

ACCEPTING WHEELCHAIR USE

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Abstract

Statutory wheelchair provision in England and Wales has been equipment led since its inception in 1990. However, users are reported to be dissatisfied with the service and a reorganisation of provision is underway that purports, in accordance with recent Government advice (DOH, 2012), to make the wheelchair user central to the supply process. However, little is known about wheelchair users perspectives of the equipment that they use to inform this process.

This study seeks to enter the world of permanent, fulltime wheelchair users, exploring their perspectives on their wheelchair; how these were formed and what affected their attitude towards the mobility equipment that they used. A theoretical model of accepting wheelchair use was developed out of the data to explain the social process that the participants described.

Adopting an interpretivist perspective and a theoretical framework based on symbolic interactionism a group of ten permanent, fulltime wheelchair users were interviewed. These took the form of unstructured one to two hour, in-depth conversations with the participants about their experience of wheelchair use. The first four participants were selected by purposive sampling. This sampling method is reported to increase the significance of the findings even in small samples (Merriam, 2001). Following this, data analysis informed theoretical sampling of six further participants to maximise variation in cases. Digital audio-recordings were made of each interview and transcribed.

Dimensional Analysis, a second generation (Morse et al, 2009) method of grounding theory in the data, was then applied. All of the dimensions of the texts were identified and analysed. Using constant comparative method shared patterns of behaviour were recognised and further analysis enabled an understanding of the social process of being a wheelchair user to be constructed.

Participants were understood to fall into one of a number of groups who had different approaches to wheelchair use. The first group were those who were lifelong wheelchair users. They had not experienced change in their abilities having never walked and their attitude to wheelchair mobility was formed on the basis of a consistent approach to equipment use. The second group had become wheelchair users later in life, having walked for some period.

Analysis revealed that the perspective of the user, on adopting wheeled mobility, affected their attitude to wheelchair use and ultimately their level of independence. For those who acquired their disabilities later in life, engagement in the process of becoming a wheelchair user was essential for them to form a new understanding of themselves from the standpoint of their altered mobility. This process was conceptualised as a transition from walker to wheelchair user and this was considered to comprise a number of stages. These were **becoming**, **embracing** and **being**. The participants were at different places in the process and the reasons for this were explored. A number of pre-existing contextual and biographical features affected each participant's response to wheelchair use. These and other factors moderated the process of change for each individual. Maximum independence was determined to be achieved when the participant embraced the wheelchair into their lifestyle, irrespective of their level of disability. This required that they made practical, psychological and emotional changes in their lives.

This study was timely in the light of the latest proposal to reorganise wheelchair provision. The findings show that the majority of wheelchair users are able to assess their needs and access the wheelchair that they require, having undergone rehabilitation or special schooling. These users have developed a lifestyle as wheelchair users. However, there are a number who come later to wheelchair use and are not offered specialist training. For them, transition into being a wheelchair user may never be completed and they make concessions to their disabilities that

result in increasing social isolation and dependency. Further work is required to determine the best way of identifying these individuals and providing support.

The individual's reaction to becoming a wheelchair user has been explored and a theory of phased transition to acceptance identified. The contribution that this study makes to our understanding of accepting wheelchair use may assist in shaping therapists' approach to wheelchair assessment, provision and skills training.

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Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed : 

Dated: 23rd September 2013

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Foreword

Organisation of this study

This study relates to the perspectives and experiences of ten permanent and fulltime wheelchair users. From the data collected by in-depth conversations an understanding emerged of how individuals interact in their social context and make decisions about their future behaviour. From this the social process of accepting wheelchair use was revealed.

Summary of chapters

Chapter 1: Background and context

This chapter describes the motivation for this study and outlines the context by introducing the wheelchair and the changing pattern of its provision over the last century in England and Wales. Once statutory provision was established for all citizens wheelchair users began to express concerns about the chairs that were provided and how they were supplied. The chapter explains why in order to address this criticism the role of statutory provider was transferred to the NHS, and the expectations of this change. Within the context of the NHS, the wheelchair is identified as a piece of medical equipment and delivered in such a manner. The chapter then outlines why it was thought that an outcome measure that recorded wheelchair user's satisfaction with the equipment that was supplied should be introduced into the NHS wheelchair service. The search to locate such a measure is discussed.

The chapter then moves to exploring the concept that the wheelchair has become more than a piece of equipment that facilitates movement for those who cannot walk. It is now perceived in many different ways. Wheelchair provision should, in response to Government initiatives, address how to be more responsive to the user's needs not merely regard wheelchair provision

as a medical device or a functional item to assist with task completion, but that an alternative more contemporary framework should be found.

Chapter 2: Disability

This chapter presents the contextual background to the study. An understanding of normality in our society is presented. In this context the historical and cultural changes in attitudes towards what constitutes disability are then discussed. The discourses on disability are offered to contextualise the experience of people with impairments in this society. The wheelchair is understood as a universal symbol of disability; the implications of becoming a wheelchair user are explored in terms of biographical disruption and change, labelling and identity.

At the end of this chapter a research question would normally be set. Why in this study that is not the case is explored.

Chapter 3: Participant profiles

This chapter gives an overview of the participants of the study. It is intended as background information that will enable the reader to form their own impressions of the world of each of the participants. This was considered to be important in a study of this type that explores the perspectives of ten different wheelchair users. It also sets out the participants socio-biographical data collected at the start of my interactions with them.

Chapter 4: Methodology

This chapter sets the research within the theoretical framework that guided the study. The decisions that were made with regards to methodology in relation to the area of interest of the research are explained. The relationship between the researcher and the participants is discussed. Researcher bias is a factor in a study so closely related to the researcher's occupational area of

interest. The strategies used in this study to ensure the trustworthiness and authenticity of the research are explained.

Chapter 5: Methods

This chapter explains the decisions that were made regarding the design of the study, participant recruitment, data collection and analysis. Ethical issues relating to the research are addressed. This includes ethical permission, the place of anonymity and consent in the research and strategies used to enhance auditability and demonstrate reliability to the reader of the thesis. It explains how Dimensional Analysis was used in the study to allow an explanatory matrix to emerge from the data that was the foundation of the theory of accepting wheelchair use presented in Chapter 6.

Chapter 6: Findings

This chapter presents the findings of the data analysis. The participants' were understood, not as one group, but in a number of different ways dependent upon how wheelchair use was adopted. Their reaction to the onset of immobility and their adaptation to wheelchair use are presented as a phased process of change informed by the final explanatory matrix. The stages of this process are explained and then the individual contextual conditions that alter the participants' reaction to wheelchair use are explained using quotes from the participants.

Chapter 7: Discussion

This chapter discusses the findings of the study with reference to some of the issues explored in Chapter 2. These relate to the individual's understanding of disability. How wheelchair use requires a social process of change to take place that alters their behaviour and self-identity and how, when the process is fully completed, the participant could be said to have accepted permanent wheelchair use.

The chapter then moves on to discuss these findings in relation to changes in the wheelchair service and practice. Finally, the chapter discusses my experience of and reflections on the research process and draws the thesis to a close with recommendations for future research and some personal observations.

Glossary of terms

A wheelchair is defined as:

“A chair mounted on wheels especially for the use of disabled individuals.”

Random House Webster’s College Dictionary

“A moveable chair mounted on large wheels; for invalids or those who cannot walk; frequently propelled by the occupant.” Princeton’s Word Net

A wheelchair is defined as appropriate if it:

“meets the user’s needs and environmental conditions; provides a proper fit and postural support; is safe and durable; is available in the country; and can be obtained and maintained and services sustained in the country at the most economical and affordable price.” The World Health Organisation (2008)

The district wheelchair service refers to the NHS provider of wheeled mobility equipment, which is free of charge at the point of contact. The wheelchairs are supplied following an assessment of the user’s clinical, environmental and functional needs. The equipment is maintained by the NHS free of charge and is revised and replaced as required. The wheelchair remains the property of the NHS throughout (DOH, The McColl Report, 1986).

Fulltime wheelchair users are those people who use a wheelchair for all their mobility. They self-propel a manual chair, with large wheels, using their upper limbs; drive a battery powered wheelchair; or if unable to propel themselves are pushed by an attendant.

Private provision refers to the purchasing of a wheelchair, either directly financed by the user, or via a joint venture with the NHS called the voucher scheme. This scheme allows the user to supplement the statutory provision by adding extra money to the voucher and purchasing the wheelchair of their choice from a commercial dealer. The wheelchair that is purchased will be maintained and repaired only if the user perceives the need for this to happen and only if they can afford the alterations.

Charity provision is used in this report to denote when a chair is purchased by a fund that is managed by a charity, i.e. Action for Kids, Whizzkidz (both of which supply wheelchairs up to the age of 26 years), The Variety Club or employer/armed forces/police service benevolent funds.

Ministry chair: issued by the Department of Health and Social Security from 1947 to 1991. Initially, a standard chair that came in one size that was issued in a box on receipt of the correctly completed application form, with a doctor's signature. Latterly, a certain amount of flexibility was introduced to allow clinicians to request chairs in a variety of sizes. However, the range was never satisfactory, and basic is the best way to describe these chairs.

Bath chair the definition of the word is "*a hooded wheelchair for an invalid*" (Longman Family Dictionary, 1984) named after the city of Bath, which attracted many invalids who visited the hot springs for which Bath is famous. This description of a wheelchair was in common use in my family home in the

fifties and sixties. However, it is now an out dated term no longer in common usage.

Trajectory is defined as a course of illness over time plus the actions taken by patients, families and health professionals to manage or shape the course

The term “trajectory” refers to the course of a chronic disease in its different stages and phases. (Corbin and Strauss, 2011). Accessed 30/06/2013
http://nursingplanet.com/theory/trajectory_model.html

Chronic illnesses are serious diseases that could last the whole life of the concerned person, affecting mental, emotional and social well-being. (Corbin and Strauss, 2011). Accessed 30/06/2013

http://nursingplanet.com/theory/trajectory_model.html

Chapter 1 Background and context

1.1 Introduction

When I was a girl my grandmother would joke about being pushed in her Bath chair when she was in her dotage. Years later when she was no longer able to walk out of doors, at the weekend when the weather was nice I would take her out for some fresh air in her wheelchair. The wheelchair that was issued to my grandmother was free from the Department of Health & Social Security (DHSS). For this reason these were known as Ministry wheelchairs. The chair was delivered in a box to her front doorstep and the family unpacked it, adjusted the footplates and added a cushion to make her comfortable.

Many years later, the same pattern was repeated with my mother. However, by the time that she required a wheelchair for outdoor mobility I was a senior physiotherapist, in the newly created National Health Service (NHS) wheelchair service. Therefore, I was familiar with the plethora of new wheelchairs that had come onto the market following relaxation of the strictly limited equipment offering from the DHSS. I was able to ensure that my mother was provided with the best equipment available to meet her clinical needs. She had a number of different wheelchairs during her last years, all issued by the NHS. As her condition changed, her wheelchair became more complex. Her final chair, which was custom made to suit her altered body shape, cost about £5,000. This was issued as an item of medical equipment that was used as an adjunct to her physiotherapy, and it was supplied as part of her on-going medical treatment. She was physically assessed for the wheelchair, which was then fashioned with the same attention that prescribing her medication or devising her nursing care plan received. As her illness worsened the wheelchair progressively became less of a mobility device and of rather greater importance in ensuring her wellbeing. The wheelchair was used for safety when she sat out of bed as she was unable to sit in a standard chair. The special seating

prevented her from slipping down, supporting her posture against the ravages of gravity. By doing this it also served to protect her skin from pressure damage as she was no longer able to move herself to change her position. However, to the rest of the family the wheelchair extended Mum's ability to enjoy occasional family outings in much the same way as her mother thirty years before. Choosing to introduce wheelchair use was a pragmatic decision that allowed limited continuation of family life for both women despite their increasing age and infirmity.

Both my mother and grandmother made the transition from walking, for all of their mobility, to wheelchair use, slowly and almost unnoticed. This change was accepted by the family as a natural progression. I never thought of either of them as being disabled. The label "disabled" had little resonance for me, accustomed as I was to working with people with a wide range of abilities every day, and I never stopped to consider the effect that the change in their abilities had on either woman.

These two scenarios, which are personal, anecdotal experiences, serve to demonstrate the change in society's perspective of wheelchair use in the years following the war. Between the commencement of State provision of wheelchairs in 1947, to everyone who met the qualification requirements, and the inception of the NHS wheelchair service in 1991, society's understanding of the wheelchair had changed. My grandmother's wheelchair could be described as a standard piece of equipment used to replace a lost function, i.e. the ability to walk safely out of doors. She was living in the community and the wheelchair merely extended her boundaries outside her home, where she "tottered" relatively safely around the furniture. By the time that my mother was in need of assistance with her mobility, the wheelchair had become an expensive item of medical equipment that required extensive assessment to determine the correct prescription, and her final chair was custom made to meet her clinical needs. This change in approach to the wheelchair in one generation accompanied the administrative changes that took wheelchair

provision from the Department of Health and Social Security into the National Health Service and a medical milieu.

1.2 Introduction of an NHS wheelchair service

The wheelchair, on becoming the responsibility of the NHS, took on new meaning. The government of the day encouraged the development of a clinical perspective towards wheelchair provision. This was in an attempt to address service users' reported dissatisfaction with the wheelchairs provided by the State (McColl, 1986) up to that point. However, when provision became part of the NHS, society's perspective on the wheelchair changed. Wheelchair use became associated with illness and disability. This change in approach from replacing a lost function to treating a medically related cause of dysfunction is a personal perspective of wheelchair provision that cannot be supported with references from literature due to the lack of research in the area throughout this period.

The restructuring of the supply process in 1991 was in keeping with changes in both social attitudes and political policy at that time. The change from wheelchair supply through a department of the civil service to the implementation of NHS universal provision was understood to be the way forwards (McColl, 1986) following a Government sponsored report by Lord McColl (1986). At the time of the McColl Report (1986) the medical model of care had considerable influence and it is possible that the aim of integrating wheelchair provision under the NHS umbrella was intended to harness the power invested in the medical community to improve users' satisfaction with the service provided.

Culturally there was support, at that time, for the view that people whose mobility was affected by impairment or illness should be treated as patients requiring a "cure" (Oliver, 1993). Wade (1992), in his seminal work on rehabilitation, suggested that as active treatment ceases to improve the patient's health and function, effective equipment provision becomes increasingly important in maintaining their quality of life (Wade, 1992). Medicine was progressively seeking to save and to extend people's

lives (American Congress of Rehabilitation Medicine, 1973) and so assistive technologies were required to enhance those lives. In consequence, it was assumed that the correct wheelchair that met user expectations and increased user function was best “prescribed” by a trained health professional (McColl, 1986). Hence, there was general support for this change of wheelchair provision from being the responsibility of the DHSS to that of the NHS. The transfer of which was completed in 1991.

