and offered practical support such as arranging an Occupational Therapist to visit him at home. This contrasted greatly with the private consultant who diagnosed Fred upon sight and returned him to his GP when that approach failed, or the GP who assessed Fred for DLA. without asking him directly about his condition. The willingness to engage with Fred on a professional level, while understanding his pain and related needs, made a huge difference to him and the respect he clearly held for Dr Steele remained throughout the research.

Susan had a very good relationship with her GP and was therefore able to talk to him about a wide variety of issues. While having treatment from her GP she told him about a complementary therapy she had recently undertaken.

*“He was really interested. He’s always interested in anything that’s complementary and never pooh-poohs anything and if something’s working for you, he’s quite happy and he did understand it and he understood the concept of it and how, you know, it would be able to do certain things.”*

(Susan, Audio Entry, 3.5 of 6)

The non-judgmental attitude which the GP displayed when talking to Susan meant that she felt able to trust him, discuss a broad range of issues and saw him as a

form of support for her tenosynovitis. The willingness of the individual to embrace therapies outside the remit of traditional medicine led to a relationship between Susan and her GP which was unrivalled throughout the research.

Having encountered what they perceived as an extremely poor level of treatment when Patrick first had a stroke (Patrick, Initial Interview), both he and Molly became involved in a wide range of activities (see the support theme in the following chapter for more information) but they also came across people willing to offer them practical support. A number of individuals and organisations worked with Patrick and Molly to improve resources and facilities for people who had experienced strokes; this included Local Authority officials and health professionals. For instance, **during the research period Patrick's** GP started up a stroke clinic checking a range of health indicators such as blood pressure and cholesterol offering information and support. The participants understood that the service was to be an **on-going one and that this was help which wasn't asked for**, but was offered. It was highly rated by Patrick and his wife (Final Interview).

Patrick and Molly were also involved in a stroke group in which they saw Local Authority staff and health professionals working together to offer information and support; for instance health trainers giving a range of information. The two groups also worked together to help the development of a training day for staff at a local hospital to help medical staff understand the experiences of people who had experienced strokes. The training day was very positively received and Patrick expressed pleasure in the thanks for his involvement.

*"I was pleased when this email arrived, because my tears were not in vain. We have been asked to go back again. The staff and the nursing homes staff cannot wait to get their hands upon us."*

(Patrick, Email Entry, 0.5 of 6)

While the initial examples outlined illustrated how individuals were often the catalyst for participants accessing services, support and information, at times, team approaches also offered substantial support. For instance, for Marie and Hermione until the original team was reshaped when a member of the team left.

**As illustrated by Patrick's experiences, Local Authority and health professionals** from within the NHS worked together with him and other people who had experienced strokes, to use the experiences to inform and educate health professionals who would work with people experiencing strokes in the future.

#### B. Third Sector Organisations (T.S.O.s)

T.S.O.s illustrated a variety of barriers and support for participants. It is evident that third sector organisations have at times a heavy responsibility towards service users and many of the participants within the research, which has been increased through the reliance placed upon them by government and governance structures. These can be divided into two key areas: Providing Information and Emotional Support, for instance Susan had been involved with a local health advisory non-governmental organisation (NGO). Initially she had attended the NGO for advice; she then undertook a voluntary role and finally obtained part-time employment.



One woman there in particular had a huge effect on Susan and gave her a range of support and opportunities.

*"So she's always supported and backed anything I've wanted to do and if I think of anything I want to do then she's happy for me to do it and to progress personally as well as whatever."*

(Susan, Initial Interview)

Through her involvement with the NGO, Susan perceived that she had developed skills and confidence which meant that she could not only represent herself and feel informed about legislation and policy designed to help disabled people and those with impairments, but she could now also support other people in similar circumstances. The provision of information and support therefore meant that her confidence and skills relating to dealing with impairments, disability and work related injuries extended substantially.

**The second area in which TSO's** impacted upon participants was through the provision of services, opportunities and practical support. The changing relationship between service users and T.S.O.s (see literature review) has blurred the lines of what constitutes a statutory agency, government structures and charities or voluntary organisations. On one hand, some usually smaller, third sector organisations and charities operate in what can be considered the traditional role of a charity, i.e. seeking to find support or opportunities for individuals with a specific remit. For example the charity which Hermione became involved in offered people with physical impairments an opportunity to sail. It was

an opportunity which she greatly enjoyed and Marie saw in her daughter a form of pleasure which had not been evident for some time.

*"Scary to see Hermione so excited independent and in control but it feels wonderful and we're all so thrilled by this..."*

(Telephone Entry, 3.5 of 6)

Both Susan and Marie and Hermione then, felt a great opportunity and support was made available to them by third sector organisations.

Other T.S.O.s undertake statutory roles for fees, which at times limited the areas in which they could work and also gave a great deal of power to individual organisations. Richard felt that the expectation of statutory bodies and other government structures was that the local branch of the TSO who worked with him were responsible for anything at all which had to do with a person with visual impairment.

*"They think, do sighted people who aren't very much in the know, everything is solved by XXXX, did you know that?"*

(Richard, Final interview)

This assumption that one organisation is the only support system needed by a service user with a specific impairment, limited the range of opportunities open to Richard. The degree of power and range of areas which the charity are involved in, led to trepidation on the part of the participant.

*"I mean it's difficult because it's a charity and they're doing it to help me. It's difficult to complain but I felt like complaining. Because I've feel embarrassed because one person has helped me a lot and the next person I thought they were pretty useless you know."*

(Richard, First Interview)

The culture of the organisation and individual within that profession therefore can be seen to substantially shape the experiences of the participants and support varies substantially depending upon the individual circumstances which the participant encountered.

### C. Expert Patient Programmes

Expert patient programmes, developed from a task force set up by the Department of Health (DoH) in late 1999, developed and piloted between 2002-2004 and implemented in 2005. The DoH offered training and support in a framework focussing upon problem solving, decision making, resource utilisation, developing effective partnerships with healthcare professionals and taking action (DoH, 2001). This programme has now become a Community Interest Company (DoH, 2001) and offers support, by developing in those who undertake the course, skills to deal with situations for themselves. One of the aspects of the course is developing effective partnerships with healthcare professionals, and it is this which can be seen to challenge the culture of professionals and thereby break down barriers which participants may encounter. The concept of 'skilling' patients so they become more articulate, confident and able to control their own situations is a shift from the traditional passive representation of 'healthcare professional

knows best' and therefore a challenge to the long-established culture within the medical profession. Organisations and individuals, therefore, are supporting people through the expert patient programmes. Two participants were involved in the expert patient programmes: Susan and Fred. Fred recalled how he felt when he was given information about this opportunity.

*"She gave me this leaflet to go on this expert pain management course, and that were the first time in this now 18 months that someone had started to give me information, not only about my condition but about people who could potentially help me."*

(Fred, Initial Interview)

Susan felt that course gave her an insight which strengthened her confidence and skills, which she appreciated having access to though wished she had encountered it earlier in her condition.

*"If this had been about 11 years ago I'd just have had so much extra support. And I just got some more emotional positivity out of it really. And erm, just saw how much other people got from it. How much it benefited other people and I thought it's really good experience for the group."*

(Susan, Initial Interview)

Fred undertook training when he had completed the course and became a trainer for future courses. He also promoted Expert Patient Programmes to other members of the medical profession in an attempt to raise awareness of the opportunities open to patients. This resulted in Fred demonstrating pleasure and passion about his involvement (Fred final interview). He also recorded positive reactions of Health Professionals involved, (Fred, Audio Entry, 5 of 6). From his perspective, this showed a cultural change on the part of professionals.

### **7.3 Perceived Legitimacy of Impairments**

The **legitimacy analysed here, often related to how 'legitimate' the** impairments and needs of participants were deemed to be. This at times related to the visibility or invisibility of their impairments and how they were perceived or defined. Although it was individuals who participants felt judged them as deserving or not, at times policies also followed these perceptions and appeared to rely upon these perceptions without apparent accountability for their decisions.

**The perceived 'legitimacy' of certain impairments was evident through the** attitudes participants experienced. It is connected closely to research question **two** 'How are self-perception and identity affected by encountering disability and the treatment participants encounter as a result?' Repeatedly throughout the research, participants were assessed through governmental structures as to the legitimacy of their needs. All the participants with invisible impairments and both participants who had experienced strokes were asked to demonstrate their needs. However, the four participants with invisible impairments each had assumptions made at different stages that there was nothing wrong with them as their impairments were not visible. The way participants felt they were perceived and treated by other people was something that every person cited as an important issue for them within the research. The more visible, therefore evident and more medically defined impairments were, generally speaking, the less questioning of their legitimacy occurred. In contrast participants with less well known and non-

**visible impairments felt a battle to be 'believed' added** to the challenges involved in seeking services, information and support.

For instance, **Fred's GP did not believe Fred's impairment was as significant as** Fred felt it to be, and by observing him walk into the surgery made the decision to not support Fred in his applications for Incapacity Benefit and DLA. without telling Fred of his decision. Fred, having substantial fibromyalgia did not have any visible signs of the extreme pain he was experiencing. While the decision may be viewed as a professional or cultural barrier, Fred felt the GP saw him as someone who did **not 'deserve' support and had no entitlement** to benefits.

*"It's the same for anyone, not just for me but most people look at someone and they make a judgement within 10 seconds of seeing you on your appearance, what you might say to them and all that and a lot of them are like nothing wrong with him 'he looks alright that's ok'."*

(Fred, Initial Interview)

Susan encountered situations where people perceived her as not disabled, for instance being challenged about her right to use a disabled entrance to a local **Authority building "by the way that entrance is for disabled people"** (Susan, Audio Entry, 5 of 6). However when she hurt her ankle and had to limp and showed **difficulties in walking, people's reactions were much more compassionate and** willing to offer support.

*"Yeah, because obviously when I did my foot, people were going 'oh what have you done, are you alright?' because you could see me limping and then it was like it's no...because to me, you know yes it was serious, but to me it wasn't... I mean having to live with this (tenosynovitis) it was nothing."*

(Susan, Audio Entry, 5 of 6)

For Flavia the challenge of being believed was an on-going one throughout the research period. At University she was told to *"pull myself together"* (Initial Interview) while asking for additional support. She also moved GP practice within the period in an attempt to find *"a Doctors' who would believe me and at least try to help"* (Telephone Entry, 3 of 6). While other people with non-visible impairments were in time able to find specialist support or work with an understanding GP, at no time did Flavia find such help; her impairments have appeared to affect little recognition from the medical profession. The only understanding she felt she had received from a government structure had been from her education authority that provided equipment to help with her studies.

This resulted in severe anxiety for Flavia and her questioning of her own right to ask for help. Indeed on one occasion she rang me up as asked, *"can you tell me, because no one else seems willing to say anything: am I disabled?"* (Telephone Entry, 5 of 6). As a researcher I was not able to comment on her status, but as will be considered in greater detail in the internal attitudes section, much of the way people perceived themselves related to how they felt they were perceived by other people. Fred also similarly questioned how he should define himself. This sense of a lack of 'legitimacy' therefore proved a substantial barrier.

David, of all the participants with non-visible impairments, spent least time explaining and justifying his impairment. However, **from David's perspective, the** limited understanding people had of epilepsy caused them to treat him differently and to want to segregate him from other people.

*"They don't want me around, they think I'm going to have a fit, they think I'm going to frighten people."*

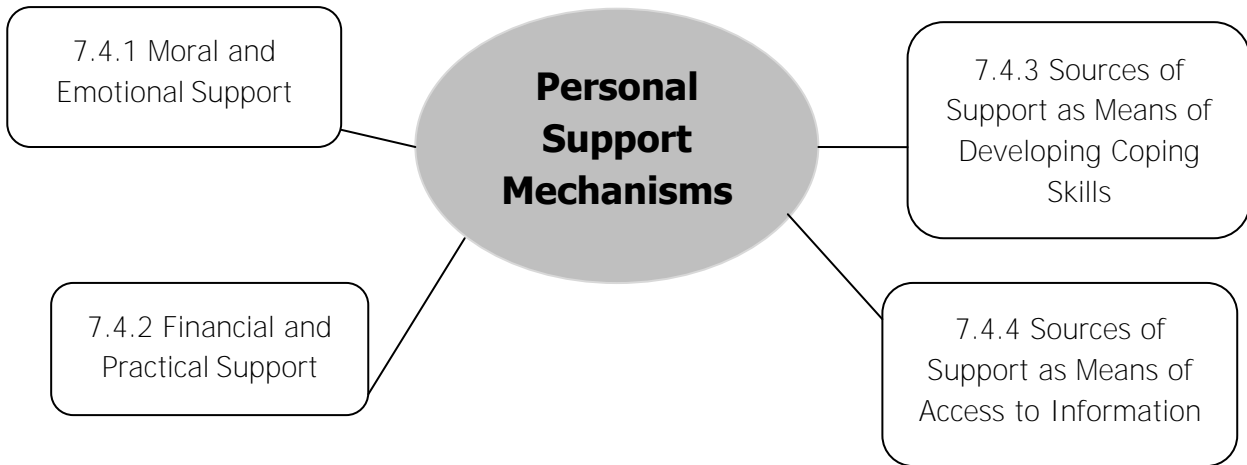
(David, Initial Interview)

What is evident throughout the analytic theme of status and legitimacy is the interplay between whether the individual or service provider is being legitimised and the fluctuating status which the participants encountered.

The participants who were doubted as to the legitimacy of their impairments most often were those with invisible impairments. The more visually evident impairments were, the less participants were challenged about them. When service providers used their autonomy to exclude participants from their facilities, this was seen by the participants involved as to be a result of funding limitations.



## 7.4. PERSONAL SUPPORT MECHANISMS



*Illustration 13 – Breakdown of Personal Support Mechanisms*

Support mechanism which individuals were able to access personally are made distinct from the support mechanisms available through professional help. Not because one has greater value than the other, but that often the support the people involved in the **research accessed from informal means and T.S.O.'s** were required when the support from professionals outlined above was not available. Support mechanisms of all forms proved extremely valuable and valued by participants throughout the research.

The initial form of informal support was that of family; in the context of this research this was primarily wives, husbands and mothers, additionally with less regularity, but not necessarily less value, was support from adult children and extended family, friends and neighbours. For those participants with intimate relationships the support they had was regularly referred to: below is a table

outlining which participants made reference to which support networks they accessed, identified or reflected upon throughout the research period.

Participant	Support Networks Specified
Edward	Wife, access group, local branch of Third sector organisation.
Richard	Family though geographically distant.
Marie and Hermione	Husband / Father, State school, Third sector organisation.
Susan	Husband, Third sector organisations, friends, children, extended family, support group, Expert Patient Programme.
Fred	Wife, Expert Patient Programme, Support Group, son and his family.
David	Socialist Workers Party (Early in research), Sister and her Family (Later in research).
Flavia	Her Mother (intermittently).
Mrs Haynes	No successful support mechanisms cited (Note only one Interview was conducted).
Patrick	Molly (his wife), extended family, friends, Third sector organisation support group and activist group.

*Table 11:– Support Networks Specified*

Support mechanisms were one of the ways in which participants were able to reduce and sometimes overcome the barriers that they encountered. The availability of support mechanisms varied substantially amongst the participants.