The new district wheelchair services were created nationwide to provide services locally, and they implemented all of the “modus operandi” of the hospital outpatient department. Wheelchair provision was placed in the context of illness, seen as being necessary to provide a means of replacing a lost function when medical interventions had failed to improve the patient’s health and prognosis. All of the processes of wheelchair provision, i.e. clinical assessment of the physical condition of the user and the setting of problem orientated objectives noted in the medical records, were influenced by established medical practice. The language used was that of the hospital outpatient department. The therapists and others working in the service developed a “gate keeper” role with respect to wheelchair provision that could be compared to the physician dispensing prescriptions for medication.

This reliance on medical power improving consumer satisfaction proved to be misplaced. The change in method of provision failed to achieve the hoped for improvement in users’ satisfaction with their wheelchairs (Audit Commission, 2000, 2003). At this time I was employed in the NHS wheelchair service and took part in devising initiatives to improve the service offered to patients, which was how service users were then regarded. Governmental reports published during this period highlighted the need for the NHS to measure performance by adding to the quality of life of an individual without necessarily extending that life (DOH, 2001; 2003; 2005). In response, the wheelchair service began to seek a validated measure to determine the effect of wheelchair provision for the service users. However, energies

were focused on improving their reported satisfaction with their wheelchairs and service and at that time little attention was paid to their experience of wheelchair provision and the contribution that the wheelchair had made to their overall quality of life.

Some years later, the Professional Doctorate course gave me the opportunity to research a topic allied to my practice. Improving the level of satisfaction that NHS wheelchair service users expressed about the equipment that was being issued was still a current concern. The two reports published by the Audit Commission (2000; 2003), had criticised both the manner of service provision and the type of wheelchairs that were supplied. These reports were widely discussed throughout the service and various initiatives put in place, to increase reported user satisfaction (Wheelchair Consultative Group Report, 2003). To date, none of these measures has delivered the intended improvement and complaints continue. This has led to initial discussions taking place to explore new ways of delivering the service (DOH, 2010).

However, this lack of improvement in service users' reported satisfaction could not be attributed to the quality of the equipment that was then being offered. Since the incorporation of wheelchair provision into the NHS, the quality of the equipment supplied has improved and the cost of the wheelchairs supplied has increased (Frank, 2000). The professional literature at this time indicates that outcome measures to evaluate the success of the equipment supplied (Maidment and Merry, 2002; Mills, 2005) were being developed. An outcome measure may be seen as evaluating some aspect of the patient's subjective experience of health and the consequences of illness (Fitzpatrick and Hopkins, 1993).

The development of a measure for use in the wheelchair service was in keeping with initiatives across the whole NHS to measure the effectiveness of interventions and facilitate reporting to managers and the wider community. In the UK, the use of a validated measure was seen increasingly as necessary to justify expenditure on wheelchair provision to the budget holders (Wade, 1992; Turner-Stokes, 1997).

Therefore, the search for a suitable outcome measure for use in the wheelchair service was becoming a popular theme across the country (Wheelchair Collaborative Group, 2003). An outcome measure for wheeled mobility provision was also being developed in Australia and North America (Maidment and Merry, 2002; Mills, 2005). Mills (2005) reported that in North America an outcome measure was necessitated by the equipment funding process. Wheelchairs were supplied in the United States by medical insurance companies, who required information readily accessible to non-clinical budget holders such as actuaries and financiers. In response to this a validated measure to assess the success of the wheelchairs provided was thought by the clinicians to be required (Mills, 2005). However, Mills (2005) suggested that an outcome measure would serve a number of purposes, not only to justify expenditure. She argued that therapists supplying wheelchairs viewed the process from a medical model of care. They wished to be seen as improving function and thus providing rehabilitation. The use of a suitable measure would facilitate this (Mills, 2005) by enhancing the scientific appearance of their decision making. However, despite the passage of time since the initial published work on outcome measures there has been little progress in the area, which a review of the literature confirmed.

It was suggested that the failure to identify a useful outcome measure for wheelchair provision was due to the lack of a common language in the specialty of rehabilitation (Wade, 1992). This made it impossible to select one measure to evaluate many of the interventions in rehabilitation, and wheelchair provision has long been accepted as part of the rehabilitation process. A "basket" of different existing measures and criteria for choosing the most appropriate has been proposed (Turner-Stokes, 1997). The selection criteria included what was to be measured, impairment, disability or handicap and in what setting the patient was seen. From the point of view of wheelchair provision these two features alone indicated a problem when trying to identify a single outcome measure for use in the wheelchair service. The client's

impairment was constant, however, the level of disability that this produced was different in whichever environment the wheelchair was used. Whether wheelchair services attempted to achieve the same outcomes for all of their clients was also questioned in Audit Commission Reports (Audit Commission, 2000; 2003).

When measuring the success of wheelchair provision a number of different measures are required for each of the various diagnostic, disability or age group of users. The environment in which the client lives and the availability of formal and informal care all significantly affect the objectives that are set for wheeled mobility equipment, and consequently the outcomes that are achieved. Some wheelchair users live in especially adapted dwellings with space for the wheelchair to move around and flat access and egress. Others in environmental and social circumstances that are far from ideal for successful, independent wheelchair use. However, community access for wheelchair users is now accepted by society and supported by legislation with the Disability Discrimination Act (1995). This suggests that there has been a change in public opinion regarding wheelchair use in the community over the last fifty years, which was the result of disabled people's struggle for greater recognition and full inclusion in society.

A wheelchair has primarily a practical function. The equipment that is issued is required to enable the user to complete tasks. This is measurable and as such has been used extensively in wheelchair research and provision. Whilst a task completion measure would be helpful in addressing certain factors affecting wheelchair use, the acceptability of the wheelchair supplied may be influenced by many different issues. The individual's perspective on their disability and how this affects the acceptability of the wheelchair has yet to be addressed. However, this drive for objective measurement has now been superseded by recent governmental initiatives in the United Kingdom.

The Quality Agenda was introduced in 1997 designed to improve patient centred care in the NHS and outcomes (DOH, 1997). The objective of this initiative was to bring choice and engagement into healthcare, putting the patient at the heart of the debate (Leatherman and Sutherland, 2007). This has been extended with the introduction of the Patient Experience Framework (DOH, 2012). The Patient Experience Framework advises that it is the patient's experience that should be central to all interactions with the service, and current thinking promotes research for patient benefit (DOH, 2012). The focus in the wheelchair service has now shifted, with the implementation of more personalised interactions with service users that encourage their involvement in all decisions regarding their treatment being incorporated into service provision. The stated purpose of this is to improve efficiency and ensure that care is geographically equitable, thereby promoting greater service user satisfaction.

The NHS wheelchair service has attempted to involve users, through local user forums, since its inception. However, these groups have been informal and addressed the issues of the small number of interested people who attended meetings. Although virtual groups have been discussed in order to access the opinions of a wider number of service users, anecdotally it seems that little progress has been made in establishing these nationally. At this time, the experiences of individual service users are not addressed. No research has been reported that explores this important aspect of wheelchair provision, and so this study was conceived to address this omission.

The stated aim of the Health and Social Care Act (2012) was to place patients at the centre of the NHS. This is to be achieved by changing the emphasis of measurement to that of clinical outcomes and to empower health professionals (DOH, 2010). Quality indicators derived from research will be required to ensure that future provision of wheelchairs offers an equitable and excellent service for all users. The main objective of this study was to enter the world of permanent, fulltime

wheelchair users and explore their perspectives on their wheelchair; how these were formed and what affected their attitude towards the mobility equipment that they used. The findings will inform improvements in service provision and enhance users' experience of the wheelchair supply process.

Demonstrating an improvement in the wheelchair service user's satisfaction with the equipment that is provided is a complex issue, and I was finding it difficult to make progress until I had the good fortune to visit a remarkable young man who was able to put all the aforementioned issues into perspective. I have his permission to tell his story. To protect his anonymity a pseudonym has been used.

1.3 The next stage - a social perspective

Simon was born with a congenital condition that is associated with progressive muscle weakness resulting in skeletal deformity. He had never walked. He has a first class honours degree and lives independently in a modern bungalow that he designed. He has help to get out of bed in the morning from his wife and he also employs a personal assistant one day a week to assist him with administrative tasks. Apart from this, Simon requires no other interventions, despite having very limited physical function and increasingly poor health that prevents him from undertaking paid work.

I was asked to visit Simon, to provide a clinical opinion on behalf of his district wheelchair service, following his application for a new wheelchair. The cost of the chair that he had selected was £14,000. Naturally, the service refused to sanction this expenditure without an independent assessment being completed. As a clinician, after a short telephone call to discuss his requirements, I arrived at his home with a preliminary prescription in mind, which would save the service several thousand pounds. I was proposing a bespoke wheelchair that would hold Simon's posture in a corrected position and be as compact as possible. This was the opposite of the wheelchair that he was requesting.

Simon was able to demonstrate in a couple of hours why issuing the wheelchair that he had selected in his situation made complete sense. It also demonstrated to me how, in adopting an exclusively medical approach to wheelchair provision, I was failing to address Simon's needs. By meeting only what were perceived to be his clinical requirements the more important issue of minimising Simon's disability and facilitating him to achieve his chosen lifestyle were being overlooked.

Simon had spent his whole life assessing and reassessing his function in the light of his progressing physical deterioration. As muscle groups weakened and he was no longer able to perform a movement he developed new coping strategies. In this way he continued to be independent, by using features provided by his chosen wheelchair, as his function decreased. He had gradually designed a wheelchair that provided him with mobility, comfort and functional independence. He understood his disease trajectory and by designing his bungalow had arranged his environment to meet his present and future needs. His wheelchair was able to provide the function that he lacked through loss of movement. He had experimented with the equipment and had developed a wheelchair that facilitated him to have the lifestyle of his choosing. He managed independently without the restrictions of care packages or resorting to a residential placement with personal and nursing care provided. When he was in pain he used the features of the wheelchair to recline his trunk and raise his legs, which allowed him to rest in his chair, rather than return to bed, which he was unable to do without assistance.

Simon demonstrated that the correct wheelchair enabled him to be independent and integrated into his community, despite considerable physical challenges. Changes in society's attitudes towards disability, service users' expectations and government policy indicate that an alternative approach to the supply process should be adopted that recognises the need for the service user to be central to the supply process. Changing attitudes and values now emphasise the need for the individual's experience to be a central pillar of service delivery. With this change of viewpoint

the role of the wheelchair has altered. It is now expected to be a universal tool enabling the user to maintain their desired lifestyle.

These changes in attitude require that wheelchair suppliers consider the user's perspective and adopt a patient centred approach. The former model of assessment and prescription is no longer satisfactory, when increasingly it is a social model of disability that is the framework for the wheelchair users' lives. Clinical examination and prescription of equipment that promotes symmetrical posture and pressure prevention may be at odds with the aspirations of the user who wishes to have an aesthetically pleasing wheelchair small enough to fit into the local supermarket aisles.

It was in seeking to understand the reasons for NHS wheelchair service users' dissatisfaction that I began to explore why the model of care that we were following was not achieving the goals that we desired. I decided that the starting point should be to research the experience of permanent, fulltime wheelchair use. In understanding the perspectives of wheelchair users, reorganisation of provision may be influenced to ensure that the user's experience is improved. To meet the service user's expectations their needs must be placed at the centre of the process.

Having determined the area of interest, the decision was made to step outside the clinical milieu and design the research study from a theoretical framework that reflected contemporary wheelchair use.

1.4 The research study

It was in this context that the research study was conceived and carried out. This study explores the experiences of people who are dependent on a wheelchair for all of their mobility. There are many different reasons to be a permanent and fulltime wheelchair user. Some are unable to regain the ability to walk following accident or illness. Others have never been able to walk due to lifelong conditions and a wheelchair has always been used for mobility.

Those individuals who are occasional wheelchair users have not been included in this research. These are people who are able to walk short distances but find that walking longer distances or out of doors is difficult or hazardous. Also excluded are those individuals who are using a wheelchair for a limited period of time such as following a fractured ankle.

The area of research was chosen in order to inform my practice as a physiotherapist working in the wheelchair service. However, it is intended that the findings of this study be widely disseminated to all those who work within the NHS supply chain through presentations at national and local meetings. A broader insight into the issues that affect wheelchair users will have an impact on my clinical interactions with service users. It is hoped that a greater understanding by staff of the attitudes of service users towards accepting wheelchair mobility will enable them to improve the provision process.

1.5 History of wheelchair provision in England and Wales

To contextualise wheelchair use, a little of the history of wheelchairs and the background to the development of universal provision are now explored.

1.5.1 The wheelchair

Wheelchairs or seats with wheels have been available for many centuries. One of the earliest recorded was that engraved on a Chinese sarcophagus dated 6AD (Kamenetz, 1969). The design of wheelchairs has changed over time and the materials used in their manufacture have evolved as technological advances, particularly in the cycle industry, provided new engineering solutions. The wheelchair has transformed over the last century. Initially, it was an item of furniture that was modified for pragmatic reasons to facilitate mobility of the invalid from one place to another, usually within a limited geographical area such as the invalid's bedroom. An example of this is Henry VIII, who required a wheeled chair later in his life. It became a way of replacing a lost function, i.e. walking for those born with disabilities or who became unable to walk through accident or illness.

The introduction of universal provision into the UK in 1947 transformed attitudes to wheeled mobility. The wheelchair has continued to evolve and is now a technically advanced and expensive adjunct to modern medicine (Frank et al., 2000), exemplified by the equipment used by my mother. Her wheelchair was her only seat and it carried out multiple roles. It was an orthotic device, a variably positioned chair for eating and relaxing, and provided her with a seat in an adapted motor vehicle for outings into the community.

Different methods of providing equipment to assist with mobility have been tried. These changes in the supply process mirror the altered status of people with disabilities in our society. An overview of the changes to wheelchair provision that took place in the UK over the last century is shown in Table 1. It was Lord Kitchener who established the first national provision in 1914. This took the form of a charity fund, the proceeds from which supplied wheelchairs to ex-servicemen wounded in the fighting. The need for charity to provide these men with wheelchairs indicates a feature of disability that became prevalent after the industrial revolution. In order to live, people were increasingly expected to earn a living through paid employment and the injuries that ex-service men sustained in the hostilities often rendered them unable to do so, therefore requiring charity to assist them with living.

During the Second World War the Ministry of Pensions was responsible for supplying wheelchairs to civilians and service personnel who had been injured in the hostilities. Wheelchair provision for the rest of the population continued to be a privately or community funded venture until 1947. With the creation of the Welfare State, responsibility for wheelchairs remained with the Civil Service but was extended to include all citizens requiring assistance with their mobility. This initiative resulted in a standard "Ministry" wheelchair being made available to anyone whose mobility was compromised, and a one size fits all approach was taken (Ham et al., 1998). The importance of the suitability of the wheelchair to meet each individual's clinical needs was not recognised by government until much later. It

was the McColl Report (DoH, 1986) that suggested that responsibility for wheelchair provision should be transferred from the Department of Health and Social Security (DHSS) to a special authority. This report was requested by the government of the day in response to growing criticism with the existing wheelchair provision. In the event, the government decided that responsibility for the supply of wheelchairs should be incorporated into the NHS and this was completed on 1st April 1991 (Ham et al., 1998).

Wheelchairs were, for the first time, to be available locally through a network of district wheelchair services. These new district wheelchair services were often opened on the same site as the local hospital. In this way established facilities such as designated car parking and links with the ambulance service provide a service freely accessible to all.

A clinician would assess each applicant and measure them in order to ensure that they were supplied with appropriate equipment to meet their clinical needs. The limited range of wheelchairs offered by the DHSS, either one that could be pushed by an assistant (attendant propelled) or one with large wheels that the occupant could wheel themselves (self-propelled), was extended. The wheelchair, which had previously been delivered in a box and left on the front doorstep for the user to unpack and set up, was to be delivered by a trained technician and adjusted to fit the occupant.

However, one problem for those making the strategic decisions about the nature of wheelchair provision in England and Wales throughout the last century was the paucity of research evidence in this area. Little has been written about wheelchairs by those who use them, and their opinion of the equipment supplied is poorly reported (Scherer, 1996). User groups are a well-established forum for communication between the users and NHS wheelchair services. It was these groups who were quoted in reports as being critical of wheelchair provision (Audit

Commission, 2000; Wheelchair Collaborative Group Report, 2003). However, little evidence has been published to support their concerns.

Government initiatives incorporated within the National Service Frameworks for Children (DOH, 2003) and Long-Term Conditions (DOH, 2005) have highlighted the need for the NHS to be more responsive to its users' needs. A client centred approach to care in the health and social services is the stated goal in current Department of Health (DOH) reports. The wheelchair service has spent the last twenty years establishing itself within the NHS. However, the client centred approaches, described in these government framework documents, have yet to be addressed with regard to wheelchair provision.

An overview of provision, from charity funding to the state supplying a wheelchair to everyone who has a clinical need for assistance with their mobility, is provided in Table 1.

Table 1- Wheelchair provision in the UK over the last 100 years

Date	To Whom	By
1914	Ex-servicemen	Lord Kitchener's Charity Fund
1939	All those injured in hostilities both servicemen & civilians	Ministry of Pensions
1948	Universal provision	Welfare State- DHSS
1991	Universal provision	NHS

1.6 NHS service delivery

Several problems with service delivery have arisen since the inception of the NHS wheelchair service. It has been difficult to recruit sufficient therapists with the required training (Audit Commission, 2000). This was due to the scarcity of suitably qualified staff, and training opportunities for staff who were employed were scarce (Wheelchair Collaborative Group Report, 2003). Therefore, waiting lists for an appointment at the local wheelchair centres have grown, which may account for the dissatisfaction with the structure and performance of the service reported by the Audit Commission (2000; 2003).

Lack of acceptance of wheelchair use was found by Bates (1993) to produce a disparity between the motivation and goals of the study participant and their therapist in respect of wheelchair provision. This finding highlighted an area that was later to be one of the criticisms of the wheelchair service contained in the Audit Commission Report on the NHS Wheelchair Service (2000). This questioned the difference in attitude of providers and users of wheelchair services in England and Wales. This disparity may be due to therapists' lack of understanding of the perspectives of wheelchair users, and is the area that the present study seeks to address.

Both the wheelchair users and those who deliver the service tended to answer criticism with arguments that highlighted a lack of resources. Insufficient funding was always cited to explain problems with service delivery and the limited choice of wheelchairs issued by the state (Ham et al., 1998). However, since the inclusion of the wheelchair service into the NHS, the range and quality of wheelchairs offered has greatly increased, however, the cost of each wheelchair supplied has escalated in consequence (Frank et al., 2000). The Audit Commission reported that service users thought that the wheelchairs provided did not meet their expectations (Audit Commission, 2000). This disparity between expectations and availability was reinforced by the government of the day's framework documents that emphasised

the need for all service users to be treated as individuals and to make informed choices about their treatment. Those attending the wheelchair service expected that their wishes would be addressed and acted upon (DOH, 1992; 1996; 1998; 2005; 2011). At the same time increasing use of the Internet allowed wheelchair users to explore available products, many of which were unknown to the personnel who worked in the service.

During the last five years, further changes have been proposed to the way wheelchairs are provided in England and Wales (DOH, 2010). These may have been in response to continued user dissatisfaction or in order to limit the escalating costs of wheelchair provision for the increasingly cash strapped NHS.

An announcement, on 22nd June 2006, by Tony Blair in Parliament heralded further reorganisation of wheelchair provision in England and Wales. A new body, the Social Enterprise Unit, was to be established to oversee the “transforming community equipment project”. The stated purpose of which was:

“to give doctors, nurses and other health professionals a helping hand in making the transition into social enterprise”

(DOH, 2006).

In becoming part of a social enterprise initiative the Wheelchair Service would encounter new challenges that the existing staff are poorly prepared to address. The Blair government seemed to be suggesting that a move away from NHS provision was being considered. Following the General Election the new administration issued a consultation document, Any Qualified Provider (DOH, 2010), that supported the former ministers’ proposals. The debate about wheelchair provision leaving the NHS and becoming a function of the commercial sector or that of a public/private finance initiative resumed. District wheelchair services were put up for tender on the NHS supply2health web site (www.supply2health.nhs.uk. Accessed 16/02/2011) and as

the writing of this thesis is completed some district wheelchair services have already left the NHS and function independently with their services purchased by the local Clinical Commissioning Groups.

Whatever the reason that changes are being discussed once again, this study comes at a time when there is an opportunity to shape new service provision. The value of qualitative research as a building block in the formulation of equipment provision processes was highlighted early in the transition of wheelchair provision into the NHS (Bates, 1993). However, no significant body of work has been produced in the following twenty years that would suggest a rise in interest in researching this area of practice. The findings of this research may be timely in helping to inform the debate.

1.7 Political interventions

Due to pressure from interest groups of people with disabilities in the 1990s, the government of the day introduced legislation aimed at inclusion and improvement of access to the community for all. These included initiatives to facilitate people with disabilities to live in the community with suitable support and to make discrimination an offence (NHS and Community Care Act, 1990; Disability Discrimination Act, 1995; Carers (recognition and services) Act 1995; Community Care Act, 1999).

The stated goal of this legislation was to facilitate people with disabilities to be full members of society. One of these initiatives included the closure of long-stay residential hospitals. This led to people, often with profound disabilities, becoming resident in the community. The purpose of this was to ensure that every citizen had equal access to the community; hence wheelchair users are therefore seen in public more often than would have been the case a generation ago. The environmental barriers to wheelchair use are slowly being addressed. The individual's right to be

involved in making decisions about their care and the requirement for choice have been extended into the equipment provision process.

Table 2 sets out the legislation and advice directly and indirectly affecting the NHS wheelchair service since its inception. However, all these changes have resulted in a greater dissatisfaction with the service offered being expressed by its users (Audit Commission 2000 and 2003; DOH 2010). A discussion document regarding the latest reorganisation of statutory wheelchair provision has already been published. This was produced in response to the White Paper relating to the Health and Social Care Act, which was introduced into the House of Commons on 19th January 2011 and received Royal Assent on 27th March 2012. The Bill will affect the wheelchair service, as it is suggested that equipment provision should become a public/private finance initiative, which will encourage any qualified provider to bid to supply wheelchairs in certain locations, replacing the NHS service.

Table 2 - Political interventions in the last century affecting wheelchair provision

Lord Kitchener set up the first national provision of wheelchairs	1914
The Ministry of Pensions was responsible for supplying wheelchairs to civilians and service personnel who had been injured in the hostilities	Second World War 1945 - 1947
Creation of welfare state, all citizens requiring assistance with mobility were provided with a wheelchair	1947
The issue of Ministry chairs - DHSS	1947 - 1991
McColl report	1986
The formation of the district wheelchair services, completed in 1991	DOH 1987
NHS & Community Care Act	1990
Framework document	DOH 1992
The Health of The Nation	1992
The Challenge for Nursing and Industry in the 21st Century (The Heathrow Debate)	DOH 1994
The Disability Discrimination Act	1995

Carers (Recognition and Services) Act	1995
Framework document	DOH 1996
EPIOC scheme - Electrically powered indoor outdoor chairs were made available to profoundly disabled users	1996
The New NHS; Modern Dependable - white paper	DOH 1997
Framework document	DOH 1998
A First Class Service: Quality in the New NHS	London, HMSO DOH 1998
Community Care Act	1999
Audit Commission report on Wheelchair Services	2000
National service framework for older people	London: HMSO, DOH 2001
Governmental reports highlighting the need for the NHS to measure performance by adding to the quality of a person's life without necessarily extending that life	DOH 2001, 2003, 2005
Audit Commission Report on Wheelchair Services	2003
Final Report on the Wheelchair Collaborative Initiative	2003
National Service Frameworks for Children	DOH 2003
Supporting People With Long Term Conditions	DOH 2005
Framework document	DOH 2005
Policy statement: Innovation, Productivity, Prevention (QIPP)	2009
White Paper Equality and Excellence: Liberating the NHS	2010
Local Innovations in Wheelchair and Seating Services	2010
Framework document	DOH 2011
Operational Guidance to the NHS: Extending Patient Choice of Provider – Any Qualified Provider (AQP)	2011

1.8 Use of literature in this study

The literature was explored and reviewed continuously throughout the research process. At the inception of the study, in order to supplement my professional knowledge, a review of work related to measurement of users' satisfaction with their wheelchairs and associated objective assessment tools took place.

Later as interest in the wheelchair user's relationship with the NHS wheelchair service became my focus, the political interventions affecting the decision to create such a service were explored, which included implementation of the wheelchair service and how its processes affected the service users. All of the evidence that was found was helpful as the study was designed in understanding where knowledge of wheelchair use was situated. Having made some decisions about the nature of the study I then wanted to explore issues related to disability. Theoretical models that suggest alternative perspectives were studied. The politics of disability became of importance in increasing my understanding of the influences that participants had experienced in their lifetimes, and investigation of these issues shaped further decisions about the design of this research. It became apparent that there was limited reporting of users' views of their experience of wheelchair use, and that what did exist was the perspective of one individual with a specific medical diagnosis early in their rehabilitation. My interest lay in exploring the perspectives of individuals who might attend their local wheelchair service; a diverse group of people with many years of experience of wheelchair use.

The literature that informed this study was accessed in a number of different ways. Online searches of databases and manual investigations of university and hospital libraries were completed. The online databases included Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Pubmed, The Chartered Society of Physiotherapy, the British Association of Occupational Therapy and Cochrane Database.

Many keywords were used both singly and in combination, and as my interests changed these were altered: initially these were *task completion, evaluation, environment, barriers, measurement* and *assessment*. Works in English from 2000 to 2013 were located. As the study commenced, the perspectives of wheelchair users and the psychological and emotional consequences of the loss of walking and the adoption of wheelchair mobility were explored. I found that there was a dearth of evidence in

this area, a finding that was supported by others (Bates et al., 1993; Reid et al., 2002; Barker et al., 2004). Later in the analysis as new concepts emerged literature on identity, human occupation, adaptation theory, biographical disruption and continuity were all explored.

Literature searching was therefore a continuous process throughout the planning, design, data collection and write-up of the research that informed my perspective on the process and increased theoretical sensitivity to emergent theories.

1.9 The wheelchair user

There are no exact figures for the numbers of people who use a wheelchair for mobility in the United Kingdom (UK), and estimates vary widely. Evidence from a report into the NHS Disablement Services Centres in England and Wales (Aldersea, 1996) indicated that there were approximately 710,170 wheelchairs issued through the NHS at that time. However, it is thought that people with illness and impairments whose walking is affected and use a wheelchair for mobility represent between 8 per cent and 10 per cent of all disabled people in the UK (Papworth Trust, 2008; Grundy et al., 1999); although it is unclear how many of these will be temporary or occasional users. There is evidence that as the population ages, the number of citizens accessing statutory wheelchair services may escalate. The most recent available figures indicate that about 72 per cent of NHS district wheelchair service clients were over sixty years of age (National Prosthetic and Wheelchair Services Report, 1993-1996).

It has been suggested that the evaluation of wheelchair provision should be based on users' views (Herbert, 2000; Audit Commission, 2000; 2003). However, there is a lack of qualitative research in the area of wheelchair provision and literature that reports wheelchair users' experiences. There are studies that concentrate on different groups of individuals with the same medical condition, such as people with spinal cord injuries (SCI) or stroke (Bates, 1993; Oliver, 1988; Barker et al., 2004; Mandy et al,

2011). Wheelchair users were interviewed in these works as part of a larger study, leading to reports on the experience of people with specific medical diagnoses rather than wheeled mobility users as a whole.

One such (Bates, 1993) was an ethnographic study into the phenomenon of adapting to wheelchair use following spinal cord injury (SCI), conducted with a single informant. This study was part of a much larger project that focused on the adaptation to wheelchair use of a group of people who had recently lost the ability to walk. It concluded that there were both emotional and pragmatic factors involved in making the transition to becoming a wheelchair user. Most importantly, it highlighted that emotional acceptance of the wheelchair affected its successful use. The suggestion was that if the patient had negative views of wheelchair use prior to requiring wheeled mobility themselves, perhaps understanding wheelchair use as a loss or personal tragedy, their emotional acceptance of the equipment was affected. Lack of acceptance then produced a disparity between the motivation and goals of the participant and the therapist in respect of wheelchair provision (Bates et al., 1993). This study highlighted an area that was one of the criticisms contained in the Audit Commission Report (2000) on the NHS wheelchair service. This questioned the difference in attitude of providers and users of wheelchair services in England and Wales. This disparity may be due to limited understanding of the service user's perspective (Bates, 1993; Furnham and Thompson, 1994).

The search revealed a lack of literature exploring the phenomenon of being a wheelchair user, which was supported by other research groups (Bates, 1993; Oliver, 1988; Reid et al., 2002; Barker et al., 2004). The value of qualitative research as a building block in the formulation of equipment provision processes was highlighted early in the transition of wheelchair provision into the NHS (Bates, 1993). Bates (1993), suggested that there was a need for descriptive research that addressed the equipment provision process, having found that there was extensive literature available on application of equipment but little that addressed the relationship

between wheelchair provision and functional outcomes. In an attempt to evaluate and place wheelchair related research into context Reid (2002) carried out a review of forty-six papers reporting on the impact of wheeled mobility. This paper was critical of the methodology of the majority of the studies that were reported and considered that this limited their usefulness as research evidence. Only ten of the studies examined were qualitative out of the forty-six papers that met the inclusion criteria for their research. No significant body of work has been found to have been produced in the following ten years to suggest a rise in interest in researching this area of practice.

The present study was based on the premise that there was a dimension to wheelchair provision that the providers were failing to recognise. The Audit Commission Report (2000) questioned the level of understanding between therapists, and others supplying wheelchairs, and the service users (Audit Commission, 2000). This lack of effective communication may be due to clinicians' poor awareness of the attitudes of wheelchair users towards the equipment supplied to them. Staff with a deeper understanding of the perspectives of wheelchair users may have an increased ability to empathise with the users that should facilitate joint goal setting with shared objectives and provide a more satisfactory service.