### **7.4.1 Moral and Emotional Support**

The first area of support is that of Moral and Emotional support, this incorporated a wide range of areas, for instance in combating isolation arising from communication challenges and reassuring participants that they are loved, supported and believed about the impairments they are experiencing.

Richard had difficulties finding people able and willing to spend time with him socially, often arising from communication issues and what he ascribed as the fear which many people had from not knowing how to respond to someone with his impairments.

*“I get very wound up by being on my own so much and I do go out and try and mix with people, but I must admit I spend an awful lot of time on my own and it’s beginning to get me down.”*

(Richard, Audio Entry, 4 of 6)

When participants were challenged by the attitudes of other people, as considered above in the sections relating to legitimacy and culture, it was often their families and friends who were able to respond to this.

*“It’s just, fortunately in the other department, I’ve got a good family and support, they help me and believe me.”*

(Fred, Audio Entry, 1 of 6)

The participants who had an extended network of support or a close partner living with them valued moral and emotional support a great deal. It was also evident when changes occurred for participants who did not always have such consistent

supplies of support, how much they valued it. For example when David moved area during the research and was located closer to his sister and her family he found that he had more support. In moving areas he had lost the support of his previous GP who he rated highly and was no longer permitted a bus pass in the new area, which limited his travel options. Despite these losses, David often **commented positively on the effects of this in terms of his life overall**; “*The phrase that comes to mind is support network; I’ll never be lonely again*” (Letter Entry, 5.5 of 6).

**Support did not only come from individuals in the participants’ lives, but the organisations such as support groups and improved access groups which people joined.** For instance Edward **recognised the value of such groups**, “*I made friends, contacts and rebuilt my confidence*” (Letter Entry, 3 of 6).

This theme of analysis then responds to research question two, in relation to how self-perception and identity are affected by encountering disability. Support often **reinforced participants’ willingness to engage with government mechanisms and to try to traverse the barriers they faced and challenge the way they felt they were perceived.**

It was not only through disability related groups that such support was found. For a number of years David had viewed the Marxism community as his primary support network (Letter Entry, 5 of 6). Indeed when David left his University degree course due to frustration regarding his treatment by the disability office, it

was comments from his comrades in his branch of the Socialist Worker Party which motivated his return to University,

*"It was because of those sympathetic Marxist Leninists with their counselling skills that I returned to University, slew the beast and got a 2:1. Every time anybody saw me, they'd collar me and say "How are you doing at University?" and they'd stand there in the street, looking at me as though I'd stolen something. They were my significant others and I daren't leave."*

(ibid)

When David felt the political movement he had been involved in for so long had 'fizzled out' after the death of a senior comrade (notes from interim telephone contact, 5.5 of 6), he felt real loneliness until moving to be closer to his sister and her family (ibid). Moral and emotional support therefore can be seen to have been accessed through family, friends, support groups and political parties. The second form of support considered here also relates primarily to people who have close intimate relationships with the participants.

#### **7.4.2 Financial and Practical Support**

The state offers some support for some disabled people, indeed the majority of the participants were in receipt of some provision relating to their impairments and specific needs; Richard, Edward, Patrick, Susan, Eric, Marie and Hermione and David were all in receipt of some benefit the end of the research period. This matter was not discussed with Mrs Haynes as only one interview took place with her; the data is missing in respect of this issue. In light of this the only participant who definitely did not receive such financial or practical support was Flavia.

Notwithstanding such support received from the state the vast majority of participants also received support from other sources, see table 11 above.

In terms of financial support, Flavia received financial assistance from her Mother intermittently throughout the research period. Flavia was living alone in her own home, had mortgage payments to make and was undertaking a degree, between bouts of ill health relating to her impairments. She was not able to access Income Support, Incapacity Benefit or other related financial support. It is not clear whether a lack of recognition of her impairments, the fact that she was a full time student, or a combination of both resulted in the extreme financial challenges **Flavia encountered. Without her Mother's financial support Flavia would have not** been able to hold onto her home, feed herself or pay for the therapy she received privately. As Flavia was unable to access any therapy through her GP, the support from her Mother was vital.

*"She'll help me in any way that she can, if she thinks that there's something that's good for me then she'll help me as much as she can."*

(Flavia, Initial Interview)

In relation to the other participants, financial support often came through the intimate relationships of husband and wife or young person and parents. In such circumstances, the financial support was something which those involved viewed as an inherent element of the relationship between them. Marie and her husband financially supported her daughter, however as Hermione was 13 at the start of her impairment and 16 by the end of the research period: this would have been

expected behaviour for a parent with responsibilities for a young person of this age. Similarly, while in partnerships where husbands or wives relied upon jointly accrued savings and assets, this was viewed as a natural process for people in a long-term relationship together. An impairment and related disability may have **resulted in one person relying more heavily on their partners' income than they** may have done without such circumstances but was accepted without apparent rancour or debate. For instance Patrick and Molly had moved home, to a more accessible one, ensuring that they stayed in the same catchment area for their greatly valued GP. This move was primarily for financial reasons as Molly had given up her job as a teacher to care for Patrick (Final Interview).

Practical support was greatly valued by the participants and undertook a wide range of activities. Sometimes such support related to physical actions, but predominantly the support was about a range of activities which showed a holistic **understanding of their partner's needs. For example, Susan's husband opened doors, vacuumed, carried shopping and was mindful of his wife's discomfort and physical limitations on a daily basis. Edward's wife read papers to him,** guided him when not at home and learnt to drive in her sixties so the couple could continue to have access to a wider range of activities.

All participants with partners stated their recognition of and gratitude to their wife or husband, (the participants with partners in this research all being married) as well as to friends and wider family who supported and encouraged them in their endeavours. Those with husbands or wives appeared, therefore, to have a person

around with a detailed understanding of what it was like to live with impairment, consequently the level of support that they had seemed to be much more intensive and widespread than those participants without partners.

**Some Local Authority employees, medical professionals, friends and in Fred's case** a Trade Union representative, also offered practical support. These again were very broad in their nature, but included directing participants towards benefits to which they may be entitled, completing forms, representation at tribunals, moving house, and helping with shopping. The inclusion of Local Authority employees and medical professionals here recognises that these individuals were, in the perceptions of the participants, going over and above their duties with the support that they offered.

**For example David's sister, her husband and adult child all worked together to help him move area. David's previous house had been in a relatively isolated area** with irregular bus services into the city centre. The new area David moved to was much more central and closer to his sister and family. As discussed earlier, the emotional support network which David identified when moving to this area was very important to him, but the practical assistance of having a support network who helped move furniture, furnish a new dwelling, and find local trades people when required is substantial in itself. For example, David described how he had been trying for some time to get his phone connected without success.



*"I'd been having confrontations about this dozy phone with people from Mumbai to Belfast but my sister, perhaps with an eye on her phone bill, sent me about my business and sorted it out within an hour."*

(David, Letter Entry, 5.5 of 6)

Previously David had been repeatedly stressed and frustrated when trying to resolve such issues. But such practical support options gave the participant recognition of how important these were.

*"I've tried to show that there are intangibles, in this case a family, that can alleviate the hardships associated with a perceived impairment."*

(ibid)

#### **7.4.3 Sources of Support as Means of Access to Information**

A pattern which is emerging throughout the analysis is that of knowing where to go and how to access information. This was demonstrated in the section at page 231 relating to getting help. It is understandable therefore that the participants should rate so highly those support mechanisms that offered information and insight into what opportunities were open to them and how to access further resources, information and where appropriate financial assistance.

**Susan's involvement within an occupational advisory team in the third sector** began as a voluntary role. She originally began working with the organisation around three years after her tenosynovitis had been diagnosed. Susan had initially sought advice herself relating to work and health and felt when able to do so that she would undertake voluntary work supporting people in similar situations. Over

time paid work had developed from her original role. By the time of the initial interview, Susan had a range of roles both voluntary and paid around health and related advice, and supporting people, evaluating services and R.S.I. group.

Susan was quite clear that she would not have been able to get all the support she needed without the knowledge she had developed through such roles. She perceived her access to information as entwined within the work she undertook, both voluntary and paid and the knowledge she developed as a result, citing in particular one individual she worked with who helped her develop her skills.

*"But unless you know about it and you ring them, you don't hear about it. You know, I wouldn't hear about stuff if I wasn't working at XXX."*

(Susan, Initial Interview)

It was through an impairment related support group that Patrick and his wife learnt about a broad range of resources to which they may be entitled.

*"There was obviously lots of people on our situation there and they would say things that they received and didn't receive and the courses they'd been on and Patrick and I just sat there with us mouths open"*

(Patrick's wife Molly, Initial Interview)

This illustrates that for some participants support groups offered a range of information and ideas that did not appear available otherwise. The arbitrary nature of accessing information is reinforced, together with the idea that individuals in similar situations can offer support that would not be available otherwise.

#### **7.4.4 Sources of Support as Means of Developing Coping Skills**

Support for some people involved in the research included developing skills for themselves, in addition to gaining information from external sources. The conclusions of this analysis will show that the development of coping skills was something which most participants developed or strengthened throughout the research period.

The most obvious manifestation of such skill development arose through pain management / expert patient programmes. Both Susan and Fred attended these and repeatedly referred to the positive changes they encountered as a result. Fred, who was at an early stage in seeking support and personal understanding about how his impairments affected him, saw some personal positive changes through attendance.

*"It gave me a lot of tools to help myself and you meet other people with **similar conditions** and it helps you start to get clear in your mind what's happening to you and accepting it."*

(Fred Final, Interview)

After completing the course Fred later went on to train and co-facilitate the course for others in the future; at the end of the research this involvement in this support mechanism had built his confidence and understanding and continued to do so.

Even though **Susan's involvement in the Expert Patient Programme had taken** place ten years after her impairments had developed, it was something she rated

highly and believed had changed her outlook. The shift that such involvement **facilitated in Susan's thinking**, illustrated that opportunities to develop coping skills for people with impairments and facing disability were valued by people with very different levels of experience and understanding of their conditions (Initial Interview).

#### **7.4.5 Perceptions of Personal Support Mechanisms in Context**

Support can be seen as a very broad range of mechanisms which the participants employed when they were available. Some access to these resources was out of the individuals control; for example resources were available in some geographic areas and not in others or someone without extended family or a partner close by had fewer opportunities than those who did. The arbitrary nature of accessing support mechanisms then is reinforced.

Participants tended to be overwhelmingly positive about the support that they had and recognise and appreciate it. However, not all support mechanisms were effective for all people. For instance, **Mrs Haynes' had a generally negative** experience at a local stroke group in comparison to Patrick and Molly, who were involved in two local stroke related groups, one which they perceived as activist and one social. Although the groups were not the same ones, both Mrs Haynes and Patrick came under the same Local Authority. There are too many variables in the experiences for Patrick and Mrs Haynes to make conclusions about the nature of the groups concerned, but it is clear then that the existence of a single type of

support group alone does not negate all the barriers which participants may face. The development of skills and access to information which appeared hard to find for many participants was helped by admission to such support mechanisms as these.

Access to appropriate forms of support appeared crucial to participants. It was something everyone involved in the research viewed as vital and helped participants move forward. For instance, without financial support from her mother, Flavia would have lost her home in her own estimation. The practical help **which Susan's husband was able to offer** allowed her a much greater range of independence, indeed in every single diary entry Susan ever made reference was **made to her husband's support. Edward, Patrick and Fred all made regular** statements that without the support they had from friends and family they could not imagine how they could face the barriers they encountered when attempting to access governance structures, services and information.

## **7.5 AGENCY**

Throughout the research participants outlined recognition of their agency or the lack of it. For many this was articulated by a sense of powerlessness when they lacked agency and a greater sense of value when they found they had the capacity to affect change within their own lives and other peoples; as Fred described it when referring to his voluntary work with other people experiencing **substantial pain, "at least I have something positive in my life" (Audio, 1.5 of 6).**

The effect of the recognition of the agency or lack therefore depended upon whether agency was perceived to be possible or perceived to be blocked. For those participants who were most involved within the diary process and particularly those who were at the initial stages of negotiating with provision or lack thereof, it is easier to see a sense of progression involved in the development of irritation in relation to agency and an urge to do something about this. In the later months of the diary process more exploration of the extent of perceived individual agency was articulated.

The nature of the lack of agency varied a great deal. The physical effects of the impairments and disabilities which people encountered did cause frustration and difficulty in accepting limitations in what and how people could live. However, this was something which people began to learn to accept overtime:

*"You know so I think it's time, I started acknowledging myself that I do have problems and I should start using things [adaptive aids] to help me."*

(Audio Entry 4.3 of 6 Fred)

However, it was the injustice which people perceived in respect of decisions made by other people or agencies who did not recognise the nature of the challenges the participants were encountering which caused the greatest amount of comment and frustration. I will be returning to this subject in Chapter Eight to

demonstrate how these challenges to entitlement and identity shaped participants experiences, and how the support or lack that they had also shaped their understanding of the agency which they perceived themselves to add.

## **7.6 CHAPTER SUMMARY**

This chapter has considered themes of analysis arising inductively from the data and from the interactions between the participants and myself. In Chapter Eight I will reflect on the data collection method and show how the themes analysed can appropriately answer the research questions. Further I will demonstrate how through understanding the identity transition and challenges a person with acquired impairments may encounter, the negative effects of these processes can be mitigated and participants can find their way through the complexities and stigma of disability and seeking help, information and resources.

## **CHAPTER EIGHT - DISCUSSION AND FINDINGS**

### **8 INTRODUCTION**

Within this chapter the data collection method is considered. I introduce a series of models relating to the themes which have been analysed within the research and demonstrate how these answer the research questions. I then introduce and discuss the Process of Disillusionment: a concept and model which encapsulates a common course of negotiation and demonstrate how participants employed this process to test, develop and strengthen their agency, thus leading to possible ways of resolving the challenge. Later in the chapter I reflect on the research and how this has impacted on me personally.

#### **8.1 COMPARISON OF DATA TYPES**

In response to research question three, relating to the methodological choices made within the research, findings show unsurprisingly that different methods could be seen to produce different kinds of data; here I describe the data types arising from the diary processes. For example, below are two pieces of data collected from David. The first form of diary collection was email and the second form used was hand written letters. David used email for the first two and half months of data collection. During this time email communication **was 'lost' or** accidentally erased on three separate occasions which caused David some real frustration. When a connection problem at home meant he lost Internet access for



a month, he began handwriting his diary entries. There were significant differences in the data received and so we discussed these on the telephone the following week. There were merits in both styles of data collection: the immediacy of email and the depth of reflection in hand written letters. Consider these examples of email and letter data types respectively.

The email accounts which David sent tended to be briefer and move quickly from one topic to another, while technological problems often resulted in loss of immediate data entries. For instance an email entry stated

*"I've just completed the first bit of the diary but it's vanished into the ether and I'm too despondent to set to and do another. I'll send you something next week so don't think I've forgotten. I'm mad as anything."*

(Email Entry, 0.5 of 6)

This was a humorous account of one of the difficulties David encountered as he did not have a driving licence or passport, which he submitted via letter.

*"The woman could have ticked the box but chose not to. She went tale bearing to an authority figure who came to look me up and down and **decided I was a little old white man who wasn't going to spend it all on bombs and veils for Arabs.** Nobody asked me my security questions, nobody looked at my bus pass or my University card, all they wanted to see was my driving license, **I've not got one** - so they gave me all the money anyway."*

(Letter Entry, 4.5 of 6)

**This humour was very much David's style in all contact I had with him, however** by handwriting his letters it also allowed him, in my opinion and by his own account, to think more deeply about the points he was making and so resulted in a more reflexive style of data. David described this in a telephone conversation as

a process “*that gave me more time to think about what I want to write*” (2.5 of 6).

Two participants, both of whom decided to use emails as their primary form of diary data collection were unable to maintain this method. Both Marie and Flavia at the initial stages of the research sent emails of diaries which produced data of a high quality. However, problems with the Internet and life events made it hard for them to maintain this involvement. When Flavia got into financial difficulties she was not able to continue to access to the Internet, while Marie encountered computer viruses early on in the data collection period and simultaneously **encountered many ‘medical problems’ in relation to her daughter Hermione (1.5 of 6)**, which affected her ability to maintain a diary. As considered below I made continuity calls around every two weeks in order to give feedback in relation to the research, clarify issues of ambiguity and offer support to the participants, this gave me the opportunity to discuss the process with the relevant participants directly.

Marie explained that supporting her daughter, particularly in recognition of **Hermione’s severe and enduring pain, left her little time to reflect in diary form.** Marie became the primary informant in reporting the circumstance and experiences they encountered, she still wanted to be involved and we agreed that when I spoke to her on the telephone we would use the opportunity to catalogue the events which had happened recently. With her agreement I recorded the

**conversations and as much as possible tried to record Marie's experiences rather than direct her in any way.**

Flavia was struggling with a lack of support, regular panic attacks and other symptoms while attempting to complete her degree. While the loss of her Internet access at home primarily stopped her from sending emailed diaries, the symptoms she was experiencing made it hard for her to maintain focus at this time, as she explained in a telephone conversation three months into the data collection period.

**The level of involvement required in capturing Marie and Flavia's experiences** was a very different one from the other participants; for while many of those involved used a range of different diary methods, they undertook their diary process without direct intervention from the researcher. The use of telephone recordings as diary data therefore unquestionably affected the data as speaking to another person while articulating your thoughts, but I argue this does not negate its value. I did not want to end the research with Marie and Flavia because the methods available were not viable for them. The use of diaries can only be fully explored and the individual needs of the participants recognised by facilitating as broad a use of different methods as possible and evaluating their efficacy. Flavia also gave permission at the end of the research period for me to use the data from a notebook she had used throughout the time period. The notebook was a collection of her thoughts and her attempts to clarify and articulate the effects of

her conditions. This data was used predominantly to explore the thought processes Flavia was experiencing during the data collection period.

### **8.1.1 Audio Diaries**

The audiotapes which three of the participants used varied greatly in terms of the individual concerned and how they used them. For example Richard produced entries when he felt this to be applicable. He would record his entries sporadically throughout the month when he experienced events which were significant for him. Richard also listened back over the audio diary at the end of the month and gave an overview of what had happened and how he was feeling.

***"Really, that sums up September. It's now Monday 30<sup>th</sup> and very little has happened to me personally. I get very wound up by being on my own so much and I do go out and try and mix with people. I've got a few friends around and mostly we do things on the phone or by texting and emailing, but I spend an awful lot of time in here on my own and I must admit it is beginning to get me down. Something must be done about that as well because the University is only once a year and we don't see each other that often. So I've been feeling a bit under the weather you know, a bit down hearted. Thank you for your call not long ago and I look forward to speaking to you again sometime, fairly soon Joy. That really is the essence of this month's tape and so I look forward to doing an October one for you."***

(Richard, Audio Entry, 3 of 6)

Fred was much more structured in his approach towards diary entries and added entries most days, except over weekends when he would fill in any events which he viewed as relevant on Mondays.

*“Thursday the 20<sup>th</sup> I’ve been gone swimming yesterday my right shoulder and my lower back has been absolutely terrible. I’ve got a cramp in my thighs, my calves, my feet I’ve not been this bad for a few days. It’s just a one off and hopefully I’ll feel better. I’ve got a FS p1 form from my employer today. This form I’ve got to fill it in and return it....”*

(Fred, Audio Entry, 1.5 of 6)

His audiotapes began purely as factually based, but within a month of entries, Fred also began to express his frustrations and emotions more overtly. This could be as a result of a greater willingness to open up as Fred became more familiar with (and felt more comfortable with) the research process, or that he experienced a greater range of frustrations and emotions as he negotiated with governmental structures. I believe that it was a combination of both elements which caused him to say for example;

*“When you’re having to use your savings and relying on people, it just doesn’t seem fair. I know that once my claim’s processed, any of that pay will be paid, but it just doesn’t seem right. I think the whole way you start a claim from start to finish is just very poor and they just don’t seem to give a monkey’s about the individuals on the receiving end of this. I know they’re doing a job and don’t want to get involved with individuals, but it is just so unjust, especially when I’ve paid my taxes and insurance all my life, thirty odd years and the first time I’ve needed some help from them, it’s just been bloody horrendous all the way through.”*

(Fred, Audio Entry, 2 of 6)

Susan completed audio diaries in a very different way, sometimes undertaking several entries on the same day and apart from on holidays, never failing to complete an entry. She tended to use the diary in a much more conversational manner, discussing family issues, a wide range of activities and even soup recipes! I felt that the process of diary keeping appeared to be beneficial to the

participants as well as to the research process and the discussions of domesticity gave a wider depth of insight into how her impairments affected the participant on a daily basis and the range of support mechanisms which Susan employed. The nature of the data therefore often required longer time to evaluate and in particular to find specific barriers and instances, this did not however negate the value of her contributions. Susan also asked for a copy of her transcript when the data collection period was complete to help her evaluate her journey. She only used emails in order to send copies of documents or data that could not be sent via tape. While some of these areas did not directly impact on the areas I hoped to explore, I made the decision to not challenge the way Susan used the diary method.

### **8.1.2 Email**

Patrick used email as his only form of providing data throughout the data collection period. The stroke had resulted in Patrick experiencing both mobility and speech limitations, bearing this in mind, email entries were the only option open to him. His emails were generally brief and factual including information regarding specific events or activities. Patrick wrote his own entries, after which Molly would add additional comments to provide context or explanation if necessary. In order to make clear who had made what statements Molly put her **additional statements in red so the different 'voices' could be distinguished.**

Patrick emailed the entries and so had control over what data was sent, this ensured that his voice was heard, but Molly (as the only other person with specific

understanding of the subject matter) was able to assist in making data comprehensible to the researcher. For example

*"Anycity Stroke group – the lesser that's said here the better I will become. Mark [Molly's additional comment (The chairman and co-founder)] irritates me I can't speak when he's there. It was a good attendance though....."*

(Patrick, Email Entry, 3 of 6)

A greater consideration of how the involvement of Molly affected the research took place is considered below in this chapter in a section entitled Interpreter or Mediator?

## **8.2 KEEPING IN CONTACT**

Interim telephone contact, as outlined above was used throughout the six months of data collection. This varied between individual participants, as some people seemed to appreciate more regular contact, while others preferred perhaps monthly conversations. All participants required feedback in the first month or two of the research to ensure that their diaries were appropriate. After this time however some people who were out when I called did not respond, while others would ring or email as soon as they returned to arrange another date for contact. The interim contact ensured that participants recognised that the contribution they were making was being used, considered and valued throughout the process. It allowed them the opportunity to ask any questions and through this to explore the research process for themselves. Many participants at the start of the data collection period wanted to know if what they had sent me was alright and receive some form of direction. I was aware of my relative power as a researcher in that

whatever I said could shape the data which was collected. I made the decision to suggest areas which they may want to include, generally by discussing the areas included on the prompt guides discussed earlier. However, I did not direct participants away from any information they chose to give me. The implications of this decision were that the amount of data received was extremely high; prior to analysis I transcribed over 300,000 words of data. This is considered at the start of the analysis section. Some participants were more interested in the process of research than others, but I made available a written outline of the research process at the start of their involvement, (see appendix I) and discussed it with participants who asked about the wider process of the research.

The on-going contact between us inevitably meant that there was a developing relationship between the participants and myself. I recognised that within this research the relationship was likely to have been significant. This relationship based research practice often meant that people were more able to understand what was being asked of them, felt an important part of research which they hoped may improve experiences for other disabled people in the future. They also appeared to develop a sense of security in the researcher. They could give what information they wanted and retain for their own security whatever they wanted to keep private.



### **8.3 INTERPRETER OR MEDIATOR?**

There were three people who could be considered to be interpreters or mediators of experiences within this research: **Marie, Molly and myself**. **Patrick's stroke had** a number of long term effects including substantial aphasia. While he had had additional therapy to improve the fluidity of his speech patterns whenever possible, there were many occasions when his speech was disjunctive and sentences could not be constructed. This meant it was extremely hard at times to understand what Patrick was trying to say. By its very nature therefore discussions with Patrick involved a larger process of interpretation than a standard interview. His diary content required me to look closely at the data, the context provided by Molly (his wife) and to continually interpret his emails to grasp the meaning of what he said. **Patrick's aphasia affected his written words as well as** his speech, but as he was able to take as long as he needed to reflect, search for the relevant word and organise his thoughts before he sent them to me, he had greater control in how his data was presented. His primary interpreter throughout the data collection period, **including the interviews was his wife Molly**. **As Patrick's** wife and carer, **Molly had a unique understanding of Patrick's speech patterns and** professionally had also worked in education with young people with learning difficulties for a number of years. I had spoken on the telephone and via email to both Patrick and Molly prior to the first interview and so understood that it may be necessary for Molly to support her husband in order for him to take part in the research and that both parties were happy to be involved upon such a basis.

**In order to ensure that Patrick's views were the ones which were expressed I was** conscious that his experiences and the data arising would be mitigated through my interpretation, as were all participants, but also that it would also be mitigated through the dual process of interpretation; first through Molly his wife and then through myself. At one point Molly left the room to make a hot drink for us all, and it became clear that without her involvement Patrick and I could not communicate with each other. Molly was vigilant to ensure that she did not put **ideas into her husband's mouth. Always initiating her statements with 'did you mean' or 'I think Patrick felt x, is that right Patrick?'** Indeed on the few occasions that Molly was giving her own views, she always ensured that she made it clear that it was her opinion alone.

**One of the ways I verified that Molly's interpretation of Patrick was accurate, is** the speed at which he would refute statements if they did not reflect his perspective. Consider this element of transcription for example.

*P: No er, we went back to (pause)*

*M: (laughs) We went back to see Mr Ashenworth*

*P: yeh*

*M: Is that what you mean?*

*P: Yeh*

***M: Yeh, but we didn't see him did we?***

*P: No, er, we got one of his henchmen*

*M: Yeh*

*P: Erm*

*M It were a lady*

*P: No!*

*M: oh sorry, sorry go on, yeh*

(Patrick, Final Interview)

As Molly spoke she was quiet and her tone was that of a prompt rather than imposing her understanding on the situation. I reflected upon these circumstances and was satisfied that the data I received did have merit despite the necessary mediation of Molly. Instead her involvement provided context and allowed a broader range of ideas to be explored than if she had been excluded from the process.

**Marie's role may be perceived initially as an ambiguous one, she described** events which happened to Hermione and the family as a whole rather than herself. **Furthermore because of Hermione's** decision to not take part in the research all perceptions of what happened were from Marie's point of view. **I saw Marie as a participant in her own right, as a carer and as a parent. Owing to Hermione's age** and the pain and changes to her body she was encountering, Marie and her husband were often the people negotiating with the governmental structures themselves rather than their daughter. Marie spoke of her own perceptions and experiences; I did not feel that she attempted to speak for Hermione, she recognised her daughter was growing, developing her own voice and identity, Marie tried to support her that need to develop independence wherever possible. **At no stage did Marie state, 'Hermione felt'..., without predicating such statements with 'I think', or 'having spoken to her'. Essentially Marie clearly set her boundaries and tried wherever possible not to speak for her daughter without Hermione's agreement.**

The researcher in such a piece of qualitative research is (as discussed within Chapter Four) inevitably a mediator of the data they interpret of that data into analysis and findings. Only by making the process and decisions which I undertook as clear as possible can I be sure that the reasoning behind my choices and direction within the research is made transparent to the reader.

#### **8. 4 PARTICIPANTS' ENGAGEMENT WITH REFLECTION - INSECURITY**

The data collection process within this research by the very nature of diary use facilitated personal reflection amongst the participants. Here it is considered in relation to the area of insecurity.

Insecurity is a complex word to define; it can be referred to an individual '**Julie seems quite insecure**'. In such terms it is a personal characteristic and may have negative connotations. However, insecurity in other contexts does not imply a personal responsibility for the event. In relation to employment for example, insecurity can refer to that which is imposed upon a person from an external source, such as '**there is insecurity within the job market**'.

In terms of this research, insecurity regarding disability was the predominant language of personal reflection, which appeared to primarily be caused as a result of external sources. Participants questioned their disability, though not their impairment. This involved the right to be seen as disabled, and to be believed when explaining their impairments and disability. It was particularly evident for

those people with invisible impairments; it was most notable therefore in respect of Flavia, Fred and Susan. While for David, the reaction he perceived from people when he spoke of his epilepsy was negative throughout the research period. The internal responses which participants outlined were almost always as a result of expectations brought about by prior experiences and negative situations which were imposed upon them.

The difficulties participants encountered in terms of accessing services and information also reflected upon their own relationship with disability. Both Fred and Flavia, for instance, asked people they perceived to be professionals whether they were disabled. It was not a decision they felt they could make for themselves.

The more participants failed to get help when they sought to access it, the less secure they became about their position. This was ameliorated for some participants through external support mechanisms, having loved ones close by or support networks of friends, disability support or access groups. The opportunities gave some participants additional perspectives, ideas for solving the problems they are facing or the feeling that someone was fighting for their corner.

The choice here is intentional; the literature review within this research looked at different models of disability, and if I were to consider internal attitudes from an individualist model this could be seen as akin to the medical model. I assert that it

is not the individual who has the disability; they have impairment(s) and are disabled by society.

**Note that although the themes of 'participant engagement in reflection' and 'informal support mechanisms' themes have been analysed separately,** the two have become intertwined within the responses to such a degree that it is helpful to see them as a symbiotic pair. Both of which relate to research question two regarding disability and identity. Support mechanisms and the language of personal reflection around insecurity are themes which relate individually to the participants; as such they can be seen to be shaped to some degree by the personal choices. I say to some degree, as personal circumstances which were beyond participant control produced a limitation of mechanisms. For example, Mrs Haynes had no surviving parents or siblings and as a single woman with no children, familial support was not available, Richard's impairment resulted in challenges to communicating with new people, which in turn limited his opportunities to extend his friendship networks.