1.10 Summary

This chapter outlined the context of the study by introducing the wheelchair and the changing pattern of its provision over the last century in England and Wales. Since statutory provision was established for all citizens wheelchair users have complained about the equipment supplied. The chapter explained why, in order to address these criticisms, the role of statutory provider was transferred to the NHS in 1991. The expectation of this change was that the service users' satisfaction with the equipment that they received would improve.

Within the context of the NHS the wheelchair is identified as a piece of medical equipment and delivered in such a manner. However, this medicalization of the wheelchair has not improved users' satisfaction with the wheelchairs provided or the service that they receive. The chapter then outlines why it was thought that an outcome measure that recorded wheelchair users' satisfaction with the equipment that was supplied should be introduced into the NHS and why it was assumed that such a measure would address users' dissatisfaction.

The search to locate an outcome measure may now be outmoded due to recent changes to the direction of NHS policies. Objective measurement and reporting were emphasised when managerialism was the dominant force. The milieu has now changed and has been replaced by a commitment to seek to improve patient experience. This suggests that a contemporary framework for wheelchair delivery should be introduced that embraces a patient centred approach.

Chapter 2 Disability, inclusion and continuity

2.1 Introduction

This chapter discusses my position relative to the key approaches to disability set within the present social, political and cultural milieu. Initially, an understanding of disability and the language that is used when issues of individual impairment are discussed is presented. A sociological perspective is adopted that focuses on the individual within our society. This includes understanding the changes to the expectations of individual's with impairments in the last 50 years most particularly with regard to their access to and engagement with their communities. The chapter then explores the impact of the disability movement on social attitudes.

The consequences of acquiring a disability to the individual are then addressed. This includes biographical disruption and the affect on life map and life choices.

The chapter closes by discussing the place of a research question in a study of this nature and why in this thesis none is offered.

2.2 Ways of understanding disability

In discussing the issues surrounding disability and the use of wheelchairs two problems arise. The first is the language that is used and the second is the model of disability that is preferred as the starting point for this discussion. The lens through which disability is examined changes the way that wheelchair use is understood. Several different attempts have been made to capture these differing perspectives in models of disability, which are discussed below.

It has been suggested that at the heart of the debate is the difficult matter of "*normality*" (Oliver, 1996). The disabled person is prevented from achieving a normal social role because of the restrictions imposed by their impairment. These lead to an inability to carry out specific functions and, therefore, a disability that result in

handicap, which could be described as a disadvantage in fulfilling a “normal role”.

Disability has been defined as:

“functional limitation caused by chronic illness or impairment or the complex interaction between the limitations of the body and/ or mind and society at large”.

Barnes, 2003

This was the most comprehensive definition found that captures the multiplicity of facets to the issue. However, a body of literature exists that supports the need for disability to be redefined in order to remove any stigma in relation to people with impairments in the twenty-first century (Crow, 1992; Campbell, 1996; French, 1994; Cahill, 1995).

The debate about language and the labelling of individuals with impairments is demonstrated by the World Health Organisation (WHO), who rewrote the definitions of impairment, disabilities and handicaps (1980) to keep pace with changing social attitudes (WHO, 2001). The objective of the WHO definition was to indicate the boundaries of what constitutes disability in our society, and the advice in this report has been adopted throughout the world. Attention turned to operationalizing these definitions into models that guide action. The WHO model of disability was one dimensional, being based on the individual’s pathology and impairments. It was suggested that disability should be considered to be a dynamic process, where personal limitations are set within the context of socio-environmental considerations, and in recent years writers have focused their attention more on this blending of personal, environmental and social factors all contributing to the individual’s situation (Masala and Petretto, 2008). However, as the attitudes of society change, the concept of what is thought to be “normal” is also redefined. This is captured in the following:

“normality is a culturally construed notion that is strongly ethnocentric.”

(Fougeyrollas, 1987 cited in Ingstad, 1995, p. 95)

Society’s perspective on wheelchair use has changed dramatically since the start of the last century (Ham et al, 1996). Legislation has been enacted that acknowledges the rights of people with disabilities. The use of wheelchairs in the wider community has been facilitated by recognition of the environmental barriers that exist that prevent their accessing public areas and being fully incorporated into the wider community. However, the wheelchair may still be perceived as reinforcing the negativity that is associated with being disabled or “different” in our society, where walking is considered to be the norm and the environment is built around standing and walking.

A model is a useful tool in a social science context to assist understanding by viewing a phenomenon from many different standpoints prompting: *“insights that would not otherwise be developed”* (Finkelstein, 2002, p. 13). Models concerned with the exploration of disability proliferated in the second half of the twentieth century, and the more prominent of these are described below.

2.3 The medical model

The most important tenet of the medical model is that impairment is viewed as a problem to be overcome. However, the wheelchair service makes no attempt to cure (Wade, 1996) the physical impairments of those who attend the service. The wheelchair service seeks only to provide equipment that replaces a lost function, i.e. independent walking. The wheelchair is tailored to fit each user’s requirements in terms of their biometric measurements and changing needs dictated by their medical condition. The foundations of the NHS wheelchair service, through implementation of the medical model, were built upon the premise that disability was a problem that must be overcome. If this cannot be achieved by curing the individual’s illness or using surgical intervention to correct the impairment a wheelchair is the only option.

Equipment provision has been described as the last resort of rehabilitation when all other interventions have failed (Wade, 1996), with the wheelchair, in this instance, being understood to alleviate the effects of impairment. However, a different perspective expressed by Shakespeare (1996) is that disability is an outcome of the medical profession's inability to make everyone the same (Shakespeare, 1996). This speaks to the ableist movement's agenda (Wilson et al, 2001) which is addressed in 2.4.

It is also suggested that another reason for the adoption of a medical model in the wheelchair service was the medical profession's increasing interest in rehabilitation, which developed as a result of improving medical interventions (Shakespeare, 1996). These enabled people that would previously have perished to survive following accidents and injuries of birth. Wheelchairs had been largely ignored by the medical profession (Wade, 1996) and considered to be the domain of the therapist and nurse. However, a doctor's signature was nevertheless required to access the equipment in the first place. The number of those living with profound disabilities has increased exponentially over the last 25 years and now the service is finding itself unable to cope with the demand for equipment (Audit Commission, 2000, 2003).

The wheelchair in contemporary society transcends the functional. It is understood as medical equipment, a tool for task completion and an item of sports equipment. Today the wheelchair is understood as an overarching symbol of disability, which is widely used throughout the world (Sapey, 2004). It is a universal statement, signifying all disabilities not merely those associated with reduced mobility.

In the latter half of the twentieth century, new ways of understanding disability were suggested. Many of these describe disability from a social rather than medical and diagnostic position. A brief discussion on some of these follows.

2.4 The social model

This alternative model of disability addresses the individual in the society in which they live and disregards their medical condition. The social model considers disability to be the result of barriers that society has constructed that limit the life choices of those with impairments. These take the form of physical, social, educational and economic constraints (Oliver, 1990; Barnes, 1991). The social model of disability was an attempt to refocus attention away from the impairment of the individual to the difficulties caused to that person by the culture and the barriers that the built environment and social attitudes presented (Barnes, 2003). It was described in a statement from the Union of the Physically Impaired Against Segregation (UPIAS) below. This group celebrate difference and argue that,

“Disability is the result of the manner in which contemporary social organisation takes little or no account of people who have physical impairments and therefore excludes them from mainstream social activities.”

UPIAS, 1976

Disability is described in this context as being imposed by a society reluctant to accept difference either *“real or imagined”* (Barnes, 2003, p. 4) which runs contrary to the aim of the UPIAS group, which was to bring people with disabilities into the mainstream and make them visible. Having brought those with disabilities together and into the public domain as a minority group the social model of disability is reported to have been utilised in the UK as a political tool (Watson, 2004).

One interpretation of the social model is that it was developed to highlight the effect of discriminatory attitudes and inappropriate physical and social environments that cause those with a disability or psychological impairment to be disadvantaged (Crow, 1992). In an attempt to influence public opinion, groups of people with disabilities, in the second half of the twentieth century, came together to take positive political action. This has been referred to as the ‘ableist’ movement or ableism (Wilson et al, 2001). These groups advanced the need for education of the

population and promotion of understanding to change the attitudes of society (Barnes, 1999). The exponents of the social model suggest that the removal of barriers, both physical and social, are required for people with disabilities to be included in society. However, it is also suggested that one interpretation of the application of the social model is that disability is socially constructed and so is effectively a "*process of subjection*" (Shakespeare, 1996, p. 97). This, it is argued, is operationalized by segregated education, negative images of people with disabilities in the media, negative cultural representations, absence of positive role models and social isolation (Shakespeare, 1996).

The social model has influenced thinking and research on issues of difference in society over the last thirty years. However, its relevance to present day issues has been questioned and new perspectives are being explored. One such attempt to redefine understanding of impairment was the disability inclusion model (Sayce, 2000). This was based upon establishing strong anti-discrimination legislation to prevent people and organisations from being oppressed. The inclusion model advocates the use of positive images of disability, emphasising strength and assurance. Wheelchair users associated with sport and the arts are promoted to demonstrate inclusivity and oneness with the rest of society.

The inclusion model emphasises the need for people with disabilities to have a strong self-identity and to reject the premise that they are either ill or weak. This runs contrary to the idea of visiting a hospital to be issued with a wheelchair and suggests that it is timely to revisit the service offered by statutory wheelchair providers.

The social model provided a tool for use in the development of disability politics. Individuals with disabilities were encouraged by this alternative perspective to consider themselves as being part of a minority group who were then able to lobby for change. The disability movement brought the issues of people with disabilities

into the public domain and it has been suggested that through this the wheelchair itself became a political symbol (Woods and Watson, 2003). The aim of the movement was to address socially constructed attitudes about what is “normal” in society. Action groups seek to encourage people with impairments to celebrate their differences. This has been called the affirmation model of disability (Swain and French, 2000). This model is demonstrated widely in the arts, where people with impairments take pride in their differences and promote a positive image. This model discusses disability as being caused by the response of society to impairment and seeks to change public attitudes by stressing the positives in being individual, often using this in public performances. This celebration of disability is in marked contrast to the lay model of disability, which anecdotally views disability as being caused by impairments that are regarded as a personal tragedy. In direct opposition to the affirmation model, the lay model describes fear of illness and impairment, which leads to the perspective that experiencing individuals are outsiders. The Paralympics in London may do much to disabuse this attitude. Baroness Grey-Thompson is quoted in a BBC news article by Peter White the BBC disability affairs correspondent as saying:

“if there is one thing that the Paralympics can do it is opening people’s minds to think ‘actually hang on, we used to have this dreadful view of disabled people; they’re work-shy; they’re benefit scroungers, but now we are a little bit more open’.”

Tanni Grey-Thompson

(<http://www.bbc.co.uk/news/uk-19428263>

accessed 22/10/2012 at 15.52).

Initially, the present study was considered from the perspective of the social model of disability. However, Watson (2004) advised that disability should be studied from multiple standpoints and the social model is principally a political approach. This was at odds with the therapist’s perspective, which informed the initial planning of

this study. Disability was understood to be the result of a disabling society that failed to incorporate all individuals' needs into the planning of the built environment and social structures (Barnes, 1991; Finkelstein, 1981). Watson (2004) suggested that the social model set out to challenge understanding of disability by considering those with impairments as being an oppressed group of people. Its use as a framework lifts disability from the individual to the social, exploring oppression of a minority group not the perspectives of the individual with an impairments. Research carried out from this theoretical standpoint would focus on the disabling environment and social structures. It was from this standpoint that I began to plan this study. Exploration of the literature sensitized me to different perspectives which affected my decisions with regard to the design of this research study.

2.5 Social implications of disability

Whichever model of disability the wheelchair user embraces it is the equipment itself that is reported to have an image problem. The requirement to use any assistive device is viewed as necessary but undesirable, and all clinical equipment labels the user as different (Sapey et al., 2004). This difference was associated in the minds of the general public with feelings of pity and charity, to the extent that the term "wheelchair user" has itself been described as a pejorative term (Merck, 1996) that focuses attention on the equipment rather than the user. This study seeks the experiences of the individuals who use the wheelchairs. However, it is impossible to use an alternative form of words without distorting the narrative and so the term wheelchair user will continue to be employed in the writing of this thesis.

Prejudice and reports of abusive behaviour towards people with disabilities are found in the media. One example of this was an article in the *Observer* 24/07/2011. This highlights the concerns of an alliance of 50 charities who wrote to the Minister of Work and Pensions to warn that government statements, with regard to initiatives concerning benefits and access to work for disabled people, used poorly considered language, which, they thought, was responsible for encouraging negative public

opinions on disability benefit claimants. The article refers to the concerns expressed by both Alice Maynard, the chair of Scope, and Jaspal Dhani, chief executive of the United Kingdom Disabled People's Council, who stated that,

“the language portrays disabled people as scroungers...has led to an increase in hate crimes against disabled people, victimisation and reinforcement of very old stereotypes and prejudices.”

Jaspal Dhani

The statement quoted in section 2.4 highlights the importance of the Paralympics in attempting to redress the national balance following this controversial political period.

The behaviour of others, without disabilities, has been observed to change demonstrating social strain when in the presence of wheelchair users (Fichten et al., 1991). These behaviours include inappropriate physical distancing, cutting short their interactions and self-deprecating behaviours. Little wonder that some wheelchair users resent the label that using a wheelchair brings. This is an example of a label being imposed on the individual because of the existence of the wheelchair rather than being chosen by them. It is this labelling that causes disruption at both a social and political level (Barnes, 2003). Barnes (2003) argues that the label is beside the point as it is the way that individuals are understood by society and the reaction that is produced that is the central issue.

It was the mutual understanding of people with disabilities being outside society that led to the formation of action groups in the middle of the last century. The writing of definitions of disability may have created a group consciousness and identity for people with impairments (Oliver, 1996) and influenced the actions of the protest movements.

The social model of disability has been responsible for drawing attention towards those with disabilities being considered as a discrete social group (Barnes, 2004).

From this perspective the social model of disability is linked to theories that explain disability as a socially and culturally constructed phenomenon (Finklestein, 2002). However, this project was conceived from the standpoint of exploring disability from the individual's perspective. A sociological standpoint that understood disability as an individual's experience of the actions of others within the present built environment, social and cultural milieu was adopted. Social behaviourism, pragmatism or symbolic interactionism therefore was understood to be the theoretical perspective that was applied to this research. It focuses on an individual's creation of meaning from experience and human actions, not on macro-social structures. However, it enables these actions to be addressed within the context of the wider society from a sociological perspective.

All the discourses and sociological theories in the models of disability may be used to inform exploration of the process of accepting disability as a consequence of chronic illness, following a life event or due to a lifelong condition.