The barriers considered previously affected the choices which participants felt able to make. For instance facing financial difficulties and not being able to get help when seeking it as a result of procedural barriers often impacted upon **participants' internal attitudes of themselves, such as Fred.**

*"When you can't get the help you need and there seems nowt you can do about it, you end up feeling scared about what's going to happen and useless."*

(Audio Entry, 4 of 6)

It is evident both in terms of barriers and support mechanisms that participants encountered, that in this context, individuals could make a huge difference to **participants' experiences. Within the research, health professionals were** the group who were most often cited as presenting professional and cultural barriers to participants, as well as one of the groups cited as offering the most support. The table at the start of the professional and cultural section illustrated that all the participants except one, specifically mentioned the health professionals and cultural attitudes as either barriers or support mechanisms they encountered, in particular the power which medical professionals were seen to hold was substantial. This reliance on how others perceive and define an individual can reinforce the stigma so often attached to disability, and in turn shape how individuals perceived their own situations.

## **8.5 EFFECTS OF INVOLVEMENT WITHIN THE RESEARCH**

The six-month data collection period began and ended with semi-structured interviews, this was explained to the participants prior to their involvement and such a structure was intended to facilitate the participants reflecting on their experiences throughout the process. They were also informed of the intention of the research as considered in the methodology section and below. In light of this,

the participants can be seen as co-producers of the knowledge that arises from this research. This will be considered in more detail at the conclusions of analysis section.

Earlier in this thesis I described how uncomfortable I felt at asking the participants to take part in the research without being able to offer them financial recompense and the ethical issues I had considered when asking people to talk about difficult, sometimes painful, things which occurred to them. However, at the end of the research within the semi-structured final interview I asked the participants to reflect on how they had found the diary process. The response was overwhelmingly positive. Of the eight participants who completed the data collection process, all said that they had gained something by involvement with the process. While this may be linked to a desire to please the researcher, it was something that many involved in the research appeared to be very enthusiastic about. Indeed Fred, David, Edward and Susan had all commented within the diary period about how helpful they had found their involvement. In terms of the diary method in particular, the main reason for valuing involvement was that it allowed participants to reflect and bring together thoughts which would not have been fully articulated or expressed otherwise. Of the eight completing participants five highlighted this as a significant factor in why they had valued their involvement. In comparison Flavia, described that the main reason she felt the diary method had not worked for her was that her thought processes were so fractured that she **couldn't get it done 'correctly' and she was worried that she would appear "like a bit of a cubist portrait"** (Final Interview). The recognition that taking part in



research can and does have an effect upon the outcomes is well established and many researchers have explored the implications for validity in acknowledging this (Maxwell, 2002:43).

Richard and David at the final interviews spoke about the involvement being *“great fun”* which they were glad they had undertaken. While all the others spoke of the reflective powers of their involvement. Marie also said that she felt it had **allowed her to “disgorge”** at times of crisis. Fred also commented that being **involved in the research had made him feel like a “trailblazer”** and so given him the confidence to challenge and push ahead in areas where he may have hesitated otherwise. Patrick spoke of his confidence increasing through writing and reflecting, though it had felt like hard work at times, while his wife Molly also reflected how positive she felt it had been for him.

The responses suggest that the process of involvement and of maintaining a diary had generally proved to be a positive one for those people who were involved and in particular in allowing them the space to reflect on what happened to them. From the research perspective, the range of data and insights gleaned from working with the participants proved an effective way of developing a wealth of data. The analysis of which will now be distilled and developed into findings.

## **8.6 USE OF A BARRIER MODEL AS A THEME OF ANALYSIS**

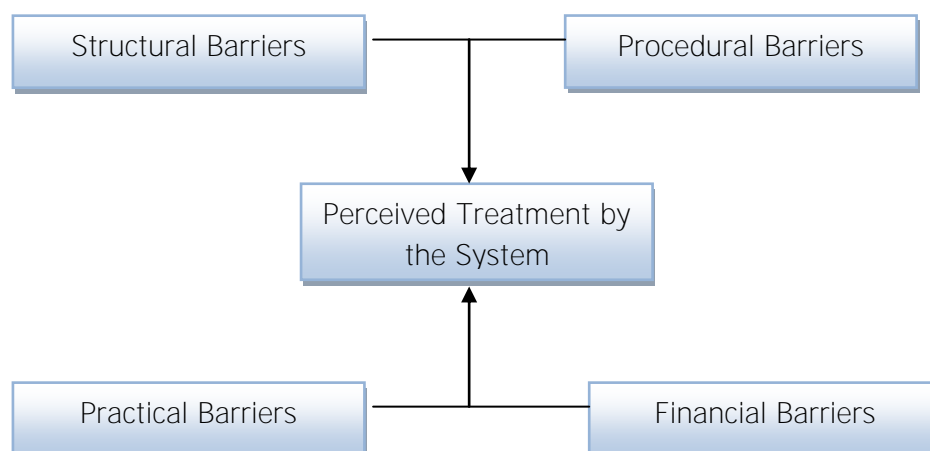
Within this research I have predominantly focussed upon barriers to be faced, rather than the support offered by professionals. There were two reasons for this decision. Firstly, it is recognised through previous work that service users encounter barriers in seeking information and in claiming benefits (Moore et al, 1994, Sainsbury et al (2003).

The second reason that I chose a set of barrier themes as a way of analysing the data related to the volume of barriers which the people taking part in the research encountered. Participants within this research did at times receive good services, information and support for which they were generally grateful, however the prevalence of barriers meant it was much easier for them to identify when obstacles were encountered rather than assistance offered.

## **8.7 APPLYING THE THEMES**

The themes which have been analysed within this research are now condensed into the two models below to illustrate how the combined effects of the barriers can increase the challenges towards accessing services, information or support in the short-term. However, these models also demonstrate how long-term effects of encountering such barriers can culminate in perceptions within participants about the individuals and systems they are negotiating with. These models are then applied to the research questions of the thesis.

### ***Perceived Treatment by 'The System'***



*Illustration 14 – Perceived Treatment by the System*

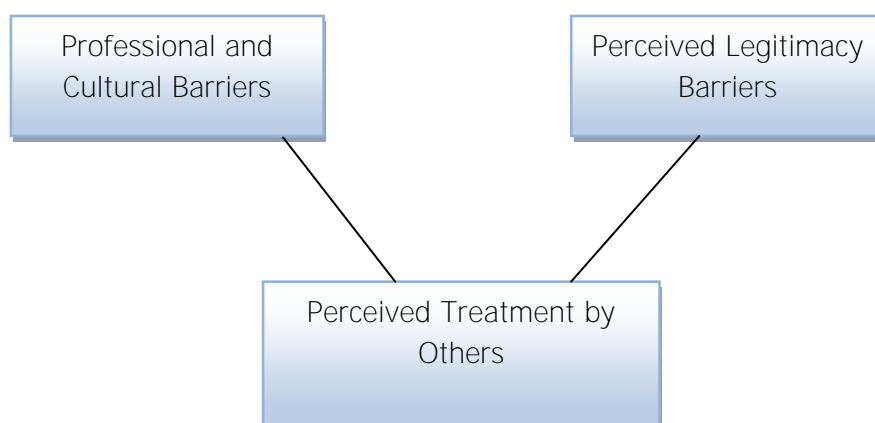
The barrier themes which have been analysed within this research are now condensed, in order to recognise larger patterns which may shape disabled **people's experiences of negotiation and seeking help**. They are combined as follows: structural and procedural barriers become one larger theme; these were areas with similarities when they were presented within the analysis, and are at times nebulous to unpick and define when encountered by people seeking access to services, support and information. Practical and financial barriers are also joined together and create a second larger theme; these were barriers which were often the most easy to identify and created a tangible obstacle.

The complex interplay of structure and process, combined with the evident and immediate nature of practical and financial barriers created for participants a **perception of how they are treated by 'the system'**. From the participants' perspective, these barriers were not related to how they were perceived

individually, but how participants saw individuals and agencies within the system as operating. The four barrier themes presented above, therefore shape how the participants perceived they were treated by the system. In terms of the critical realism employed within this research, the individual can be seen as the person at the centre of each of these models, in this case, perceiving the system from within. The barriers that shape these perceptions are the social reality which surrounds the individual perceiving events as they occur in her or his life.

**'The system'** as presented by the researcher, and demonstrated through the **participant's perceptions**, in this context acknowledges the plethora of systems: a vast complex entity which was seen as immensely daunting by the people who took part in this research.

### ***Perceived Treatment by Others***



*Illustration 15– Perceived Treatment by Others*

The theme of professional and cultural barriers has been aligned to that of status and legitimacy. The similarities between these barriers overlapped considerably,

both within the evidence presented and the resulting outcomes for participants. In light of this these will be amalgamated into a single theme relating to the common element between these areas: attitudinal barriers. It is this larger theme which is considered within this model. Together these attitudinal barriers represent some of the ways in which participants felt others perceived them. This, in turn, shaped the expectations and perceptions of the participants when negotiating further with structures in the future. From a critical realist perspective, this model representing **the individual's perceptions about how they were treated by others** challenged the idea of how much agency they individually held.

The attitudinal nature, of an individual or organisation, is often unspoken and so it is hard to **ascribe any definitive 'intent'**. **What has been shown here are the effects** of such behaviour upon the participants and how these were perceived. It is evident from the analysis considered that many barriers in relation to this area incorporated some degree of expectations about how the participants, disabled people and claimants in general, should behave and how they are viewed. It is also **difficult to define explicitly what any of the discussed organisations' values** are, but again it is possible to illustrate how participants perceived them. The professional and cultural barriers encountered often related to assumptions and expectations on the part of the professionals concerned and the cultural values exhibited within these professions; while the theme of legitimacy illustrated governmental structures and representatives making judgements regarding participants. Further consideration of these models and other themes of analysis,

are incorporated into the discussion of how the findings address the research questions.

## **8.8 ANSWERING THE RESEARCH QUESTIONS**

In light of the analysis and models presented to assist with interpreting the data, the original questions asked in the research can now be considered.

### **8.8.1 Research Question One:** *What factors affect the expectations of, and services received by the participants?*

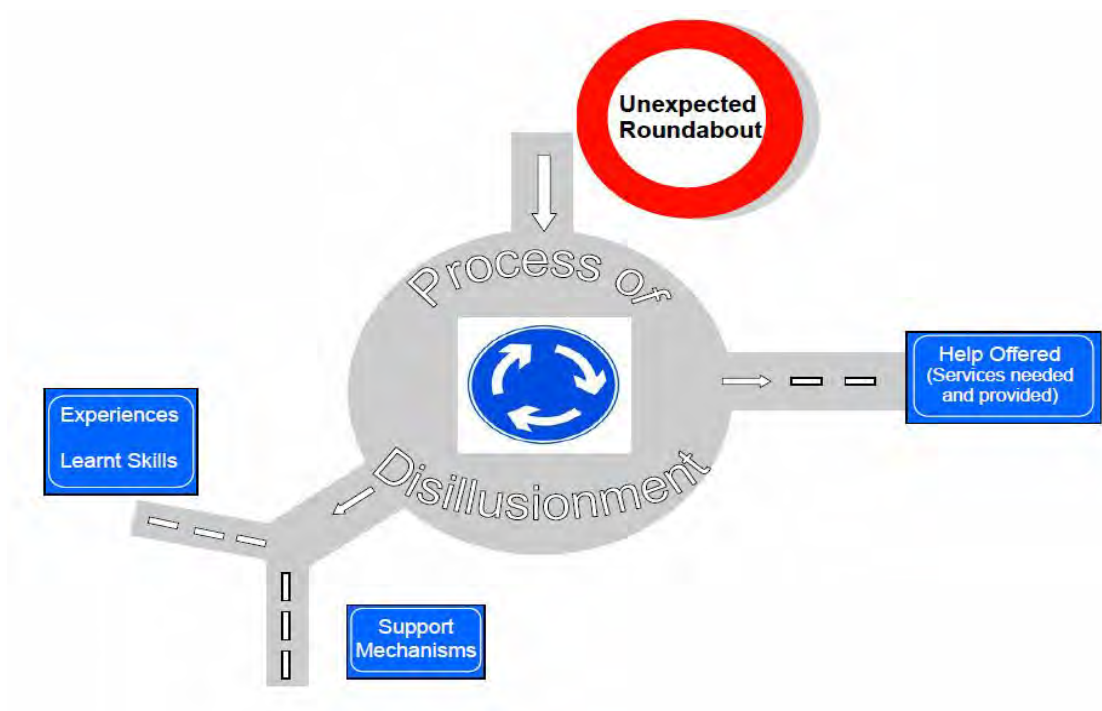
The experiences of, and services received by the participants varied greatly depending on many factors. The variables upon which the expectations and **services were dependant included the nature of an individual's impairment, their** personal support mechanisms, and what barriers and / or professional support they engaged throughout the process.

The barriers which participants encountered affected their expectations and services received and naturally participants encountered different barriers at different times. Some barriers tended to be impairment specific: for instance many practical barriers regularly affected Richard, while attitudinal barriers were evident particularly in participants with invisible impairments. However the single barrier encountered by all participants most often was that they did not know where to look for help or information when it was needed.

The model above gives an indication of how the perceptions of the participants can be seen in order to interpret to their experiences. Participants predominantly began with the belief that support was available to them and over time became increasingly frustrated when barriers became apparent. This can be demonstrated through the process of disillusionment represented and discussed below.

### **8.8.1.A The Process of Disillusionment**

The analysis of the data revealed that participants encountered a range of barriers and, on some occasions, opportunities to resolve these barriers. When barriers were not resolved, the result was often participants experiencing a process of disillusionment. If people negotiate with governmental structures who they have not encountered before, much of their perceptions are likely to be based upon their initial experiences with those structures: these perceptions are harder to alter in the future. If those experiences are negative, therefore their perceptions of those structures will also be negative and they will seek instances to support their perspective. Their attitudes towards authority and structures and their willingness to challenge and engage will be dramatically weakened. It will become harder for people encountering such circumstances to confidently or assertively relate to those structures, or to representatives of government related agencies who they may see as part of the negative structure, and so a self-fulfilling prophecy can arise.



*Illustration 16- Process of Disillusionment*

Participants expected that they would look for the services or information which they need and would find and receive the necessary support, help or information. However, as the analysis demonstrated this was seldom the case at an initial stage of approaching such structures; hence the roundabout represented above is an unexpected one for people seeking support and information at a point of transition and stress in their lives. Instead people can encounter a loop of seeking help, being refused that service, or having access to it blocked by barriers. They are therefore unable to go any further forward, which resonates with many of **Flavia’s experiences for instance, in the months in which she could not find any support in relation to her impairments.** The result is disillusionment and individuals



can remain in this frustrating cycle without obvious means of breaking out of the roundabout and moving on.

To demonstrate how the process of disillusionment relates to the experiences of disabled people, consider **Fred's attempts** to receive support and information at the early stages of having to leave employment owing to impairments. He expected to contact representatives of government agencies, get the information he required and be able to make informed decisions for himself about his next steps, as his diary entries attested. This was not an unreasonable expectation on his part; indeed previous academic work suggests that service users do not generally have high expectations.

*"People's expectations and demands for services are usually modest; a broad look at their circumstances as a means of equipping them to make an (sic) informed choices about requesting help."*

(Ellis, 1993:42)

However as Fred contacted agencies and was unable to get through, or representatives of governance structures undertook to call him back and failed to do so, he became increasingly disillusioned with the process. He encountered practical barriers, such as the venue in which the appeal in relation to Disability Living Allowance was held being inaccessible. Financial barriers were evident when he received no financial support during this time and expressed real concern in relation to this while his claim for Incapacity Benefit (IB) was being processed. Cultural and professional barriers were presented in the way his invisible impairments were perceived by some members of the medical profession and

procedural barriers were evident, for instance in the way in which his IB was processed in a system which was complex and opaque to Fred.

It is not only the barriers which participants encountered therefore which shaped their expectations, but the process of disillusionment itself. For as a person became more frustrated by the process and cynical towards it, the harder it became to expect to receive and / or demand provision. In terms of wider society, having individuals disillusioned with the system and support they receive has negative consequences. Disillusioned people are less likely to become involved or engaged in activities and disengaged from wider social involvement or political interest (Oliver and Zarb, 1989). They are also less likely to want to return to the wider environment, such as work or become proactive in many other improvements which they may be able to make in their own lives (Pinder, 1995). The barriers and process of disillusionment that disabled people can encounter then has negative effects for them as individuals and also for wider society.

The participants, as has been illustrated, all experienced a range of circumstances including barriers, resulting in frustration and cynicism on the part of those involved in the research. The loss of confidence in the system led to participants becoming less willing to engage and becoming cynical towards the very structures **they encountered; 'cynical' being a term regularly employed by participants within** the research. This was particularly evident when the barriers people encountered appeared to be personally motivated and related to how they were perceived by

others, rather than impersonal obstructive bureaucratic practices of the system. This will be referred to again in relation to research question two.

There was no doubt that participants felt lost and frustrated with elements of the system and the powerlessness of being perceived as a passive recipient, rather than having any influence over the processes which happened to them. The gap **between people's expectations and actual services and support they were able to receive** was substantial; the recommendations section at the start Chapter Nine will consider how a more specific assessment of this relationship may be developed.

**8.8.2 Research Question Two:** *'how are self-perception and identity affected by encountering disability and the resultant treatment?'*

**People's self-**perception and the language of self-reflection that they employed, particularly relating to insecurity, were very much influenced by how the participants perceived they were being treated, both by the system and by others. This, in turn, affected how much they were willing to challenge that treatment. In terms of self-perception and identity the treatment and reaction of individuals appeared to have a greater impact than the unsympathetic system itself. The most crucial barriers therefore in relation to research question three are those **defined as attitudinal barriers, those of 'professional and cultural' barriers and of 'status and legitimacy'.**

It was not encountering impairment alone that caused participants to be insecure about how they were viewed or their rights, but the way they were perceived that they were spoken about, judged and constrained by others, particularly health professionals and agents of governance structures. For instance, those with invisible impairments often had **battles being 'believed' and David felt the manner** in which he was treated by the Disability Office at his University had a hugely negative impact upon him.

A set of assumptions was demonstrated within this research, based upon professional and cultural barriers and beliefs about how disabled people should **act, and whether they 'justified' being** helped (page 270). Assumptions were also made on a system wide level, from the point of view of some participants, about a **person's intellectual ability if they** had specific impairments. For instance;

- The assumption which Marie perceived in the DSS response to enquiries, that if Hermione was unable to write she lacked the mental capacity to control her finances.
- Richard also felt an assumption was evident in relation to the Direct Payment literature, that people who were unable to read text or Braille were likely to have a learning disability.

Participants may on some occasions have had very different perspectives from the representatives of the structures they encountered and may have been inaccurate in the way they felt others perceived them. In the two examples given above, for instance it is possible to see alternative perspectives and motivations on the part

of the government agencies. For example it may be that the DSS had previously encountered situations where other people claiming on the behalf of disabled people misused their authority and took advantage of the claimant. In the situation in relation to Richard and the audio-tape regarding direct payments, it is possible that financial constraints limited the number of formats available or that the system was in its infancy in that geographic area which meant an appropriate format and level of explanation was not available for Richard. It is not a question **of who is 'right or wrong' in respect of attitudinal barriers, but that they cause for** the disabled person another barrier to face, in particular one which challenged them as an individual.

For many participants then the challenge they encountered was the need to be seen as individuals with a range of needs and roles, which need to be considered holistically rather than as an isolated set of symptoms or impairment. Impairment **and disability are only one aspect of a person's identity and for some** participants it was not part of the way they defined themselves. Their age, gender, ethnicity, sexuality and life experiences are likely to also shape their identity. However the way they felt they were treated by others often affected participants' own sense of themselves.

Governmental structures were often unable to recognise the whole person; many of the participants have more than one element of their identity which came into play at the same time. However, participants faced situations where the culture and structure of some agencies and professionals could not cope with multiple

elements of identity. Examples of participants having dual requirements which resulted in barriers follow:

- Richard having sight and hearing limitations and diabetes;
- Susan having tenosynovitis and an injured ankle;
- Flavia being a University student and having Post Traumatic Stress Disorder.

Each of these combinations meant that the individual had more than one facet which needed to be considered alongside other elements of their identity. These required recognition in order to provide effective support for that person.

I have demonstrated that attitudinal barriers often lead to participants questioning their rights to ask for services and help or to define themselves as disabled. However their self-perception was also mediated by what support mechanisms were available to them. If, for instance, they received what they perceived to be bad treatment, but were supported at home and in their personal life, it was much more likely that they could withstand the challenges of that poor treatment. The same could apply to receiving support from an individual within the system, such as a health professional, who may act as an advocate for participants. On these occasions how people saw themselves and their rights to good quality services were considerably strengthened, and if the services or information were not available but the professional support remain, the disabled people were more likely to continue to search for what they needed. Further consideration will occur

later in this chapter of the way in which support mechanisms could challenge the **dominance of barriers within a person's life.**

**8.8.3 Research Question Three:** *how do the methodological choices made within this research influence its outcome?*

The research successfully involved people with a range of impairments and experiences of services, facing different challenges at that point in their lives. A central issue for a half of the participants at some point, was whether or not their **impairment was believed or understood, and that 'disability identity' was not** necessarily central to them or could be questioned by them themselves and others. The research has successfully included disabled people who might not always feel that their experiences and perspectives are recognised and heard.

Working with participants over a six-month period and using a tool which encouraged articulation of experiences and reflection clearly influenced the outcomes of the research. The diary system and length of time of involvement within the research have, as shown, shaped the nature of the data received, in terms of depth and reflexivity. It is also useful to note that seven of the eight participants who completed the research expressed an interest in the dissemination of the findings. The process of reflection employed throughout the research has facilitated in some of the participants a desire to become more politically active and aware. This involvement can be viewed as an empowerment

tool with which to widen participation and result in more active and informed groups. As they can use or disregard the research as they choose, participants are left in control about how much they extend their involvement in dissemination of this research.

The participants can also be viewed as co-producers of knowledge and research findings within this thesis, in the interim contact which we had and through the elements of their lives they chose to reflect on and support, as well as those elements which they chose to not discuss within this arena. It is possible therefore that the participants could see themselves empowered by their involvement, however I need to acknowledge that participants who are engaged in a long period of reflection may not represent the majority of people seeking to negotiate with governmental structures at the point of acquired impairments.

Participants, in respect of this research self-selected, by expressing an interest in involvement. They negotiated with me in terms of the type of diary they chose to employ and have demonstrated themselves to be highly articulate, reflexive individuals who were willing to commit to **six-months' worth of involvement. It is** possible therefore that the methodological choices I have employed here shaped the research by the level of commitment and skills it required from those people who agreed to take part. However without having a data collection period of such a length and without asking the participants to recall and reflect on their daily lives when negotiating with external structures, the wealth of insight developed through the methodological choices would not have been captured.



## 8.9 WHERE DO WE GO FROM HERE? RESOLUTIONS

A range of barriers have been presented demonstrating the complexity and interwoven nature of the challenges which participants encountered. The experiences encountered by participants as demonstrated within this research are not isolated incidents; previous research has confirmed that this is a long-term problem for successive governments (Ellis, 1993; Moore et al, 1994; Sainsbury et al, 2003). It is also a set of challenges which a significant number of people face; disability is an area which affects far more people than may be initially supposed. Indeed statistical evidence suggests that over well over 15% of the UK population are limited by illness and disability at some point in their lives; based in 2001 census material and that 15% experience long term illness limiting their activities and employment (Atkinson et al 2007). This may also lead on to poverty for the individual:

*"There was more than an even chance of experiencing poverty for those disabled for three or more years."*

(Atkinson et al, 2007:52).

This is therefore a significant problem with very real impact for many people. As illustrated, many of the barriers people faced appeared to **be unintentional 'by-products' of larger systems which** were perceived as inflexible and unable to respond to, or indeed recognise the individual and at times specific nature of the

participants' needs, while others related to how wider society perceived different forms of impairment and disability.

Individuals experiencing the process of disillusionment, alongside impairment and disability, may be more likely to remain locked into battles with a system, be cynical towards that system and be unable to move on or develop some equilibrium within their lives. However, the process of disillusionment is not irreversible in every situation; consider for example how many barriers were in place when Patrick's first sought to negotiate with professionals, after having a stroke. Yet Patrick continued to seek to improve this system by his continued involvement in education and awareness raising work with medical professionals.

There are two sets of recommendations I am presenting here therefore, the first group relate to the ways in which the data demonstrated participants breaking through the process of disillusionment. The second are suggestions generated from my observations and are intended to be directed on as more strategic level, These will therefore be considered within the concluding chapter.

### **8.9.1 Three Routes to Resolution of the Process of Disillusionment**

#### **8.9.1.A Getting Help when it is Needed**

The most immediate way of resolving the challenges of the process of disillusionment and the array of barriers which participants encountered when

seeking information, support or help, was that the provision they needed could be available, appropriate and timely. For instance, Marie and Hermione felt that Hermione could no longer remain at the private school where she had previously been a pupil, owing to the physical barriers of the building and the attitudinal barriers of some of the staff. The information and support offered to them by the state school with specialist provision which Hermione eventually entered was of huge importance. It was greatly valued and ended what could have been a lengthy cycle of barriers which the family faced at the time. Provision when it was required or professional information and help when it was sought, was one of the least common ways of breaking from the disillusioning processes and array of barriers when negotiating with governmental structures.

### **8.9.1.B Informal Support Mechanisms**

Informal support mechanisms provided a range of functions for the participants. Financial, practical, emotional and moral support were often roles which were required relatively early within the process of negotiating with wider structures. Later within such negotiations many participants found the value of such support mechanisms in terms of developing coping skills or information which they had not been able to gain elsewhere.

Such support mechanisms were of huge importance to participants and of major importance in their negotiation process. The support mechanisms open to Patrick, for example, can be seen as integral in his continued improvement and ability to

challenge and attempt to shape the treatment which he and others in his situation may face. This suggests that the support mechanisms a person cultivates or has at their disposal can influence how hard they find the process of negotiation.

The very nature of personal support mechanisms is that they are ad hoc, individual and often able to respond to circumstances immediately, means that this way of breaking through barriers is of great importance. In light of these characteristics it is also a route which can be used in conjunction with any other method, in particular the final route which is explored here: that of learnt experience.

#### **8.9.1.C Learnt Experience**

As people negotiate with governmental structures seeking the provision or information that they require and identify how to access appropriate support, they learn how some elements of the system work and adapt their behaviour accordingly. For example, Susan described how she retained copies of all correspondence and requested receipts of emails she sent in order to have evidence of discussions which had taken place. This was not something which participants automatically began to do when they were negotiating with structures. But as documents were lost, or representatives of governance structures stated they had not been informed of certain pieces of information, participants began to recognise that such methods were necessary. There are two elements to the route of learnt experience which I wish to recognise here. Firstly that learnt experience can be an empowering route to removing barriers, as a

person learns skills for themselves it is likely that their confidence and ability to negotiate will improve. Secondly, however the process of learnt experience usually incorporates a process of trial and error and can be a lengthy way of learning how to negotiate with such structures, building a set of negative expectations and inevitable delays as the person negotiating learns by their experiences.

There are ways to circumnavigate the errors, frustration and time delays often associated by learning through personal experience. These relate to the use of informal support mechanisms particularly through the route of learning through other peoples personal experiences, so that it is not necessary to repeat the mistakes and delays which they encountered in their own journeys of negotiation. Within the process of disillusionment illustration (page 323) therefore there is a **'slip road' represented which allows people a way to leave the cycle of frustration** through incorporating other peoples experiences into their own understanding.

The three routes outlined here most often achieved the resolution of barriers as demonstrated through the process of disillusionment model. These are abbreviated and reiterated here for clarification:

1. Participants encountering a professional(s) willing to support and assist them; consider for instance the support that Fred received, and valued, from Dr Steele;

2. The personal support mechanisms that an individual had at their disposal or developed, such as friends, family and support groups provided a second route to transcend barriers;
3. The final common route for barrier resolution was through the learnt experiences of participants, when negotiating with structures and seeking help, through a process of trial and error.

### **8.10 AGENCY**

The two final routes outlined above demonstrate the importance of agency for the participants. Throughout the research participants outlined recognition of their agency or the lack of it. For many this was articulated by a sense of powerlessness when they lacked agency and a greater sense of value when they found they had the capacity to affect change within their own lives and other peoples. As Fred described it when referring to his voluntary work with other people **experiencing substantial pain**, "*at least I have something positive in my life*" (Audio Entry 1.6).

The effect of the recognition of the agency or lack, therefore, depended upon whether agency was perceived to be possible or perceived to be blocked. For those participants who were most involved within the diary process and particularly those who were at the initial stages of negotiating with provision or lack thereof, it is easier to see a sense of progression involved in the development of irritation in relation to agency and an urge to do something about this. In the

later months of the diary process more exploration of the effects of the agency was articulated.

The nature of the lack of agency varied a great deal. The physical effects of the impairments and disabilities which people encountered did cause frustration and difficulty in accepting limitations in what and how people could live. However, this was something which people began to learn to accept over time;

*"You know so I think it's time, I started acknowledging myself that I do have problems and I should start using things [adaptive aids]to help me."*

(Fred, Audio Entry 4.6)

However, it was the injustice which people perceived in respect of decisions made by other people or agencies who did not recognise the nature of the challenges the participants were encountering which caused the greatest amount of comment and frustration. The determination which participants demonstrated therefore was an essential element in altering their circumstances.

## **8.11 REFLECTIONS**

Undertaking this research has been an intensive process of learning for me and has expanded my academic knowledge in many areas including qualitative research and the use of diaries within social research. I made the decision to embark on research in relation to impairment and disability because I was aware of some of the challenges which disabled people encounter. The research has given me a much deeper insight into the struggles and challenges which the

participants encountered regularly and which are likely to affect other disabled people within the UK. In practical terms, the experience of undertaking a lengthy piece of research has widened my skills, in areas such as participant recruitment, ethical considerations of involvement and the practice of analysing data. It allowed me the opportunity of working intensively with participants and the challenges of juggling the expectations of the University, my supervisors, the ESRC who funded the research, the participants and myself.