The way that individuals make sense of their situation may be considered from a psychological standpoint as being one of psychosocial adaptation. The theory of adaptation stems from early work by Jean Piaget (1896–1980) who was seeking to explain how human beings change to accept an altered environment. A psychological standpoint would adopt the premise that adaptation in this study was required by the individual to come to terms with the losses that they experienced following cessation of walking. This theory would address the adoption of wheelchair use as a stress inducing situation that was accompanied by loss or grief reactions and uncertainty. The basic concepts would include stress (Falvo, 1999), recognition of crisis (Livneh and Antonak, 1997), loss and grief (Burke et al., 1992). These trigger responses that include shock and anxiety, denial, depression, anger and adjustment (Livneh and Antonak, 2005). Coping strategies will be developed, which fall into three categories, denial, maladaptive and adaptive (Hamilton and Kasser, 2009). The present study is addressing life transitions considered as social

processes within a personal and sociological context. However, this must include individual's emotional and psychological reaction to their cessation of walking and the permanent use of a wheelchair.

2.6 Biographical disruption

Disability may be a lifelong experience or one that follows a life event, sudden or gradual. This has been investigated through the conceptual framework of disruption to life continuity from many perspectives. Acquired disability was considered from a sociological perspective in this research and wheelchair use was thought of as a biographical disruption for individuals who had previously walked (Strauss, 1987; Charmaz, 1987; Frank, 1995).

It has been argued that for those with a progressive disease, disruption may be experienced as a series of events that accompany each stage of the disease process. Gradual loss of function creates new challenges (Iwama et al; 2009) for the individual as the concept of disability is introduced into their lives. However, Liggett (1988) suggests that being "disabled" is not the accepted self-identity of many people with physical impairments. For those with gradually deteriorating conditions becoming a wheelchair user may be understood in this context as function changes and disability slowly becomes their reality. Alternatively, disruption to life continuity may be a single event that changes the mobility and life course of the individual, who then rebuilds their life and health from this point. Change is therefore a feature of the lives of those who start to use a wheelchair for all mobility, having walked for a period of time. As a researcher understanding this change depends upon the theoretical approach adopted. However, re-establishing a sense of continuity following biographical disruption requires making adaptive changes in an attempt to preserve and maintain existing life structures or to create a new altered life style.

Central to the concept of continuity is plans and aspirations. This has been described in many different ways. One of the interviewees in Frank (1995) describes "the

destination and map ...used to navigate" life (Frank, 1995,pp:1). Similarly, life is understood, in the Kawa model, as a river flowing through time and space (Iwama, 2009). Life course is discussed by Becker (1993) whilst Charmaz (1987) talks of disrupted plans and altered lives and the struggle to "*re-establish valued lives and realise hopes to live on their own terms*" (Charmaz, 1987,pp:283). Each writer underlines the necessity for "*the need to construct some semblance of continuity when catastrophes interrupt the normal flow of life*" (Becker, 1993, pp:148). In this study the term life map is used extensively to describe the human requirement for a planned way forward that influences our actions and sets out our hopes for the future.

2.7 Area of interest of research

My area of interest was the wheelchair user's perspective on wheelchair use. This has become a current issue following advice from the Department of Health (DOH, 2012) that patient experience should be central to all interventions. Understanding the service user's opinions will be helpful in informing the implementation of improvements to wheelchair users interactions with the service. Evidence is required to support change of practice and this study will add to this.

In exploring the contextual issues of wheelchair use, the complexity of the subject became apparent. It was clear that to set a research question was impossible. Grounded theory is helpful in exploring processes (Glaser, 1978). How individual's react to becoming a wheelchair user and interact in their social context through use of equipment for mobility is foundational to this study. It is also stated that researchers need to enter the research area with no preconceptions open to attending to the concerns of the participants (Dey, 1993). The decision was to explore the experience of permanent, fulltime wheelchair use and to allow the issues that emerged from the narratives of the participants to define the question.

2.8 Summary

This chapter explored alternative discourses on disability and recent changes in social attitudes towards people with impairments in our society. The improved

sensitivity facilitated by the search informed my decision to explore an area of interest, wheelchair users' experiences with and perspectives on their chairs rather than setting a research question that would usually be stated at this point in the writing of the thesis.

In order to make the findings more accessible to the reader, the next chapter presents a brief overview of the participants of this study, which may be read in conjunction with the findings to provide clarity.

Chapter 3 Participant Profiles

The rationale for introducing the participants here is to allow the reader an overview of the unique stories that each individual told. The socio-biographical data presented in table form at the end of the chapter is referred to in Chapter 6.

These profiles provide context to the experiences and perspectives that have been analysed and have informed my understanding of the social process that is accepting wheelchair use.

3.1 Jeffrey

Jeffrey was a retired physician with an acquired disability, who began to use a wheelchair full time when he was 25 years old. He attended public school and was an academic high achiever who went on to medical school. He contracted polio when he was 3 years old. However, Jeffrey could walk using callipers and crutches throughout his schooling and medical training. He started to use a wheelchair fulltime when he was a houseman. He described this as a “*purely pragmatic*” decision. Using the wheelchair saved time when he was on call.

Jeffrey was married with children and grandchildren. He had made changes to his family home to suit his needs and these enabled him to live independently with occasional help from his wife or passers-by when he was out alone. He disliked most of the equipment – rails, stair climbers, utensils that were designed for people with disabilities – and said that they “*look appalling*”. He tried not to use this type of product in his home wherever possible, choosing a commercially available item and adapting it to suit his needs. He stated that he had made few concessions to his wheelchair use.

Jeffrey had the financial means and the knowledge to supplement the NHS wheelchair provision and to change his home as was required. He had developed post-polio syndrome later in life, which meant that his condition was no longer

stable. His physical abilities were changing and he experienced pain at times. However, he was able to change his equipment to keep pace with his slowly worsening physical condition. He enthusiastically customised his wheelchair to suit his changing impairment. He said that he had made developing his wheelchair into his “*hobby*”. He visited national equipment exhibitions and researched new developments in wheelchair technology on the Internet to find different solutions to enable him to overcome all new physical losses as they manifested themselves. He accepted his increasing level of physical impairment as a challenge that he addressed and overcame by adapting his equipment, home and lifestyle. He drove a “people mover” vehicle with hand controls and was independent in the community, even though he was no longer able to lift his wheelchair into and out of his vehicle. He described how he overcame this new challenge. He had an outgoing personality and self-confidence. Therefore he was able to ask people passing by to assist him by lifting his wheelchair into and out of his van when he was travelling alone. He liked people and was happy to approach strangers and ask for help when it was required. He found that people were interested in his wheelchair and the ways that he had adapted it to meet his changing physical needs. He considered the wheelchair to be of positive assistance in maintaining his chosen lifestyle.

3.2 Malcolm

Malcolm volunteered early in his interview that he had never been able to walk because he was born with cerebral palsy. He was a twin, and his brother was not affected. His family, none of whom had any experience of wheelchair use, were supportive and he stated that as he was growing up he was included in all activities in which his brother participated. Malcolm was 49 when he was interviewed, and was a manual wheelchair user with a fulltime job as an administrator.

He had attended a special school where he considered that he was given the skills that he needed to give him confidence in the wider community. He lived alone in an adapted flat rented from a housing association. Because the nature of his physical

disability was unchanging, and his home was purpose built for wheelchair use, he did not require any assistance from outside agencies to live independently. Malcolm drove a car fitted with hand controls and he was able to transfer independently into the vehicle and then pull his wheelchair in beside him. Malcolm listed his hobbies as enjoying the theatre and gourmet food. He was an active amateur sportsman.

3.3 Joshua

Joshua was a 22-year-old undergraduate at university. He too was born with cerebral palsy and he also felt the need to state this at the start of his interview. He had never been able to sit independently or to use his lower limbs to stand and walk. He attended a special school for all of his education prior to starting his degree course. Joshua lived in halls of residence that were suitable for students who used wheelchairs, and in the holidays he returned to his parental home. No other member of his family used a wheelchair. At the family home Joshua had a downstairs suite of rooms especially built to meet his requirements. Whilst at the university he was supported by visiting carers, and at home by visiting carers and his mother. He said that his parents and siblings had always been supportive and that he was included in all family activities.

Joshua was unable to use his arms to propel a wheelchair and so used a large powered chair which had a number of sophisticated features. This chair was supplied by a charity that funds equipment for children and young people with disabilities. He said that the look of his wheelchair was important as it was part of his image. This was why he chose to have his equipment supplied by a charity rather than accept an NHS wheelchair that would not look as good. He explained that often it was his wheelchair that people would talk about when he first met them.

Joshua was certain that the curriculum delivered at his special school gave him the confidence to leave home and attend university. He was able to move independently around the university campus, which had a number of environmental barriers to

wheelchair use. He used the local buses and taxis when he left the campus to go into town. He hoped to work in the charity sector or for a non-governmental organisation when he graduated. He had made plans for his life and ambition.

3.4 Matt

Matthew was an outgoing young man who worked as a grounds-man at a golf course before his accident at the age of 19. This was a car crash in which he injured his spinal cord. He described a daily pattern to his life before the crash as work then down to the pub for the evening. He used to participate in sport in an informal way with the lads but never joined a sports club. He explained that he *“hadn’t thought of it and he didn’t know how”*. Clearly, he needed someone to notice his potential and give him guidance, as he was to become an elite sportsman following his accident, winning a Paralympic gold medal at the Beijing Olympics, of which he was tremendously proud. He was sure that if he had not had the accident and received specialist assistance he would never have had the opportunity to develop as a sportsman. Because of his sporting prowess he was sponsored to train and compete. However, he supplemented this income with light industrial work on a casual basis when able. He was a single man who was supported by visiting carers. He lived alone in a purpose built wheelchair-adapted bungalow where he could carry-out all tasks from his wheelchair.

His wheelchairs were provided through a number of different sources. His main chair was purchased through the NHS using the voucher scheme via his district wheelchair service. He also received money from different charities and Sports Council grants that he spent on the more sophisticated equipment essential to compete at high level in his sport. He stated that the standard equipment available from the NHS was unable to meet his requirements either for his everyday needs or to allow him to participate in his chosen sport. He had strong arms and so used a self-propelled wheelchair; he drove a car with manual controls, transferring into the

driver's seat and then pulling the wheelchair in beside him. He too was confident to ask for help if he required it.

He believed that the look of his wheelchair was important and that its function was considerably improved by the adjustments and modifications that he carried out. He was learning all the time about his particular requirements from his wheelchair and designed these into each new chair that he brought. Although, he had had no contact with or interest in people with disabilities before his accident he had become a confident and proficient wheelchair user who excelled in his chosen sport which gave him purpose and achievement.

3.5 Patrick

Patrick was a retired 73-year-old married man. He had been using a callipers and crutches to walk since contracting polio in his early teens. This continued until his middle years when he acquired his first wheelchair. He was married and lived in a house that had few alterations to facilitate wheelchair use. He also owned a cottage in the country that he reported had no adaptations. He was assisted when necessary by his wife and did not require any additional care.

Patrick attended mainstream school and trained as a teacher. However, as his physical condition deteriorated he changed his occupation because he could no longer stand for long periods. As he aged, his muscles had become progressively weakened through post-polio syndrome and arthritis. He gradually became unable to walk with callipers and crutches and when interviewed he used a wheelchair all of the time. He enjoyed driving his car, which had hand controls. However, he increasingly required his wife to assist him with this. She helped with transfers into the vehicle and by folding and stowing the wheelchair in the boot of the car. It was she who usually pushed the wheelchair when out- of- doors as Patrick was unable to self-propel due to pain and weakness in his shoulders. However, he stated that he had not thought about obtaining a powered wheelchair.

3.6 Sue

Sue was a retired nurse, who was 51 years old and had been a permanent wheelchair user for 11 years when interviewed. She had a slowly deteriorating medical condition that could prove fatal. It was this condition that caused her to retire from her teaching post in the nursing school. She became a lecturer when she was no longer physically able to nurse on the wards. She was married with a supportive family and she had visiting carers. She had no experience of wheelchairs before entering the nursing profession and no one else in her family had a disability. She stated that it was her mother who found the wheelchair most distressing.

Sue's home was adapted to allow her to sleep downstairs in a purpose built room with an en-suite wet room. Her mother brought her a powered wheelchair when she began to find it difficult to use her NHS manual self-propelling chair. Her powered wheelchair allowed her to continue to be an active homemaker and with activities outside the home, which included voluntary work at the local cathedral. She considered that the wheelchair facilitated social interaction. Her experience was that she had no problems approaching strangers for help if required when she was out and she had found that the wheelchair gave her an affinity with other people with disabilities which was an asset in her voluntary work. She considered that the wheelchair was allowing her to continue to use the skills that her nursing career gave her even though she was no longer well enough to work.

3.7 Chantelle

Chantelle was 22 years old and she had used a wheelchair since sustaining a spinal cord injury when she was 15. Following rehabilitation she was transferred to a residential care facility as she was unable to return to her family home. Subsequently, she had moved into a purpose built housing association flat that had room for live-in carers. Therefore, Chantelle was rarely alone. However, she described accepting help from others as difficult. Her accommodation was arranged through her social worker, on whom she had come to rely since leaving the

rehabilitation unit. The NHS supplied her manual wheelchair and she had obtained a powered chair through a charity. Having this wheelchair enabled her to go out on her own, which was tremendously important to her.

She maintained close links with the friends that she made when at school. She also had a group of friends whom she met at the rehabilitation centre. She was single but would like a boyfriend. However, she stated that the wheelchair stopped her from meeting anyone.

She was unemployed and had no interest in completing her disrupted education. She had been unable to develop, what for her, would be a meaningful daily routine. Her main occupation was shopping or going out with her friends to public houses. She believed that by having sophisticated features on her powered wheelchair she was more able to “*fit in*” with others, i.e. her friends who were all able to walk. She considered that the most important feature on the powered wheelchair was the ability it gave her to raise the seat on the chair to maintain eye line with her friends when they were standing or sitting on high bar stools. Such a wheelchair is not available from the NHS and so she had purchased one with charity funding.

Without the physical ability to drive a car or strongly propel a manual wheelchair, the powered chair allowed her to have independence without having to ask someone to accompany her outside her home. Her NHS wheelchair was a manual self-propelled one. She found it increasingly difficult to propel this as her arm muscles, she said, were weakening. Therefore, when she was forced to use the manual chair, usually because the powered chair had been damaged and was awaiting repairs, this made her frustrated. However, she went on to describe how the powered chair was often unable to be used because she had accidents when she was on the way home from an evening out. Her behaviour was no different from that of her friends, however, in having a little too much to drink driving her chair became erratic, resulting in repercussions in the form of breakages to her wheelchair

that took time and money to repair and often restricted her independence for many weeks while replacement parts were obtained.

3.8 Kathryn

Kathryn was a 28-year-old woman with cerebral palsy who had never been able to walk. She had attended both special and mainstream schools and a further education college specifically for people with physical disabilities. She lived with her partner in a purpose built bungalow that she rented from a housing association. Her partner was also employed to provide her with care on a full-time basis. Although she had not found paid employment since leaving college, Kathryn described herself as *“always busy”*. She was a governor at the special school that she had attended. She travelled extensively, unaccompanied, on public transport. She described experiencing many obstacles in the built environment and because of others’ attitudes towards people with disabilities her experiences had led her to become an advocate for others and a campaigner for disability rights.