The uncertainty I had about myself, prior to beginning this research, made me question my own identity in terms of impairment and disability. However, having undertaken this research I have come to understand the frustrations, doubts and disillusionment that the participants experienced, in which I was able to see both parallels within my own life and disparities. The similarities I encountered are based upon shared experiences such as an inability to access services, support **and information at the point of need and in dealing with other people's** expectations and assumptions about what people with impairments could and could not do. I now recognise that previously **other people's perceptions of my** impairments mattered to me a great deal. The differences between the **participants' experiences and my own were particularly evident in terms of long-** term support needs and pre-existing knowledge in negotiating wider government structures. The extent to which my personal experiences might have shaped my understanding is open to discussion, but without my personal experiences and own insight, I would not have been able to understand and analyse the data in the way that I have. Throughout this study, I have sought to give voice or create



awareness of the experiences and ideas of the participants as well as those of my own, and distinguish clearly between the two.

Reflecting back now, I felt empathy towards the participants in the determination they required and demonstrated, during their negotiations to gain the support, information and help they required: this altered how I saw myself, as I recognised a similar determination in myself. It also made me see my own impairments in a different light and helped me question the value I placed on external perceptions of myself. Thinking in detail about nuances of the social model of disability, how **disability can relate to identity and how other people's perceptions of disability** informed my own has helped me to reflect, shape my understanding and self-perceptions and so has made me a stronger person.

There have been elements of the research which I would approach differently, given the opportunity, such as the way I organised and collated diary entries in the first few months caused later administrative headaches when seeking to access data. However my immediate regret is that the research was not as timely as I would have liked, owing to personal circumstances. There have been as a result, for example, differences in individual policies that have been highlighted within the analysis. I feel that the findings are still valid as the experiences of negotiating with wider structures and searching for appropriate support and information which the participants encountered, remain. For instance, procedural and structural barriers have not been simplified, nor have there been any reported substantial shifts in the professional and cultural approaches towards disabled

people. Lessons can be learnt from the research, these will be considered explicitly within the final chapter of this thesis.

In hindsight I would also have thought more deeply about the effects of working so closely with participants for six months, although I made the finite nature of the data collection period clear, both prior to involvement and throughout the research period, verbally and in all related literature. I was in contact with participants usually every two weeks throughout a six-month period of time and this built a deep relationship between myself and the participants. However, I feel that for some of the participants as well as myself, a sense of loss occurred at the end of the data collection period, with the end of the close communication we had previously had. I have come to terms with these emotions, but now recognise some of the challenges of undertaking research in this kind of area.

There were also many elements of the research which I valued greatly, for example the diary method. Participants used the process of diary completion as a way in which to reflect on their experiences, formulate in their own minds about how and where they fit in as disabled individuals seeking help, support and information. Many participants were also enthused by the idea of using the dissemination of the research for the purposes of illustrating their experiences on a local level. I am proud, therefore, of the opportunities I have been able to offer to the people who made the commitment to become involved. In addition I too have been able to apply the knowledge I have learned from their experiences as well as my own to inform my approach towards working with disabled people,

recognising an overarching commonality within their experiences and diary use as a method of social research in the future. I have also beneficially been able to use my learning from this to shape other work I have undertaken, including teaching on some of the elements relating to consultation with service users and analysing raw data.

I have come to recognise the tensions in the power disparity between structures and agency through the individuals who seek to negotiate with them and have sought to identify the real impacts of failures within systems. The diary system proved invaluable to my understanding, for although through previous advocacy work and my own experiences had given me some insight into the challenges people encounter when seeking to get help, this process of data collection gave me a reflective insight to a depth which I do not believe would have been available to me through any other method. This method also enabled me to see positive examples of effective administration in large-scale systems; when participants encountered positives, in systems functioning effectively, individuals working hard to assist the people seeking their help, and of participants learning skills and confidence through their own experiences or through the support and advice of others. I am so pleased to have utilised a diary method which was flexible and responded to the individual needs and personalities of the participants; it gave me a wealth of rich data. The variety of diary types employed and the willingness of the participants and myself to negotiate with each other when changes occurred or were required further added strength to this data. Reflecting back, I see how this system worked because of the way in which

participants allowed me to have insights into their lives, for which I am extremely grateful. Without their willingness to engage, I would never have been able to develop my understanding.

The strength of the participants has inspired me: through their perseverance and humour. Prior to beginning this research I defined myself as quite a strong individual, and this research has given me the opportunity to see how other people have built their strengths by incorporating a range of personal support mechanisms and development of agency. I began to think about the fact that I did not have as many external support mechanisms as many of the participants within this research did, and saw how much they valued and benefited from these resources. It has allowed me to recognise how elements of my own life may be improved by strengthening the support mechanisms around me. While I felt sad to recognise these perceived gaps in my own life, I was inspired personally to reach out to others more widely. For instance, my social involvement in **group based activities including a women's football team and an a capella choir** were motivated by my own reflections on this research.

The personal struggles which participants encountered have shaped my understanding of what it means to negotiate with large structures and seek help at times of vulnerability. Throughout the research period I maintained reflective diaries of my own feelings and reactions to the whole process. The following is an excerpt from my reflections towards the end of the data collection period, which I include to demonstrate some of the insights and perceptions I developed through

working so closely with the participants. Marie informed me that medical professionals stated there were no further treatments or options available for Hermione, who would now become a permanent wheelchair user (Email Entry, 5.5 of 6). The hope the family had maintained about the temporary nature of **Hermione's impairments had been crucial to them. I reflected on my personal** reactions to the news.

*"I felt sick and wondered about how hard this would be for a family I had grown to know and care about. From my point of view I was torn between acting as a researcher, some theoretically independent person, while acknowledging my feelings regarding what the family were going through and how sad and hollow it made me feel. Recognising that their emotional reactions, of course were likely to be much more intense than mine."*

(Reflective Thoughts re Marie and Hermione, Joy Fillingham, 8/12/2006)

I recognised the therapeutic value of keeping this diary as it helped me acknowledge my feelings and to reflect upon them in a safe environment that would not impact negatively upon the participants. This demonstrates the way in which I responded and dealt with what can be an intense relationship between the participants and researcher.

The rich understanding I have gleaned through the participants and through undertaking this research has helped me recognise the importance of trying to create awareness and inspire change, through seeking to influence both the structures of social reality and the ways in which individuals can see themselves and respond to the challenges they may face. I am excited about the possibility of doing so. I now have an insight into the differences between policy and practice for individuals. My own position is now clearer as an individual and as a

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researcher with impairments and some experience of disability. I am now able to be more confident in defining my own identity, rather than focussing on how I am perceived by others.

The whole process has motivated me to continue my work in this arena with the hope that it will inspire change in policies and attitudes relating to disabled people, and so one day lead to better experiences for people with impairments.

## **8.12 CHAPTER SUMMARY**

This chapter has considered data types and amalgamated the themes of analysis to create models illustrating participants views of the systems with which they negotiate and their views of other people, particularly individuals who represent such agencies. The process of disillusionment has been developed to demonstrate the experiences of disabled people seeking to access provision and information. Routes to resolution of the process of disillusionment have been illustrated as possible ways forward.

## **CHAPTER NINE – CONCLUSIONS**

### **9. INTRODUCTION**

This research began by outlining how discourses of disability have impacted upon disabled people's lives throughout time immemorial and demonstrating that how disabled people are viewed has a direct bearing on how they are treated. Chapter Three developed these ideas further by considering how identity may be shaped, changed or challenged by disability and showed that for some disabled people, particularly those who acquire impairments, issues such as stigma and other **people's perceptions**, together with their own understanding of disability may shape their experiences and identity. Chapter Two looked at the issue of disability predominantly from an external, structural position, while the third chapter focussed in more detail on the micro and individual elements of the debate. Chapter Four effectively framed this by exploring how Critical Realism was applied to this research and how such a methodology captured the experiences of the participants so effectively. This chapter also outlined many of the decisions made in respect of research design, including the research questions and explained the basis behind such choices. Chapter Five introduced the data and the participants to the reader and began to consider how this data could seek to answer the research questions. Chapter Six analysed the data as barriers (and potential aids) for participants, further reinforcing the structure agency division adopted in this work, while Chapter Seven looked more at the micro elements and effects of attitudinal barriers and support mechanisms. Finally, Chapter Eight considered the

use of the diary as a research method. It detailed how the data analysis answered the research questions and introduced the theory of the process of disillusionment and models of analysis developed through this work.

Critical realism as the methodology for this research allowed examination of the interplay between structure and agency through generative mechanisms viewpoint. It echoed the structure of the work and facilitated different perspectives of reality by recognising the differing perceptions of individuals by placing these in a broader context.

## **9.1 ORIGINAL CONTRIBUTION**

This thesis has presented a detailed piece of research and analysis and used a unique approach towards longitudinal diary use within qualitative research. The process of disillusionment can explain how individuals encounter challenges when seeking help support and services and can also provide possible ways of resolving this challenge on an individual level. However there is a danger of emphasising only the elements of agency which the participants and perhaps a broader range of disabled people with acquired impairments can develop. This is reminiscent of many of the discussions and fears relating to the social model of disability, in terms of acknowledging individual differences and may place the responsibility for the disability back onto the individual. Comparatively, therefore there could be a similar danger in placing the emphasis away from structures within which the person lives. While offering disabled people the skills to be able to negotiate and



respond to the challenges they may face when seeking support from external governmental structures may prove empowering to some individuals, not all disabled people will be able to undertake such a role, or will wish to do so. Particularly at the point of acquiring impairments: stigma, the expectations of themselves and others relating to disability alongside impairments and a renegotiation of identity which many people encounter are substantial enough demands. Resolving the significant barriers which disabled people face is not their responsibility in isolation: wider society has a substantial obligation in ensuring support for people who need it and seeking equitable opportunities for all citizens. Offering disabled people the skills to challenge such situations does not negate that responsibility, which is why strategies are now considered which could be employed on a larger scale to assist disabled people.

## **9.2 STRATEGIC RECOMMENDATIONS IN RELATION TO GOVERNANCE STRUCTURES**

The suggestions made in Chapter Eight with regards to minimizing the effects of the process of disillusionment are possible routes which may assist people dealing with disability on an individual basis. There are a number of ways in which these barriers may be able to be tackled on a wider and less arbitrary source; the five which follow identify some of the key areas where measures may be taken to lessen the challenges. While these may be seen as an aspirational representation of ameliorating barriers, it does highlight some of the key areas of concern demonstrated within the research.

### **9.2.1 Provision of Information**

The recognition that the first few times people contact agencies for information, support and advice they are not likely to understand the systems in which they are negotiating in is essential. These initial experiences can shape future expectations and perceptions of governmental structures, often adversely. In light of this guidelines should be available both on line and in a variety of formats about the options which may be open to a person and how processes work. These also need to be widely publicised. A clear system of explaining what rights to redress an individual may have, needs to be available and consistent in its application. Running parallel to this information, stating when any given piece of material has last been verified or updated to ensure that the information given is accurate would make the process more transparent.

### **9.2.2 Participation and Consultation**

Although participation and consultation were not areas in which many participants were involved (four were asked to participate and only two agreed) it is an area in which I believe a significant resource is being overlooked. The depth of understanding and experiences which the participants demonstrated throughout the data collection period are current resources and sets of perceptions, which governance structures on both a local and central level are not incorporating into their understanding. These are recommendations into the different ways in which further participation and consultation may occur. When participation and

consultation is taking place, disabled people may be interested in taking part if they are informed fully of the remit from the outset. For example if consultation can only hope to shape a single area of policy, this needs to be made clear to people who may then decide to be involved.

The opportunities to comment and consult need to be varied, for instance by allowing different formats, of both meetings and material. Rather than one formal meeting which may be imposing or inaccessible to some people, it would be helpful to broaden the range of opportunities to participate. Providing accurate feedback about involvement and consultation which has taken place, outlining what has happened as a result of that consultation and what is intended to happen in the future, are examples of good practice which could make the process more meaningful for all involved.

### **9.2.3 Acknowledge Attitudinal Barriers**

A shift in attitude is required to recognise that disabled people are not a homogenous group: they have diverse needs. Some of the needs of the participants and disabled people can be resolved through simple actions, but that **this can only occur if fewer assumptions are made about disabled people's needs** and instead their requirements are recognised holistically. A broader discussion and awareness of the range of disabilities people may encounter would improve understanding and challenge attitudinal barriers in this area.

#### **9.2.4 Soft Skills**

Recognition of the need, and finding ways to promote, '**soft skills**' within people working with the public which may improve the services which disabled people are receiving, are essential. Professionals are trained in a specific skill set relating to their own area. However there appears no evaluation system or set of expectations which the public are informed of in relation to this area. An explicit recognition of the value and importance of communicating with a broad range of people in diverse way could facilitate a more effective way of working.

#### **9.2.5 Developing Continuity**

Systems of continuity may greatly improve the system for disabled people, either in the form of case workers or extended communication techniques which inform people which section of a system is holding documentation pending a decision for instance, outlining what has happened in terms of a process or request for help and what is the next step. Although some attempts have been undertaken to do this, there remains a lack of transparency and continuity about processes and structures as demonstrated within the research. Such an approach is particularly relevant in larger scale systems.

### **9.3 APPLICATION OF THESE FINDINGS FOR THE FUTURE**

The UK is currently contending with a time of economic hardship and so increasing financial constraint on the provision which is available. The challenges faced by governmental structures and successive governments are unlikely to diminish in the foreseeable future and these are long term issues. There is a danger therefore that the systems people encounter when seeking help, will become harder to access, that advisory bodies may not be funded and that how people seeking support are perceived may become subject to further scrutiny. In light of these circumstances I assert that the findings and recommendations of this research become more relevant in helping to understand and respond to need and barriers towards access during difficult times.

### **9.4 RECOMMENDATIONS FOR FUTURE RESEARCH**

Much more research needs to be undertaken in relation to how to break and challenge the process of disillusionment and how it can challenge practice. Recognition of the distinctions between policy and practice can and should be much more explicit than they currently are now. Only through such discussions and acknowledgement at governmental levels could the gaps be lessened.

In terms of diary use, similar research using variant formats of recording peoples **experience's** may lead to greater insight into the methodological impacts of different types of diaries within social research, particularly in order to capture the

experiences of people who may not be able to commit to the level of reflexivity and complexity encapsulated here.

Previous research has already demonstrated that people from Black and Minority Ethnic communities may have very different experiences of disability. Similar research specifically targeting people from such communities therefore would extend knowledge within this area.

The process of disillusionment and the related models considered within the previous chapter require deeper consideration and application. Questions need to be asked, for example, could this process be applied to other groups of people encountering oppression and other people seeking services and support generally? Does the degree of disillusionment relate to how long a person is blocked by barriers or do other factors come into play? How much do the discourses around an individual affect the levels of structure and agency they may hold?

Finally, **specific distinction needs to be made between people's expectations and the actual services which they receive**, in order to identify if the process of disillusionment itself directly affects the resources and information finally received.

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## **Appendix 1**

### **Themes and areas for Discussion in Interview.**

- Could you tell me about your impairment or disability?  
(Prompt only as required)
  - i. When did you first notice it?/ When did it occur? (depending upon nature of impairment)
  - ii. Do you feel it affects your day to day life? (Ask to expand if necessary)
  - iii. How do you feel other people respond to you?
  - iv. Do you feel your impairment affects how people respond to you?
  - v. Do you feel your impairment is a part of who you are?(Ask to expand if necessary)
  
- Do you feel you need help?
  - i. (If yes) What sort of help do you need?
  - ii. (If no) move to next section)
  - iii. Have you asked for help?
  - iv. (If yes) From whom?
  - v. How did you feel about it?
  - vi. Do you get the help you need?
  - vii. (If no) Why do you think that is?
  
- Are you involved in any support or pressure groups in relation to your impairment?
  - i. (If yes) Can you tell me about that?
  - ii. (If no) Could you tell me why?
  
- Are you aware of government or local government policies aimed at helping people in situations similar to your own?
  - i. (If yes) Ask to expand (If any of below list not mentioned, prompt for additional comments.)
  - ii. (If no) Prompt e.g.s D.D.A., partnership working, liveability and well-being themes.
  - iii. Have you had contact with the Local Authority in relation to your impairment?
  - iv. Have you had contact with the Local Authority in relation to any other issues?
  - v. (If no move to point vii)
  - vi. (If yes) Did you feel your impairment affected this contact in any way?)
  - vii. What policies do you feel should be in place to support people in situations similar to your own?

Recap of what project involved and if it is clear to the participant what is being asked of them.

## Run through diary options

- Demographics (Remind participant of confidentiality)
  - Could you confirm your name, age and date of birth?
  - How would you define your impairment(s)?
  - How would you define your ethnicity?
  - What is your educational background?
  - Are there any other factors in relation to how you identify yourself, that you want to talk about?
  
- Is there anything else you would like to add to what we have discussed to date?

### *Ensure participant*

- 1) *Is clear of what is expected of them and what they can expect from me.*
- 2) *Is willing to proceed*
- 3) *Has no outstanding questions*



## Invitation to take part in Research

**Are you a person who has recently experienced disability – either directly, or because you have a disabled child?**

**Are you trying to access services, information or support as a result of disability or mental health concerns?**

**Would you be willing to share your experiences?**

### **What is the research about?**

XXX Social Services is supporting a research project, run from the University of Birmingham, to find out what it's like for a range of people with different disability or impairments when seeking information, support or services. The research will explore people's everyday experiences -- including seeking help from different service providers -- and whether or not people are able to have their say about the help they receive.

### **Who are we looking for?**

We're looking for 10 people altogether, five from this area and five from another part of the country. These people will have

experienced a disability or impairment which has led to a change in circumstances (usually within the last twelve months) and has included a need for information, services or support. We want to include people of different ages and backgrounds with a range of disabilities such as sight or hearing loss, mobility problems, mental health problems and other non-visible impairments such as chronic pain, as well as parents of young disabled children under the age of six.

### **What would this involve for you?**

If you are interested in taking part, you would be asked to:

- Take part in an initial interview
- Keep a diary about your experiences for six months in a format of your choice: e.g. by tape, e-mail, in a written diary or another method if you prefer, and send your diary entries to the main researcher Joy Fillingham
- Take part in a final interview at the end of the six months, when you can see and comment on how your experiences to date have been written up
- Decide if there is anyone that you want the findings to be sent to at the end of the research.

### **What control would I have over this?**

If you take part you can ...

- Find out more detail about the research if you want to
- Decide what experiences you include in your diaries
- Comment on how your experiences are reported
- Withdraw at any stage and / or request your contribution should not be included.



Your contribution would remain anonymous, but a copy of the findings will be sent to the Office of the Deputy Prime Minister and the local Council, and anyone else you choose who may be interested in the results.

### **What support will I get?**

- The main researcher, Joy Fillingham, will keep in regular contact with you throughout this time. The means of contact and how often it takes place will be agreed with you
- You can contact Joy with any queries and she will respond promptly
- Your expenses such as postage and stationery will be paid, as well as any child-care or other carers' costs you may have to pay while you attend the interviews (where appropriate).
- You can borrow a tape recorder if necessary.

### **Why should I be involved – and what's in it for me?**

We hope the chance of being able to explore your experiences at what can be a challenging time will provide an opportunity for you to have an impact on how services and information are provided.

### **How can I find out more?**



### **Appendix 3 - Sampling Criterion for Inclusion**

- ❖ At least one participant has an impairment relating to their vision, in order to identify, for example, how responsive local governance and service delivery have been to requests for alternative formats.
- ❖ At least one participant has a hearing related impairment, arising in adulthood. This is in recognition of the fact that the remit of this work is people who have recently experienced impairment, while BSL speakers have traditionally experienced their deafness since birth. I am aware through earlier work and conversations with BSL speakers that people usually consider themselves to be a linguistic minority rather than hearing impaired. While this may be as a result of artificial cultural construction, as argued by Corker, (2002), any group who have dramatically different expectations of governance structures and service delivery and identify as a separate community stand outside the remit of this research. By selecting people who develop a hearing related impairment in adulthood I intended to explore the experiences of people who did not have an immediate established network available to them as I wished to understand how and if people renegotiate their own identity and sought appropriate support and services.
- ❖ At least one participant should be a wheelchair user.
- ❖ At least two of the participants should be parents of children who have recently been identified with impairments, preferably of different age groups.
- ❖ At least one participant should have mobility impairment but not be a permanent wheelchair user; such an inclusion would allow insight into how much structures are established for people with visually evident impairments but which do not fit into the traditional perception of disability.

- ❖ At least one participant has a non-visible disability, such as epilepsy or osteoporosis. This will continue to challenge how structures are able to respond and provision developed and delivered, when based upon traditional expectations of disability, but encountering impairment outside the stereotypical image. It is recognised that this is a very broad category, but the scope of this research does not make it possible to explore all areas of disability. Keeping open a great range of non-visible impairments for possible inclusion within the project, has allowed me the opportunity to seek out participants best fitted for the research and develop some insight into attitudes towards people who are not immediately perceived as having impairments.
- ❖ **At least one of the participants experience's mental health issues.** The negotiation of structures and service delivery for people first experiencing such issues, or initially having been identified as someone with mental health issues is likely to be a significant and demanding time. Coming to terms with mental health issues in light of the significant stigma attached to such impairments and simultaneously with the experience itself would be a great challenge. By working with a participant at this stage, it may be possible to explore how the treatment of people with mental health issues impacts upon their renegotiated identity. The concept of stigma in relation to specific impairments will be linked in to the theme of identity and will be explored later in the research.
- ❖ A decision has been taken not to include a person with learning difficulties within this research. Firstly as learning difficulties are **usually, though not always, identified and 'diagnosed' early in life;** therefore it is unlikely that a person would be suddenly faced with such a condition. Secondly from previous experience, and depending upon the degree of difficulties experienced, people with learning difficulties can require an intensively supportive infrastructure in which to flourish,

which the research may not be able to offer while working with such a broad range of other impairments.

## Appendix 4

Themes and areas of discussion for final interview

1. Reflecting back on the last six months have changes occurred to the way you view your impairment(s) / disability
  
2. Reflecting back on the last six months have changes occurred to the way you view the following as a result of your impairment / disability
  - a. government,
  - b. local authority,
  - c. service providers,
  - d. other people you have come into contact with
  
3. Do you feel you have received help if you asked for it.
  - a. If yes please explain
  - b. If no why not do you think?
  
4. Are you aware of any more policies aimed at helping people such as yourself than you were six months ago. If yes please discuss.
  
5. How do you feel about the pen portrait?
  
6. How do you feel about the way you have been represented in the text? Discuss
  
7. How did you feel about the diary process

8. At the start I asked what could be done, e.g. what policies could be put in place to assist / support people in situations similar to your own. Any further thoughts in this issue?

9. Any immediate thoughts about dissemination?

Recap what will happen now.

Write up Department of Communities and Local Government 20,000 report by October 2007, (can therefore become involved in dissemination from May onwards next year) detailed thesis may take approximately one year longer. Copy can be available.

10. Any other issues you'd like to discuss?

## Appendix 5

Draft One

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### **DIARY ENTRIES**

**Below are a list of organisations and services that you may come into contact with. It is not expected that you will have contact with all of them, but the list is meant to prompt you about what kind of information we would like to know about. Please also include any other contact that you have had, which you would like to discuss.**

**In relation to each one please say.**

- 1. Who the contact was with?**
  - 2. When did it take place?**
  - 3. How long was the contact?**
  - 4. What sort of contact was it? E.g. Phone, letter, email, in person etc.**
  - 5. Who was the reason for the contact?**
  - 6. Please tell me about what happened?**
  - 7. How did it make you feel?**
  - 7. Is there anything else you wish to share about experiences you have had recently?**
- 

The pilot response from this prompt tended to be short sentences and did not encourage the 'voice' of the participant to be heard.

The next attempt was in fact even more structural than the first, but was intended to offer a system by which participants experiences could be 'mapped' and then considered in greater detail separately.

**Please record and contact you had had in relation to the following in the last seven days.**

Which Organisation was the contact with? Tick.	Please	What sort of contact? letter, phone, in person, etc	What was the reason for the contact?	What day and how many times was the contact? How long did it last?
GP				
Physiotherapist				
Hospital Consultant				
Counsellor / Therapist				
Psychologist				
Bathing Services				
Community Nursing Services				
Day Services / Day Care				
Occupational Therapist				
Meals on Wheels				
Home Care				
Disabled Living Centres				
Rehabilitation Services				
Respite/Residential Care Services				
Optician				
Dentist				
Social Services				
School				
Education Authority				
Nursery				
Transport Services				
Benefits Agency				
Neighbourhood Office				
Housing Association				
Housing Department				
Leisure Services				
Advocacy Services				
Voluntary Agency (please specify)				
City Council Department (please specify)				
Support / Self-help group (please specify)				



Other (please specify)			
------------------------	--	--	--

For each entry

1. Please tell me about what happened
2. How did it make you feel?

Is there anything else you wish to share about experiences you have had recently?

---

## **Draft Three**

---

### **For each contact you have, please say**

**What sort of contact? e.g. phone, person, letter etc**

**What was the reason for the contact?**

**What day and how many times was the contact? How long did it last?**

**For each entry**

- 1. Please tell me about what happened**
- 2. How did it make you feel?**
- 3. Is there anything else you want to say about experiences you have had recently?**

The following guidelines are here to remind you of the areas we would like to know about, but please use whatever approach you feel to describe your experiences.

Thank you for your input.

GP  
Physiotherapist  
Hospital Consultant  
Counsellor / Therapist  
Psychologist  
Bathing Services  
Community Nursing Services  
Day Services / Day Care  
Occupational Therapist  
Meals on Wheels  
Home Care  
Disabled Living Centres  
Rehabilitation Services  
Optician  
Dentist  
Social Services  
School  
Education Authority  
Nursery  
Transport Services  
Benefits Agency  
Neighbourhood Office  
Housing Association  
Housing Department  
Leisure Services  
Advocacy Services  
Voluntary Agency (please specify)  
City Council Department (please specify)  
Support / Self Help Group (please specify)  
Other (please specify)

---

## Appendix 6

Please record and contact you had had in relation to the following in the last seven days.

Which Organisation was the contact with?	Please Tick.	What sort of contact? letter, phone, in person, etc	What was the reason for contact?
GP			
Physiotherapist			
Hospital Consultant			
Counsellor / Therapist			
Psychologist			
Bathing Services			
Community Nursing Services			
Day Services / Day Care			
Occupational Therapist			
Meals on Wheels			

Home Care		
Disabled Living Centres		
Rehabilitation Services		
Respite/Residential Care Services		
Optician		
Dentist		
Social Services		
School		
Education Authority		
Nursery		
Transport Services		
Benefits Agency		
Neighbourhood Office		
Housing Association		
Housing Department		
Leisure Services		
Advocacy Services		
Voluntary Agency (please specify)		
City Council Department (please specify)		
Support / Self-help group (please specify)		

Other (please specify)		
------------------------	--	--

**For each entry**

**1. Please tell me about what happened**

**2. How did it make you feel?**

**Is there anything else you wish to share about experiences you have had recently?**

## Appendix 7

Diary

Please record any contact you may have had with the following in the last seven days

	Which Organisation was the contact with? (please tick)	When was the contact?	How long was the contact?
Doctor			
Physiotherapist			
Hospital Consultant			
Counsellor / Therapist			
Transport services			
Social Services			
Psychologist			
Community Nursing Services			
Neighbourhood Office			
Benefits Agency			
Housing Department			
Housing Association			
Dentist			
Optician			
Meals on Wheels			
Day Services / Day Care			

School			
Nursery			
Occupational Therapist			
Rehabilitation Services			
Disabled Living Centres			
City Council Department (please specify)			
Voluntary Agency (please specify)			
Support / Self-help Group (please specify)			
Disabled Living Centres			
Advocacy Services			
Respite/Residential Care Services			
Other (please specify)			

In relation to each contact, please

1. Tell me about what happened
2. How did it make you feel
3. Is there anything else that has happened recently in relation to your impairment which you want to share?

## Appendix 8

### Final Diary prompting System

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#### For each contact you have, please say

**What sort of contact? e.g. phone, person, letter etc**

**What was the reason for the contact?**

**What day and how many times was the contact? How long did it last?**

**For each entry**

- 1. Please tell me about what happened**
- 2. How did it make you feel?**
- 3. Is there anything else you want to say about experiences you have had recently?**

The following guidelines are here to remind you of the areas we would like to know about, but please use whatever approach you feel to describe your experiences.

Thank you for your input.

GP  
Physiotherapist  
Hospital Consultant  
Counsellor / Therapist  
Psychologist  
Bathing Services  
Community Nursing Services  
Day Services / Day Care  
Occupational Therapist  
Meals on Wheels  
Home Care  
Disabled Living Centres  
Rehabilitation Services  
Optician  
Dentist



Social Services  
School  
Education Authority  
Nursery  
Transport Services  
Benefits Agency  
Neighbourhood Office  
Housing Association  
Housing Department  
Leisure Services  
Advocacy Services  
Voluntary Agency (please specify)  
City Council Department (please specify)  
Support / Self Help Group (please specify)  
Other (please specify)

---

## APPENDIX 9

### Hudson and Hardy, 2002

#### Five categories of barriers to coordination.

##### **Structural**

- *fragmentation of service responsibilities across agency boundaries, both within and between sectors;*
- *inter-organisational complexity*
- *non-coterminosity of boundaries*
- *competition-based systems of governance.*

##### **Procedural**

- *differences in planning horizons and cycles;*
- *differences in accountability arrangements;*
- *differences in information systems and protocols regarding access and confidentiality.*

##### **Financial**

- *differences in budgetary cycles and accounting procedures;*
- *differences in funding mechanisms and bases;*
- *differences in the stocks and flows of financial resources.*

##### **Professional/cultural**

- *differences in ideologies and values;*
- *professional self-interest and autonomy;*
- *inter-professional domain dissensus;*
- *threats to job security;*
- *conflicting views about user interests and roles.*

##### *Status and legitimacy*

- *organisational self-interest and autonomy;*
- *inter-organisational domain dissensus;*
- *differences in legitimacy between elected and appointed agencies.*

(Hudson and Hardy, 2002:54)

**Fillingham's** Adaptation of Barriers Model

A Structural

- Fragmentation of Services
- Complexity of Structures
- Non-coterminosity across boundaries

B Procedural

- Accountability
- Complexity of Process

C Financial Barriers

- Financial Barrier Overview
- Funding limitations or a matter of Procedure?