Kathryn was never able to sit without support or to stand and she could not use her arms to propel a wheelchair. Therefore she was unable to move independently, like Joshua, until she was issued with her first powered wheelchair. She vividly described this moment. The wheelchairs that she used were supplied exclusively by the NHS and she was satisfied with the equipment and the wheelchair service.

Kathryn stated that she was happy with her life, she was in a committed and stable relationship and she hoped to start a family in the near future.

3.9 Maeve

Maeve was retired and lived alone. She had attended mainstream school and had little experience of people with disabilities until she became a wheelchair user herself. She was 60 when interviewed and had used a wheelchair for 15 years. Maeve had a slowly deteriorating disease that could be fatal. She first used a wheelchair for outdoor mobility. However, when interviewed she was unable to

stand or transfer independently and so she had carers from an agency who visited four times a day to help her with personal care, housework and cooking. She sat in her wheelchair from the time that her carers left in the morning until they returned to help her to bed in the evening. She reported that she had little contact with her family but that she had lots of friends.

Maeve described the wheelchair as helpful in allowing her to continue doing her own cooking for some years. The house, in which she lived alone, was not adapted for wheelchair use, and she described her life as severely restricted.

However, Maeve described herself as an outgoing, gregarious lady. Once her illness forced her to retire she spent her time organising and performing in shows for the elderly, which she said were very popular. The work that they entailed was voluntary. Maeve had the ability to co-opt help from performers, coach drivers and others to ensure that the shows were a success despite being without funding. She described these performances with pride and an obvious sense of fulfilment. Her inability to continue with this activity as her illness worsened was a tremendous loss to her. As her impairments had increased she had become socially isolated, unable to leave her home because of access issues, and weakness in her arms meaning that she was no longer able to propel her wheelchair.

Maeve used a basic NHS manual wheelchair. She had been assessed for a powered wheelchair through the NHS. Unfortunately, her application had been refused. Maeve did not have the means to purchase a powered chair herself. However, in her interview she failed to mention that her home was not spacious enough for her to use a powered wheelchair nor did it have suitable flat access for a heavy wheelchair. As her physical abilities changed she had been unable to make plans for her future and to change her home to accommodate a larger wheelchair. Some alterations would have made her life easier and facilitated task completion. When she was interviewed at home she was unable to care for herself or her home and was totally

dependent upon others help to remain in her home. She had little access to the community and was becoming socially isolated.

3.10 Di

Di was a 33-year-old single graduate who walked until she was 13, when she had an accident injuring her spinal cord necessitating fulltime wheelchair use. She had strong arms to self-propel her wheelchair and participated in wheelchair sports of all kinds. Following her rehabilitation she completed her education, at the school that she was attending at the time of her accident and went on to university. On graduating she obtained employment some distance from her parental home. She lived alone, with no outside assistance, in a partially adapted flat near her office. This she said was a cause for constant concern to her mother. However, she was loathe to lose her independence by moving closer to her parents.

Di considered the wheelchair that she used as a fashion accessory on which she would spend whatever was required to provide her with the image and the standard of engineering that she was seeking. Di stated that her wheelchair was an extension of her body, an adornment and a tool.

She drove a car, and had exacting standards when she chose the car, which were mirrored in her selection of wheelchair. She explained that she would not accept a standard NHS wheelchair because her comfort and function would be impaired. She regarded the features of the self-propelled chair as very important when she was at home. However, it was the appearance of her wheelchair that was of greater relevance when she was out in the community. She was a well-integrated member of society with plans and ambition.

Each participant was telephoned before their interview to make arrangements. At this time their socio-biographical details were completed if not previously collected and they were asked where they would like their interview to take place. Two participants asked to be visited at home because they found going out difficult. For

convenience one was interviewed at his halls of residence and an additional three at home for logistical reasons. The other four were interviewed at the offices of the social or sports club that they attended.

The socio-biographic data that were collected have been tabulated below. These indicate the diversity of the participants interviewed.

Table 3 – Participants’ biographical details

Participant name	Male or Female	Age	Age began to use wheelchair	Have walked or never walked	Age grouping identified
					0–29 Y 30–49 M 50–75 O
Jeffrey	M	60+	25	W	O
Malcolm	M	40+	0	N	M
Joshua	M	20+	0	N	Y
Matt	M	20+	19	W	Y
Patrick	M	70+	40	W	O
Sue	F	50+	40	W	O
Chantelle	F	20+	15	W	Y
Kathryn	F	20+	0	N	Y
Maeve	F	60+	45	W	O
Di	F	30+	13	W	M

Table 4 - Schooling and employment details

Participant name	Special school or mainstream	Married/partner or single	Formal care Y/N	Employment
Jeffrey	Mainstream	Married	N	Retired professional
Malcolm	Special	Single	N	Employed
Joshua	Special	Single	Y	Studying
Matt	Mainstream	Single	N	Employed/training
Patrick	Mainstream	Married	N	Retired professional
Sue	Mainstream	Married	Y	Retired professional
Chantelle	Mainstream	Single	Y	Unemployed
Kathryn	Special	Partner	Y	Unemployed
Maeve	Mainstream	Divorced	Y	Retired
Di	Mainstream	Single	N	Employed Graduate

Table 4 refers only to formal care from paid carers. Also included are the participants' marital status, schooling and employment details.

An indication of the functional disabilities resulting from the participants' impairments was demonstrated by their need for **formal care** to be provided. The married male participants both mentioned that their wives carried out caring roles, and this was understood as **informal care**. However, this assistance was not considered by the participants to be beyond normal expectations within the family circle. Two of the female participants received formal care. One, who was in the 50–75 age group, was married and had visiting carers to assist her. The second, in the younger age group, 0–29, was in a longstanding relationship and her partner received payment for the caring duties that he performed. Both are reported as receiving **formal care**.

Table 5 presents the participants' wheelchair and accommodation information. It shows that half of the participants predominantly used a manual chair and the rest used powered wheelchairs, along with who supplied these chairs and whether their home environment had been adapted to facilitate the wheelchair used.

Two participants had homes that were not adapted for wheelchair use. One chose to use a manual chair that was supplied by the NHS the other stated that she had no choice as the NHS would not provide her with the powered chair that she wanted. However, she did not have the space or access at her home to accommodate a powered wheelchair.

Table 5 - Wheelchair and accommodation details

Participant name	Choice of wheelchair propulsion	Makes allowances for wheelchair in lifestyle	Who supplied the wheelchair
Jeffrey	Manual self-propel becoming difficult-power pack added	Deteriorating chooses when to change chair and home as required	Private purchase
Malcolm	Chose to self-propel	Home w/c adapted	NHS
Joshua	Powered	Necessity/home is w/c adapted	Charity
Matt	Manual self-propelling	Choice/home is w/c adapted	Charity
Patrick	Manual self-propelling	Choice/ Home NOT w/c adapted	NHS
Sue	Powered	Necessity/ home is w/c adapted	Private
Chantelle	Powered	Choice/home is w/c adapted	Charity
Kathryn	Powered	Necessity/home is w/c adapted	NHS
Maeve	Manual self-propelling	No choice/ home NOT w/c adapted	NHS
Di	Manual self-propelling	Choice/home is w/c adapted	Private

3.11 Summary

The chapter has provided background information and colour to enable the reader to understand the quotes that are offered to evidence the findings of this study. The data set out in Tables 3 – 5 provide an overview of the participants socio-biographical and wheelchair information for clarity. These data were used in conjunction with that from the interviews to explain the process of accepting wheelchair use that follows.

Chapter 4 Methodology

4.1 Introduction

This chapter seeks to set the study within the theoretical framework that guided the research. The ontological and epistemological foundations to the study are explained, and decisions, with regards to methodology in relation to the area of interest of the research, are discussed.

The selection of participants is explained within the context of the methodology adopted, which is a grounded theory approach, Dimensional Analysis (Schatzman, 1991). The reasons for the selection of this perspective are explained.

The chapter concludes by addressing how the issues of trustworthiness and researcher reflexivity are managed in this study.

4.2 Outlining the methodological decisions in this study

Having established the area of interest of the study, the literature on methodology was explored in order to determine a theoretical framework to underpin this project.

As a novice researcher I found the variation in terminology of all of the major works in this area to be challenging. I have therefore chosen to base this justification of the theoretical stance chosen in this thesis on suggestions of Cresswell (2007). Ontologically, the study assumes that reality is subjective and context bound and that each participant constructs their reality through their experiences of the world as they perceive it. Therefore, there is no one single reality – it is dynamic and changes with experience.

It was in order to inform change in the NHS wheelchair service provision that an understanding of the perspectives of permanent and fulltime wheelchair users was sought. Little evidence of the wheelchair user's opinions had been found when preparing for this study and in order to inform changes to provision an understanding of these were essential. To collect these perspectives I planned to sit beside the participants in their worlds and to listen to their experiences, attitudes

and concerns. Epistemologically I have therefore placed myself to minimise the distance between the researcher and the researched. In taking the research into the “*field*” (Schaztman and Strauss, 1973, p.1) I have spent time with the participants in an attempt to understand the context of their lives as well as their narratives. The participants were empowered to share what they wanted to convey and in this thesis their voices are used to explore the concepts. The report of the findings uses quotes from participants to provide evidence to support the analytical decisions that I have made. However, the researcher, an experienced clinician, had experiences and perspectives at the start of the enquiry which are acknowledged to have influenced my interpretations of the data. All research is understood to be value-laden and that biases are present (Cresswell, 2007, p17).

The final report has been written in a personal “*literary*” (Cresswell, 2007, p17) style using language associated with qualitative research. I have collected varied and detailed data that was then analysed in order to define a generalised experience of wheelchair use. Epistemologically this study was carried out from a subjectivist and social constructivist/interpretivist perspective. The area under examination was complex and descriptive and I wanted to interpret the data using my existing knowledge and to understand a social process: being a wheelchair user. The study therefore satisfies the suggested conditions necessary for qualitative research outlined by Denzin and Lincoln (2005, p3).

This was the starting point for making the decision on selection of the research methodology. In order to carry-out the study a methodological position has to be selected.

A number of different methodologies focus on the lived experiences of individuals and were considered in respect of guiding this study, each had implications for the findings.

Had a narrative study been chosen it would have focused on collecting the experiences of a single person using a number of different sources of data, such as interviews, letters or diaries. These experiences may be chronologically connected (Czarniawska, 2004, p 17). Alternatively, in a narrative research study a small number of individuals might contribute to a composite story of an event or phenomenon (Polkinghorne, 1995). This methodology was rejected as there is little written evidence in the area of wheelchair use to inform an understanding of individuals' life experiences, either singly or as a group of wheelchair users. Data collection was planned to be from interview transcripts. This study does not seek to situate the context of the experiences of participants within any particular area of life, work, culture or historic experience. The wheelchair is present all of the time and affects all aspects of life. Within a group of participants, becoming a wheelchair user could have happened at any time and in a number of different ways. Narrative research would have taken the experiences of wheelchair users and "re-story" the case discovering causal linkages (Cortassi, 1993). This study focuses on the experiences of wheelchair use as reported by individuals. It was the reported differences in these experiences that led to an understanding that a social process was being described, which was unique for each individual. It was this social process that I sought to explain by constructing a theoretical model (Schatzman, 1991).

A phenomenological study would have described the phenomenon of accepting wheelchair use for several individuals through their lived experiences. These experiences are conscious and directed towards an object. Initially, it was thought that the wheelchair was such an object and that phenomenology was a suitable methodology to guide this study. However, the main objective of phenomenological research is to distil the universal essence of the human experience (van Manen, 1990), the "how and what" that was taking place (Moustakas, 1994). This study analysed the lived experiences of individuals and interpreted their narratives to

provide an explanation of a social process. My involvement in the wheelchair service informed my starting perspective as a researcher and this was acknowledged as a part of the research process. To bracket (Moustakas, 1994) this experience was acknowledged to be impossible as the therapist tends to interpret all information provided. These reasons influenced the decision to choose an alternative methodological approach.

An ethnographic study would be interested in the shared patterns of behaviour developed in a specific cultural setting and requires large numbers of participants, who are often geographically close and interacting with one another. Wheelchair users usually live in communities where walking is the norm and wheelchair users are in the minority, often having little access to others with mobility issues. This gives rise to a perspective that is principally influenced by the behaviour of others reacting to a minority. An ethnographic study would consequently be inappropriate in this research. Participant observation is most often the method of data collection, with the researcher becoming immersed in the culture that is being researched (Cresswell, 2007; Atkinson and Hammersley, 1994). The description of the daily lives of wheelchair users in an institutional setting may be addressed from this perspective. However, ethnography did not offer the approach that was required to explore the lived experiences of individual wheelchair users living and working in the community that was required in this study.

A case study approach (Simons, 2009; Stake, 2006) was considered to allow the exploration of a number of participants' perspectives to inform the case. This methodology is used when contextual factors surrounding a case are the main concern in a study, and a detailed description of the setting for the case is prepared. Contextual factors have an impact on the individual's perspective of wheelchair use and vice versa. However, I wanted to gather wheelchair users' perspectives on their wheelchairs and study these perspectives. The paucity of evidence on this subject has already been discussed, and participant observation, a main data collection tool

in case study research, would not have addressed the area of interest of the study. This approach was therefore not progressed.

A grounded theory approach provided flexible guidelines for collecting and analysing data of the lived experience, and from this to construct a theory that was grounded in the data themselves. The collection of the data was carried out by interviewing experienced wheelchair users and gathering their individual perspectives on wheelchair use. By comparing and contrasting these data, accepting wheelchair use was understood as a social process of individual transition.

4.3 Symbolic interactionism

The data were collected and understood using a symbolic interactionist theoretical perspective (Blumer, 1969) the development of which was influenced by pragmatist philosophy (Charmaz, 2006, p. 7). Reality is understood to be created in the mind of each participant (Corbin, 2009) and developed through “*practical actions [taken] to solve problems*” (Bryant and Charmaz, 2007, p. 609). The wheelchair, viewed through this lens, was understood to have a symbolic meaning for each participant that was created in the mind of the participant through interaction with others and these were subject to change.

This study explored the wheelchair user’s attitudes expressed during in-depth interviews. The decision to conduct interviews with wheelchair users led from a desire to understand the world of the participants, to listen to their stories, and with them, through the use of language, to understand their perspectives. Observation of the participants in the field was helpful in providing context to the data collected and greater understanding of the world of the individuals interviewed. However, this form of data collection was regarded only as background information. The perspectives of the users, i.e. the creation and modification of the meanings that the wheelchair had for them, was understood through the in-depth conversations. The

perspectives were those stated at the time of the interview and are acknowledged to be undergoing constant development and alteration.

Face to face interviews took place in order for participant observation to capture the context that situated the participants. I joined the participants in their world and together we co-constructed a shared understanding of their perspectives of wheelchair use through the symbol of language. However, it is understood that both in the collection of the data and during the analysis of the transcribed interviews, interpretation was constantly taking place (Charmaz, 2006).

4.4 Background to the methodology

It was an ethnographic research project looking into death and dying (Glaser and Strauss, 1965) that led to the development of grounded theory (Glaser and Strauss, 1967). Glaser and Strauss suggested a means of grounding theory in the data using *“conceptualisation, constant comparison and gradual abstraction to form new theories”* (Timmermans and Tavory, 2007, p. 491). Barney Glaser was trained at the department of Sociology at Columbia University (Glaser and Strauss, 1967) and was experienced in using descriptive statistics and comparisons (Stern, 2009). Anselm Strauss’s research background was at the department of Sociology at Chicago University.

Before their collaboration, Strauss, a theoretical sociologist already had a body of work and publications to his name (Stern, 2009). Chicago school sociology was built on the foundations of pragmatist philosophy and ethnographic fieldwork (Stern, 2009). Strauss was experienced in theory generation and symbolic interactionism. His work was influenced by an approach developed by George Herbert Mead and John Dewey (Blumer, 1969). He understood reality to be complex, socially derived and multi-layered. Meaning for each individual stemmed from their social interactions and altered as that individual considered and renegotiated their understanding of the world and their experiences (Blumer, 1969).

Glaser and Strauss collaborated together in a study on death and dying (Glaser and Strauss, 1965). During this time much of the development work on grounded theory methodology took place. The death and dying study was an ethnographic research project that required the development of new analytical strategies to arrive at explanatory theories for social behaviour (Charmaz, 2006). It was during this collaboration that the foundations for their seminal work *“The Discovery of Grounded Theory: strategies for a qualitative research”* (Glaser and Strauss, 1967) were laid.

4.5 Selecting the methodological approach

The area of interest of the research lent itself to aspects of grounded theory. In planning this study the decision was made to use an approach that grounded the theory in the data. However, my reading led me to question whether to use a classic grounded theory method (Glaser and Strauss, 1967) or one of the more recent developments of the approach. Glaser (1992) had suggested that these developments of the original method were not grounded theory, but merely a way to ground theory in the data (Glaser, 1992) and produce thick description. Seven variations of the approach have been identified (Denzin, 2005). This proliferation of different applications of the original grounded theory methodology is understandable as this is now reported to be one of the most widely used qualitative research methodologies (Payne and Payne, 2004). The suggestion is that *“as people change so do the methods that they are using”* (Corbin, 2009).

The development of grounded theory marked a major departure in the evolution of qualitative research by providing a technique to develop explanatory theories out of the data. Previously, the most prevalent research methodology was deductive, applying formerly devised theories that were tested and confirmed or refuted by the data. The grounded theory method allows decisions about the data to be both inductive and deductive. Initially, an inductive stance allows understanding and theory to grow from the data. This is then explored, deductively, by returning to the original data for confirmation or refutation.

Grounded theory methodology allows the research to develop out of an initial area of interest (Glaser and Strauss, 1967). This was appropriate in this study, where an issue had been identified that required greater exploration. Grounded theory methodology is valid when little is known about a specific issue (Morse, 1994). I was attracted by the prospect of grounded theory assisting me to explore “*what is going on*” (Glaser, 1992, p. 41). The study was not based on a previously formed theory. The ontological and epistemological approach to the research required that the data lead the analysis and, by a process of induction, to understand the concerns of wheelchair users.

4.5.1 The Divergence

Grounded theory method, as described by Glaser and Strauss in “*The Discovery of Grounded Theory*” (1967), was used extensively by researchers in the areas of Sociology and Health Studies from its inception. This required that the authors, and those who learned the methodology from them, were asked to further develop the technique described in the text of the 1967 work. This was to facilitate the understanding of novice grounded theorists. In trying to achieve, this Strauss and Corbin published “*Qualitative Analysis for Social Scientists*” in 1987. This led to what is widely referred to as the “divergence”. In trying to produce a helpful handbook for students, Strauss had, in Glaser’s opinion, unilaterally changed the original grounded theory method to the extent that the methods described in the 1987 text were no longer grounded theory. His thoughts were expressed in “*Basics of Grounded Theory Analysis – emergence vs. forcing*” (1992). Glaser (1992, p. 3) writes that in following the Strauss and Corbin (1987) approach what is achieved is:

“a forced, preconceived, full conceptual description, which is fine, but it is not grounded theory”. Glaser (1992)

The suggestion was that the use of additional elements within the analysis forces the data and so leads to description and verification, not the emergence of theory that is the essence of grounded theory method. However, clarification of the original text

was requested by students who found the lack of detail made operationalizing the method in their own research difficult. This often resulted in poor levels of abstraction being achieved (Schatzman, 1991). Also Strauss advocates that the researcher actively seeks conceptual categories in the data, causing the fit to be “forced”. In contrast Glaser believes the categories will emerge with iteration (Locke, 1996; Melia, 1996) and advises patience.

4.5.2 Evolution of the grounded theory method

Many different methods of grounding theory in the data have been described. Charmaz, (2006) suggests a constructivist grounded theory, and Clarke, situational analysis (Clarke, 2003, cited in Morse, 2009, p. 17). Charmaz describes the proliferation of grounded theory methods as being “*like a family*” (2007, p. 12). Certain features described by Glaser and Strauss (1967) in their original work are present in the new “*offspring*” and others are missing. Glaser would not consider these to be true grounded theories; merely description and the verification of theories formed by forcing the data (Smit and Bryant, 2000).

In this research study, certain processes that are discussed by Glaser and Strauss (1967) in “*The Discovery of Grounded Theory*” were used. However, the traditional grounded theory method was not comprehensively followed and therefore this cannot be described as a research study that uses the grounded theory method. Dimensional Analysis (Schatzman, 1991) was then explored because it offered the novice researcher greater structure when analysing the data to facilitate an understanding of the process of acceptance of wheelchair use from the users’ narratives.

4.6 Dimensional Analysis

Dimensional Analysis (Schatzman, 1991) was described by Dr Leonard Schatzman, a colleague of Drs Glaser and Strauss in San Francisco. He supervised postgraduate students who were completing studies using grounded theory method. In helping them to organise and analyse their data he realised that he was offering an

alternative method of analysis (Bowers and Schatzman, 2009; Robrecht, 1995; Kools et al., 1996).

Dimensional Analysis has its own procedures and epistemological assumptions. Schatzman (1991) described the importance of establishing the full extent of what the data has to tell us. This, he wrote, was a foundational part of a symbolic interactionist approach to research. The researcher's perspective should be centred on human interactions in their natural setting (Robrecht, 1995, p172). However, Dimensional Analysis is informed by the core ideas and practices of Grounded Theory (Glaser and Strauss, 1967; Glaser, 1978; Strauss, 1987) and there "*is considerable overlap between them*" (Bowers and Schatzman, 2009, p. 90).

Dimensional Analysis offers a procedure to follow in order to logically manage data and facilitate abstraction. I was aware that my preconceptions might, if not managed systematically, allow me to close my exploration of the data prematurely and limit abstraction. I was also conscious of the need to be explicit about the discovery processes in this thesis to allow audit to take place. The explanation of the social process was created, without forcing, from the data and compared to existing theories (Glaser, 1992). Glaser (1992) would question the use of a structured analysis as suggested in dimensional analysis (Schatzman, 1991) in the same manner that he refused to accept the additional structure to the analytical process that Strauss and Corbin (1990) had developed to explicate the original grounded theory method. Glaser's concerns regarding "*emergence vs. forcing*" were studied and noted (Glaser, 1992). In choosing to use Dimensional Analysis I took account of the alternative methods of grounding theory in the data and the debate surrounding their creation.

Dimensional Analysis closely follows the naturally acquired process that all of us use in making everyday decisions. It provides a format that allows the researcher to make comparisons of "*dimensions*" (Bowers and Schatzman, 2009, p93) across a number of different participants and to establish the range of each.

4.6.1 The process of Dimensional Analysis

Dimensional Analysis (Schatzman, 1991) provides a structure within which to organise the data and suggests a number of defined stages. These are dimensionalising; differentiation; forming the explanatory matrix and integration. Initially, the data must be fragmented and organised under headings. The complexity of the issue under consideration is understood by breaking down the whole into its parts or dimensions and properties. The dimensions should be conceptualisations of the portion of data that they describe. This is guided by the starting perspective of the researcher which is acknowledged to change as the process continues (Schatzman, 1991). Having named the dimension, the properties of each are compiled by returning to the data and comparing participants.

The number of dimensions increases with iteration with the text. Certain dimensions become of greater significance than others as the explanation for the behaviour under examination takes shape. This process is called differentiation. However, Schatzman, (1991) emphasises the importance of examining each dimension from different perspectives. It is perspective that directs the selection of dimensions but also influences their organisation and relevance in relationship to one another. Some dimensions will be developed and revisited and elaborated, combined or redefined; some will become redundant, viewed with reference to the data in its entirety. Each dimension is understood within the context of the perspective from which it is viewed. However, the researcher's perspective is seen as relevant when exploring the data, in that prior knowledge facilitates comprehension and guides the ordering of the dimensions. The theoretical sensitivity of the researcher is an important feature shared with grounded theory.

The next stage is to form an explanatory matrix. Personal and objective considerations change the way that the issue is viewed. Dimensional Analysis allows the researcher to designate the object of the analysis and to attribute dimensions with properties. However, these will be altered by the context in which they are

viewed and the conditions that apply. Each perspective controls the assignment of the dimensions. The dimension may be elevated to a perspective or used as context describing central action, interaction or process. A continuous process of questioning the analysis and referring back to the data produces new properties and dimensions in a cyclical manner (Robrecht, 1995). The essential feature is that the dimensions are saturated with evidence from the text.

In order to monitor the analytical progress throughout dimensionalising, memos are written, noting the researcher's ideas as they unfold. The memos guide and audit the process through the building of an explanatory matrix and onto the integration stage (Kools et al., 1996), which happens when a central organising explanation is identified.

Organising dimensions under the headings of context, condition, process and consequences (Kools, 1996) leads to the recognition of a central explanatory matrix that provides an understanding of the social process being explored.

The matrix is formed from a selected starting point as shown below:

- **Perspective** guides the arrangement of dimensions from a particular viewpoint.
- **Context** provides the boundaries of the inquiry in which dimensions are embedded.
- **Conditions** shape the actions or interactions.
- **Processes** are the actions or interactions that are the result of specific conditions.
- **Consequences** result from the processes.
- **Designation** is the abstract concept that explains how dimensions and their properties affect the phenomenon. The perspective can be demonstrated to be related to a designation by following the matrix.

The full explanation of the process develops from this. The analytical memos that were created throughout the process to develop analytical points are used to guide the writing of the theory. Following the explanatory matrix a substantive theory is produced that accounts for the behaviour that is being explored.

The methodology that guided this study varies in a number of ways from classic grounded theory (Glaser and Strauss, 1967). Schatzman (1991), states that he "*was an advocate of Grounded Theory as a general approach to qualitative research*" (Schatzman, 1991, p. 305). However, in the light of his experience with students he felt that greater explanation of the procedures of analysis when grounding theory in the data would be helpful. "*The Clarification and Development of Grounded Theory*" that Strauss and Corbin published in 1990 led to the "divergence" with Glaser. Schatzman was able to develop his methodology, allied to and using some of the practices of grounded theory, independently and published his theory in 1991 ensuring that it was called "Dimensional Analysis" and not linking the new method too closely with classic grounded theory. In publishing his work on Dimensional Analysis, Schatzman was responding, as a teacher, to the same questions that Strauss and Corbin were addressing with their work (Strauss and Corbin, 1990).

Dimensional Analysis of data shares some stages with grounded theory. A classic grounded theory emerges from constant comparison of the data. This is used in Dimensional Analysis to confirm patterns and linkages of dimensions and properties across the text of single interviews and across all participants. This facilitates understanding by increasing the number and abstraction of the dimensions and properties. By applying a structured approach, as suggested in Dimensional Analysis, the unfolding of an explanation can be demonstrated. Grounded theory method has been described as "*serendipitous*" (Bryant and Charmaz, 2007, p. 23) because it provides no overarching model for the novice researcher to follow. Glaser's advice to the student is to be patient and to allow "*emergence through constant comparative coding*" (Glaser, 1992, p. 94). This is difficult to apply,

particularly when new to research and lacking the confidence necessary to wait before drawing conclusions. Dimensional Analysis addresses this issue in a manner that follows natural decision making. Each facet of the phenomenon is acknowledged and then patterns identified in the data. The sequential method suggested facilitates and guides abstraction in the analytical process.

4.7 Theoretical sampling of data

Theoretical sampling (Glaser and Strauss, 1967) of data was used in this study. However, it took place later in the analysis when further data collection was required to answer new questions identified by the preliminary analysis of the texts of the participant interviews completed early in the data collection process. It was applied in two ways. At first it took the form of returning to participants that had already been interviewed with supplementary questions. Once an awareness of specific issues of interest developed, theoretical sampling was then used to select later participants.

The initial four interviews were considered to be exploratory in establishing interview technique and beginning to inform my understanding of the participants' perspectives. Reading and rereading of these texts gave me an impression of the issues and facilitated the sampling decisions on subsequent participants and topics of interest to be aware of in their interviews.

Table 6 - Comparison of some key components of grounded theory method and those used in this study

Elements of research methodology	Original grounded theory method	Operationalizing this study
Theoretical perspective	Joining of objectivist and symbolic interactionist perspectives	Pragmatic, symbolic interactionist and interpretive perspectives adopted. Perspective of researcher acknowledged and owned.
Original approach to the research	Used in qualitative studies, all may be considered to be data	Accounts of wheelchair users' experiences jointly created and interpreted by the participant and researcher.
Approach to the data collection	Inductive and cyclical, selection of participants informed by theoretical sampling	Case study approach. Sampling both purposive and theoretical, informed by developing insights.
Analysis	Constant comparison	Iteration with each transcript and comparison across all transcripts.
	Line by line coding	Identification and naming incidents or opinions in the text. Dimensionalising
	Naming of categories	Conflating and differentiation of dimensions to increase breadth of account.
	Comparing with data	Form and reform matrix to increase level of abstraction.
	Theoretical sensitivity	Prior knowledge informs initial dimensions. Later as theoretically sensitised develop new areas of interest Return to literature with greater understanding.
	Theoretical sampling of next participant	Aspects of participant biography initially sampled then as theoretical possibilities developed returned to ask further questions of theoretically sampled participants.
	Early conceptualising and development of hypothesis	Conceptualising delayed. Identify the "all" then both inductive and deductive reasoning. Increasing abstraction.
	Compare with data	Constant iteration with data.
	Look for patterns and linkages	Patterns and linkages identified. Form and reform matrix until a final comprehensive explanation formed
Memo writing	Throughout process	Maintenance of journals, memos and data organisation diagrams.
	Integration	Bringing together of all dimensions to explain the phenomenon in a final explanatory matrix.
Theories	Grounded theory that is substantive but may lead to formal theory with new work	Development of an understanding of a basic social process

The selection of the research methodology influenced my decision to commence the research without setting a research question. In keeping with Glaser's advice (1992, 1998) when completing a grounded theory it was acceptable only to identify an area of interest. The research study was then designed with the lived experiences of permanent and fulltime wheelchair users being the chief data source. This approach met my objective, which was to explore with wheelchair users their perspectives on their wheelchair; how these were formed and what influenced their attitude towards the mobility equipment that they used.