D Practical Barriers

- Getting Help
- Access and Obstructions
- Mobility and Transport
- Resolving Practical Barriers

E Professional and Cultural Barriers

Professional and Cultural Assumptions and Expectations  
About how participants should act.

- Health Professionals
- Agents of Government Structures
- Education Institutions

**About what was in the participants' best interests.**

- Health Professionals
- Educational Institutions

**Did Participants 'justify' receiving help?**

F Help and Support from Professionals

Health professionals

Third Sector Organisations (T.S.O.s)

- Provision of Information and Emotional Support
- Provision of Services, Opportunities and Practical Support
- Expert Patient Programmes

G **PERCEIVED 'LEGITIMACY' OF IMPAIRMENTS**

## Appendix 11. List of Data Collection

### Edward

Initial Interview →	Month 1				Month 2				Month 3				Month 4				Month 5				Month 6				← Final Interview
	WK 1	WK 2	WK 3	WK 4	WK 5	WK 6	WK 7	WK 8	WK 9	WK 10	WK 11	WK 12	WK 13	WK 14	WK 15	WK 16	WK 17	WK 18	WK 19	WK 20	WK 21	WK 22	WK 23	WK 24	
Data Collection Entries	3	1	0	0	0	1	2	2	3	4	3	2	5	3	0	1	0	3	2	2	0	3	2	1	
Flavia	Month 1				Month 2				Month 3				Month 4				Month 5				Month 6				← Final Interview
	WK 1	WK 2	WK 3	WK 4	WK 5	WK 6	WK 7	WK 8	WK 9	WK 10	WK 11	WK 12	WK 13	WK 14	WK 15	WK 16	WK 17	WK 18	WK 19	WK 20	WK 21	WK 22	WK 23	WK 24	
Data Collection Entries	2	2	2	3	3	4	2	5	1	0	2	3	1	2	3	4	4	3	4	2	2	1	2	1	
Patrick	Month 1				Month 2				Month 3				Month 4				Month 5				Month 6				← Final Interview
	WK 1	WK 2	WK 3	WK 4	WK 5	WK 6	WK 7	WK 8	WK 9	WK 10	WK 11	WK 12	WK 13	WK 14	WK 15	WK 16	WK 17	WK 18	WK 19	WK 20	WK 21	WK 22	WK 23	WK 24	
Data Collection Entries	3	4	2	4	3	4	2	5	3	0	2	1	3	4	3	6	4	2	3	2	1	2	3	3	

**Susan**

Initial Interview →

Data Collection Entries

Month 1				Month 2				Month 3				Month 4				Month 5				Month 6			
WK1	WK 2	WK 3	WK 4	WK 5	WK 6	WK 7	WK 8	WK 9	WK 10	WK 11	WK 12	WK 13	WK 14	WK 15	WK 16	WK 17	WK 18	WK 19	WK 20	WK 21	WK 22	WK 23	WK 24
9	7	8	7	2	0	8	9	5	6	4	9	4	6	5	7	4	0	8	9	6	5	8	7

← Final Interview

## APPENDIX 12

### Mrs Haynes

**Mrs Haynes is in her early 60's and had a stroke three and a half years prior to the start** of the data collection period. She had previously worked in administrative roles and was in full time employment at the point she had a stroke.

Mrs Haynes did not have a strong support network, having no immediate family and was living alone in rented accommodation prior to the stroke. She spent seven weeks in hospital after the stroke and felt pushed out and forced to make a decision about where she would live in the future before she was mentally strong enough to do so. The result as Mrs Haynes perceived it, was that she had moved into a retirement home at the age of 58 when if she had been given a little more time and the opportunity to make decisions when the clarity of her mind had improved, she would not have chosen such an environment for herself.

Mrs Haynes is a shrewd woman with a clear mind and a capable air; the stroke affected her mobility and movement of one hand. She felt that the stroke had affected her life substantially, not just in terms of the physical changes, which she viewed as a nuisance, but in terms of how people treated her and the isolation brought about by her new living arrangements. The retirement home was in an isolated position in a hilly area some way away from the town centre and with no evident local amenities.

The retirement home had no permanent warden at the time of the research and there were no contact information, support or complaint process available. Items disappeared from the home and there had previously been verbal and physical assaults occurring. Mrs Haynes had tried to challenge these circumstances but without success. She felt her experiences had changed her personality rather than the stroke itself.

## **Appendix 13**

Dear Participant,

My name is Joy Fillingham and I am the researcher in relation to the Enabling or Disabling Governance Project. Firstly I would like to say thank you for agreeing to take part in the research project. This document is intended as a guideline to the research process. However if at any stage you are unclear about this process or have any additional questions please contact Joy whose contact details are below.

### **Aims of the Research**

The research is looking to explore what people who have recently become impaired or disabled experience when trying to access services and the structures that organise such service delivery. It hopes to answer questions in four main areas;

- a. What factors affect the expectations and services received by the participant's?
  
- b. How are service delivery, recent legislation and governance structures perceived, and impact, upon participant's lives?
  
- c. How are self-perception and identity affected by encountering disability and the treatment participant's encounter as a result?
  
- d. How do the methodological choices made within this research influence its outcome? \*

\* The methodological choices refer to the use of the diary method and the style in which Joy intends to write this research.

### **Structure of the Research**



There will be a semi-structured Interview between yourself and Joy in which the main themes of the research will be explored and an agreement will be reached about what form of diary is to be used. You will then be asked to keep a diary in that format for six months and send your data to Joy. How often you add entries will be up to you, though you would be asked to make an entry **at least** once each week. You will have regular contact with Joy except you prefer not to, this will usually be every two weeks, unless you have queries or issues which you wish to discuss with Joy outside this.

#### You have the Right to...

- Withdraw from the research for whatever reason at any point while the data is being collected.
- Refuse to do anything in relation to this project which you do not wish to do.
- Request that interviews are not recorded if you do not want them to be.
- Have a report of the findings arising from the research, and access to additional information if you want.
- Be involved in deciding who should hear about the findings of the research and in what way, if you wish.
- Complain about your treatment, either to the researcher's supervisor or Head of Department.

#### You are Asked to...

- Have two semi-structured interviews at the start and end of the diary process.
- Keep a diary in a format which is practical and suits you, for example by using a tape recorder or writing down your experiences.
- Make at least one diary entry per week, though you can enter as many as you wish.
- Send you data to Joy in a method that will be agreed between you.
- If you feel unsafe, uncertain or uncomfortable at any stage speak to Joy, or if you do not feel able to do this, speak to her supervisors

#### The Researcher

Joy Fillingham is currently undertaking a PhD in the Institute of Applied Social Sciences at the University of Birmingham and is paid an educational stipend for three years by the Economic and Social Research Council; ESRC, and the Office of the Deputy Prime Minister; OPDM. This funding however is only to cover living expenses and Joy is not employed by either of these groups and will independently investigate the issues and produce findings. Joy previously worked in charity management and has a long term interest in issues relating to disability and impairment.

Joy can be contacted;

- 

- [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

■ Joy is contacted by phone or email and is unavailable for more than a few days, the recorded message or email will explain this fact and state when she is expected to return. Other than when she is unavailable Joy will seek to return contact within two working days.

Joy is responsible for

- Ensuring that participants have complete anonymity and cannot be identified by any third party at any point of the process.
- Provide this document in different formats, according to participants' preferences, including in audio, large print version and translation into other languages.
- That participant's are informed and supported throughout. E.g. by providing further details of the process to any participants who wish to know more.
- Ensuring that involvement in the research does not cause participants any expense, for instance postage, stationary or contacting the researcher.

Thank you for you support and involvement – I look forward to working with you.



THE UNIVERSITY  
OF BIRMINGHAM

Institute of Applied Social Studies  
School of Social Science

APPENDIX 14

## Consent Form

### Enabling or Disabling Authorities

I confirm that I agree to take part in the above project, through interviews, diary entries and other agreed contact.

I understand what this entails, having discussed it with the researcher and having been given a Key Points Sheet and sent a Project Information sheet and agree to be involved in the study.

I agree to the interviews and conversations being recorded.

I agree to share this information though understand that it will be anonymised.

I am free to withdraw this agreement at any time, without reason.

Signed: .....

Print: .....

Date: .....

Please sign two copies of this form and keep one for your own records. If any other format is preferred, please discuss this issue with the researcher Joy Fillingham.

## Appendix 15

### Key Points

Hello my name is Joy Fillingham, I am a researcher from the University of Birmingham and am currently undertaking research working towards a PhD and am sponsored by the ODPM\* and ESRC\*.

- I would like to ask you about your experiences relating to you impairment or disability, in order to identify and try to improve the support, direction and provision for people in similar situations in the future.
- If at any time you are unclear about any issue in relation to this project or what I am saying, please let me know.
- This handout is for your reference, but please ask about any issues which are of interest to you that are not included.
- I would like to remind you that you have control of your involvement.
  - You are welcome to ask questions whenever they occur to you.
  - Through discussion with myself, you can decide the format that is best for you to receive documents and contact.
  - If there are any questions which I ask you that you don't want to answer, you don't have to.
  - If you are unhappy at any stage please let me know and I will try to resolve your concerns.
  - If I am unable to deal with your concerns or you feel unfairly treated by the research, you have the right to complain to my supervisors and / or Head of Department, there details will be provided upon request.

- If you feel at any stage that you are unable to continue further, you have the right to withdraw from the research.
  - If you decide to withdraw from the research you also have the right to request that data you have previously provided should not be used either.
  - Any contact will be agreed between yourself and myself, though if you wish to contact me at any point throughout the research, my contact details are shown below. Under usual circumstances if a message is left for me requesting contact, I will respond within two working days.
- 
- The information that you give to me will be kept confidential, and some personal details may be changed in the final report to protect your identity; although your own words and ideas will not be altered.
- 
- Involvement with this research will, include
    - i. An initial interview in person.
    - ii. A period of six months when you are asked to keep a diary in a format of your choosing,
    - iii. That on a regular basis to be agreed your diary data will be sent to myself.
    - iv. During the six month period I will keep in regular contact with you if you are happy for me do so, e.g. via telephone or email. The regularity of such contact is to be agreed, but would be expected to be at least once every two weeks.
    - v. A final interview in person. At the point of the final interview, you will have an opportunity to see how your input has been written up so far, in a format that suits you and comment on the content.
- 
- Once the research has been completed, if there are certain people or organisations whom you would like to see the results, we will discuss this and seek to distribute information to them appropriately.
- 
- With your agreement the research will be recorded throughout, this information will only be used by myself in relation to this

piece of research and will be used to help me remember what we have spoken about and therefore assist the research process. It will be kept securely and with confidentiality in mind.

- Being involved in this research is recognised as a valuable contribution and the research will aim to ensure that you are not out of pocket. E.g. providing materials such as paper, pens, envelopes. Reasonable travel expenses and childcare costs will be made available in relation to the semi-structured interviews.
- The research will be distributed to government departments, local authorities and a range of other bodies. With the intention of making a genuine difference to how people with impairments and or disabilities will be treated in the future and it may also help you to share your experiences.

### Joy's Contact Details

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

[Redacted]

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## APPENDIX 16

### Notes and comments from Pilot Testing 13 March 2006.

Pilot testing took place with two volunteers, one of whom has encountered visually impairment for around six years, one who is a wheel chair user with MS and has identified her position for around 14 years. Both are involved an access group in the geographic region in which they live, consequently they knew each other well, but were interviewed separately. The two will be keeping a diary for a month, one which will be emailed to me, the other which will be written and posted; I will be maintaining contact with one via the telephone and the other via email.

In relation to the interview the following points I felt were of particular note.

#### General Issues about experiences of Participants

##### *Who Is Responsible?*

In rural areas there is great confusion about which services and resources are covered by the town and which by the county council. When the access group and individuals contact these bodies to raise issue in relation to disability or access they have been referred back between a range of agencies for some time before being able to identify which accepts responsibility. Although this is not likely to arise in the same way with the areas in which the full research will be undertaken, it may be worth recognising as a particular problem in relation to rural areas.

##### *Example*

An inappropriately built ramp has remained unusable since it was put in last year. This has not been resolved as it has not been possible for Mrs F to identify who is responsible; four different parties refer the matter on to others within the circle. Mrs F does not currently have the energy to be able to challenge this.

##### *What information do service users receive and when?*

NHS assessment for needs of a participant with increasingly degenerative MS. Mrs F was told she was entitled to assessment; which would help her situation but there was a considerable delay. However only after the after the assessment process was she told that she would not be entitled to any service provision as a result of her husband's income.

### Experiences of Access group Involvement

The access group has had some successes in challenging their services and treatment, though also a share of failures. They have not been consulted in any capacity and feel that their impairments limit how much they are able to do for themselves. The participants said that they really need 'an able-bodied' person to work with them in order to be effective in challenging discrimination, as no members of the group felt they had the strength or energy to make demands or co-ordinate action etc.

It was apparent (and acknowledged by both) that being involved in the group had given them a voice and 'some purpose', though the group generally were isolated and dependent upon the actions of five people, three of whom have degenerative conditions, hence what they saw as a lack of power.

### Time, Identity and Definitions

#### *Time and Identity*

The participant who had encountered his impairment six years ago, Mr A, described himself as still angry about it and left wondering 'why me'. He did not see his impairment as having anything to do with who he was as a person, or how he saw himself. Mrs F, on the other hand saw her impairment as an integral part of who she was.

*Age* - Mrs F was in her early 50's at the point of discovering about her impairment, Mr A in his early 70's.

#### *Definitions*

Both participants were aware of the social model of disability and the Disability Discrimination Act, but no other policies or legislation which is in place. They have received no information from

any authority and all information has been gleaned through their own actions. Neither Mr A or Mrs F described or saw themselves as impaired. Mr A described his impairment as a “severe loss of sight” and felt the term impairment was far too vague. Mrs F said earlier she would describe herself as having “difficulties in walking” and now described herself as a “wheelchair user.”

#### *Issues arising from the Pilot*

Both participants did not respond well to questions directly relating to accessing / negotiating of services and reported little or no contact for example with inaccessible buildings or documents in inappropriate formats. However it became clear through discussions that having had bad experiences with certain venues and services, the participants avoided those situations in the future; getting their families support to deal with the elements with which they couldn't negotiate. This was I think something that we had suspected; that the negotiation of structures and services tends to take place in the first few years and once people have developed understanding or distrust of organisations or departments, those opinions tend to remain.

As an example at the end of the second interview, both participants spoke to each other about a certain post office being inaccessible to wheelchair users, but Mrs F's knowledge had been based in her attempts at access nearly ten years ago, because Mr F had been to the building within the last three years, he was able to confirm that it was now accessible.

#### *Alterations to the Interview Process arising from the Pilot*

The participants did not respond well to the terms used, for example about disability affecting them; I negotiated a new term with the first participants Mr A, which he much preferred, which asked about areas in which he felt his “independence was challenged”. The second participants Mrs F also stated she found it much easier to relate to the questions I was asking when it was raised in such terms.