4.8 Demonstrating fit, work, relevance and modifiability

Research must be believable to the reader and demonstrate honesty. Glaser and Strauss gave, with the introduction of Grounded Theory Method, credibility to qualitative research (Robrecht, 1995) that was lacking at that time. However, ways to ensure the rigour of such studies were difficult to achieve. The authors of Grounded Theory suggest that in order to evaluate a grounded theory study the issues that are addressed are those of *“fit, grab and work”* (Glaser and Strauss, 1967, p. 224). Assessing whether a study has fit grab and work may be undertaken by asking the following questions. Have the findings truthfully represented the data? Are they relevant and do they explain the data that was collected? The researcher should explain the steps that informed their decisions with regards to the data analysis. This is demonstrated by maintaining an audit trail of the research process and by demonstrating the interpretation process.

To address this issue, the concept of *“trustworthiness”* has been suggested for use when examining qualitative studies (Guba and Lincoln, 1985; 1989). Trustworthiness is associated with the credibility, transferability, dependability, confirmability and authenticity of the research.

4.9 Credibility

The issue of the credibility or rigour of a study of this nature is sometimes questioned because of the active role that the researcher plays at the centre of the research. The interaction between the participant in an interview situation and the researcher and the creation of the data; the analysis of that data and the researcher’s perspective and background must be acknowledged. The researcher is part of the interpretive research process. This has been described as an interaction between the researcher and the world that is studied (Turner, 1981). The theories that are produced from such interactions always include part of the researcher (Altheide and Johnson, 1994). A number of strategies for assessing the quality of qualitative research studies have been suggested (Guba and Lincoln, 1985; 1989; Elliott et al,

1999; Marshall and Rossman, 2006), describing similar factors that should be considered to enhance the credibility of qualitative research. First, a recognised theoretical frame of reference and research approach should be used (Cresswell, 2007). Rigorous data collection procedures must be employed and described in order for the reader of the study to judge their effectiveness (Reid, 2002). Participant checking of the transcripts of their interview and the data codes derived from this and their verification of the interpretation of their experiences for accuracy should take place. However, the researcher and participants may have differing perspectives of what occurred at interview, and opposing views on the nature of the findings that affect the validity of the research (Sandelowski, 1993).

It has been suggested that multiple analysts, triangulation with other data sources and comparing two or more qualitative perspectives might be employed to enhance credibility (Elliott, 1999). The measures used in this study are described below.

In this study in-depth interviews were completed, ensuring that the participants had sufficient time to fully explore what they understood to be the pertinent issues. This was recorded on a digital voice recorder and was then transcribed into text. The participant was asked to read their transcript to judge the accuracy of the data gathered in reflecting their intended opinions. A research diary was completed immediately upon leaving the interview. This recorded the impressions of the researcher at that time. This was in order to limit the loss of aspects of the interview that the transcription process may not have captured.

As the analysis took place emerging concepts were discussed with some of the participants who expressed an interest in continuing to be involved with the research beyond the in-depth interview. A judgement was made concerning which participants to contact a second time, based on their health status and availability. It has been suggested that as the researcher is an integral part of the data collection process, the credibility of the study is dependent upon their honesty, their knowledge and their prior experience in the area of study (Patton, 1990).

To enhance credibility the data were analysed using constant iteration throughout each text and, as the analysis progressed, across all of the texts once the collection of data was completed. This ensured prolonged engagement by the researcher with the interview data. Constant comparison techniques also facilitated triangulation of the data across each interview and throughout the transcripts of all of the interviews. The intersections of issues were identified in order to strengthen the credibility of the emergent findings, having been verified throughout all of the transcripts.

Credibility and trustworthiness is enhanced by peer review. The analysis was discussed with my supervisors at every stage of the process, who were able to give expert advice on the research process and to develop my critical thinking and writing skills. The research was discussed at interdisciplinary research and education meetings at my place of work. These gatherings provided the opportunity for me to test my developing theories with other clinicians and defend my decisions in a safe environment.

4.10 Enhancing research dependability, confirmability and authenticity

It is suggested that all research and knowledge is value laden. This is addressed by making explicit the values that were brought to the research study. The reader of the thesis is offered an understanding of the assumptions that influenced the researcher whilst carrying out the work (Payne and Payne, 2007). As an experienced clinician many opinions about wheelchairs and their use had been formed. Therefore, minimising the possibility of researcher bias from influencing the findings of this study was a concern if alternative methodologies had been adopted. However, a grounded theory approach assumes the experience of the researcher to be foundational in the research process. Previous familiarity with the research area was used when making comparisons across the data. The research milieu was entered with my perspective acknowledged and owned (Glaser and Strauss, 1967). Changes in my thinking and decisions with regard to the course of the data analysis were noted throughout the process by use of memos, theoretical, analytical and reflexive.

Reading continued to increase my sensitivity to the data as the data collection and analysis progressed. As each new development in my understanding of the data was made a memo was written and then the literature in the area of interest was explored.

4.11 Reflexivity

Reflexivity has been described as the researcher being part of the research (Lipson, 1981; Hutchinson, 1993) and is now considered to be an integral component of interpretive studies (Cresswell, 2007; Simons, 2009; Bryant and Charmaz, 2007). However, there is conflicting advice about the knowledge that is brought to the study or is learned in preparation for data collection (Morse, 1994). The researcher should attempt to become aware of their preconceptions and by acknowledging these to minimise their affecting the process (Berger and Keller, 1981; Hutchinson, 1993). However, it is the reflexivity and creativity of the researcher that are central to a grounded theory and bring the

“truth of the social situation into being” (Stern, p.217).

It is acknowledged that this is based on the theoretical position that there are multiple truths and that these are created by the mind of the individual through interaction with others. It is argued that by accepting that the researcher brings prior knowledge and experiences to the inductive process they are free to be creative without the restrictions that discounting this tacit knowledge creates (Cutcliffe, 2000). Researchers take a stance towards the data in interpretive studies and shape the story that emerges from the data that is co-constructed (Gilgun, 2005).

A research diary was used to record my thoughts, feelings and understanding of incidents throughout the process. These insights were referred to during the writing of the thesis. In addition, a number of different techniques were used to create memos that indicate staging posts in the analytical process and ask further questions of the data. These memos, written during analysis, map the development of my

thinking and form an audit trail of how decisions were made. These formed the foundations for the later drafting of the thesis.

4.12 Transferability

Transferability refers to the application of the findings of this study into other contexts. The use of thick description and the voices of the participants have been incorporated in the writing of the thesis to elaborate the theory. It is suggested that by using “*detailed description*” (Cresswell, 2007, p. 209) in the text the reader is able to make comparisons with other areas, identify similarities and differences and draw conclusions as to the findings. The study was carried out by in-depth interviews with participants and captures their perspectives as understood by the researcher at that time in that place. Therefore, the degree to which this can be transferred to other settings is debatable and it is for the reader to make judgements as to the effectiveness of this strategy. The collection of data continued until there was a sufficiently detailed understanding of the perspectives to create a coherent theory of accepting wheelchair use. This was tested throughout the research process by discussion with other professionals and wheelchair users.

4.13 Summary

The chapter describes the methodological decisions that were made to guide the study. The social world was understood ontologically as relativist and from an epistemological standpoint as interpretivist. The researcher’s perspective was that of a pragmatic philosophy and a symbolic interactionist theoretical viewpoint. The choice of methodology used in this study, a second generation (Morse et al,2009) development of Grounded Theory (Glaser and Strauss, 1967) known as Dimensional Analysis (Schatzman, 1991) to guide the research was discussed, the detail of the application of which follows. The chapter concludes by discussing the trustworthiness of this study and how it was demonstrated in this thesis.

Chapter 5: Methods

5.1 Introduction

This chapter explains how the study was conceived and conducted in such a way as to provide an audit trail of the research process to enable judgements to be made regarding the reliability and dependability of the findings.

The process of recruiting and selecting participants is described together with how the ethical issues relating to the research were addressed. Participants were chosen through both purposive and theoretical sampling and the reasons for this are discussed.

Socio-biographical information was collected at the first contact with the participant or at the start of their interview. How this was used in this study and how the data were analysed using Dimensional Analysis (Schatzman, 1991) is then detailed.

5.2 Study design

This study set out to explore the participants' perspective of using a wheelchair for all mobility which was from the inception of the research regarded as more than a functional issue. Each participant had a different perspective to offer formed from their experiences and their interpretation of these. The method of data collection chosen was in-depth conversations with the participants. To do this I joined with the participant in a place of their choosing and listened to their accounts of wheelchair use (Schatzman and Strauss, 1973). These accounts were recorded and then transcribed.

The research design took a case study approach to the collection of data. Each interview formed a part of the case, being a wheelchair user. Each participant provided a unique perspective of the case, the summation of which was regarded as providing a fuller picture of the phenomenon: being a wheelchair user. The narrative approach allowed the participant to set the boundaries of the exploration and report only the experiences that they were comfortable to share. The inclusion of Chapter 3,

Participant Profiles, which describes the participant's socio-biographical data in detail, is unusual in a grounded theory. However, its inclusion was thought to enhance the narrative and literary presentation of the thesis and facilitate the reader's understanding of how the substantive theory was generated from all of the participants interviewed. The theory was devised to be applicable to a diverse group of wheelchair users, such as the clients of district wheelchair services. This makes it of benefit to clinicians in many fields.

Data collection was guided by constant comparison, returning to the literature as new concepts became of interest and theoretical sampling of participants. Each interview provided one individual's perspective. In this study it was the uniqueness of each participant's experience that illustrated the complexity of the area under investigation, and, by comparing and contrasting the differences, a social process of accepting wheelchair use became apparent. However, it was important to capture "all" (Schatzman, 1991: p. 306) that was being described within the data first, in order to reveal all aspects of the phenomenon.

An understanding of the complete experience of being a wheelchair user (Simons, 2009) through the use of dissimilar cases was sought. This could have been achieved by use of survey data (Currie, 2009). It is suggested that this is a valid way to identify suitable participants in a grounded theory. However, due to the cyclical nature of data collection, analysis and selection of the next participant in this study it is argued that the data provided by the first participant will shape the unfolding understanding of the process (Cutcliffe, 2000). The socio-biographical data of each participant were collected at the initial discussion, and from this purposive selection of dissimilar cases took place. It must be acknowledged that this was carried out from the original cohort of volunteers that were from a limited cross-section of the wheelchair using community of the south-east of England. The groups contacted were reflective of the service users of local wheelchair services. Cultural differences, in attitude towards wheelchair use, which exist in this country due to the diversity of

ethnicities represented in the census, were not addressed. I chose initially to interview on the basis of the participant's age and place of residence. Theoretical sampling to answer new questions as analysis progressed informed later participant selection. However, as all the participants had at one time an active social life outside their homes that led to their being members of sport and social groups, this indicated that they had a level of financial wellbeing to fund these trips and that they were culturally integrated into their community.

The researcher in this study was the main instrument for both data collection and interpretation. It is acknowledged that the data were captured at a moment in time and subject to change. The findings of the study are locked in time and place, and that the participants and researcher have all moved on.

The data were the researcher's interpretation of the interview transcripts, and the analysis used interpretive methods to reach the findings. The aim was to capture the variability of human action and the different influences that determine this and to understand the processes involved. In so doing, quotes from participants' interview transcripts have been used to evidence their experiences and to illustrate how decisions were arrived at.

5.3 Time line of study

Seeking volunteers who agreed to be interviewed for this research study took place from June 2007. This followed the granting of permission to proceed with the study by the University Ethics Committee. Data collection commenced in September 2007. Interviews took place throughout 2008 and the initial interviews of all ten participants were completed in July 2009.

This was a cyclical pattern of interviewing, transcribing, analysing and reflecting and at the same time writing to develop my understanding and reflections. Constant iteration of each transcript produced new areas of interest and contributed different properties of existing dimensions. This revealed gaps in the data. Participants were

contacted a second time in order to develop my understanding of issues that had emerged during the analysis. All data were collected by July 2010. At this point it was considered that theoretical sufficiency (Charmaz, 2009) had been achieved. It is acknowledged that data collection in this study could never be complete because of the changing nature of the perspectives of the participants and the developing insight of the researcher. However, as richness came from the detailed method of analysis (Urquhart, 2013) exploring at the sentence level what the data contained theoretical sufficiency was reached when no further insights were discovered.

In this study, writing facilitated the development of the theory and began at an early stage of the work as a whole. This was initially through memo writing and the maintenance of a reflexive journal. At a later stage these were then brought together alongside an explanatory matrix to form an account of the social process that was being explored. Writing, revising and editing of the text continued up to hand-in of the thesis.

5.4 Ethical approval

Permission was sought from the University of Brighton Research Ethics and Governance Committee and was given in March 2007. Enquiries were made with the associations that I chose to approach for volunteers to assist with the research and with the hospital ethics committee, where I worked, to ensure that no further permissions were required. These all indicated that no further ethical committee approvals were necessary because the study was to be conducted wholly outside the NHS, in my own time and not on NHS property. The importance of separating my professional and research work is explored in 5.6.

Participants were recruited from social and sporting groups of disabled people and each group functioned as an independent entity. The chair persons of these groups were approached and they were able to confirm that as the University was

overseeing the conduct of the research they were confident that the study would be managed appropriately.

5.5 Professional accountability

Professional attitudes and codes of conduct which are the foundations of my practice as a physiotherapist were adhered to in the data collection process. All information that was disclosed by the participant was judged within these codes of conduct. However, I was ethically responsible to act on any information that was divulged by the participant at interview that I considered required further action. The professional guidelines of the Chartered Society of Physiotherapy (2002) were followed. However, no information was divulged that, judged by these standards, was thought to require further action.

5.6 Access to participants

I thought it important to separate my clinical and research roles for a number of reasons. First, I wanted to avoid any sense of coercion that might have been the case if I had approached my NHS clients to participate. I wanted the participants to enter into an open and constructive conversation unfettered by concerns about their narrative affecting their relationship with their wheelchair service. I also wanted to avoid any likelihood of my knowing personnel mentioned at interview with whom I might have been working. The strategies deployed to ensure this were that all the social and sporting groups who were approached to recruit participants were based outside the geographical area in which I lived and worked. The study was exploring all wheelchair use, not exclusively those supplied by the NHS wheelchair service. I did not want the impression to be given that I wished to investigate the conduct of the participant's own wheelchair service.

To obtain access to participants I approached several social and sporting groups of wheelchair users to ask for volunteers for the study. Participants were enrolled from the membership of various sporting clubs who met at a specialist sports centre. The facilities at this centre were designed to meet the needs of people with disabilities,

having adaptations that allowed wheelchair users access to the weight-lifting and other gym equipment and with special adaptations to the changing rooms. A number of different wheelchair sports clubs meet at these premises, including wheelchair football, wheelchair formation dancing and wheelchair basketball teams.

My objective was to recruit participants who were as diverse as possible, and so a second group of participants were enrolled from the membership of two associations of people with disabilities. These were sited in different geographical locations, one in a rural setting and one situated in an urban environment. This was planned so that different experiences would be captured. The environmental barriers that they experienced were different according to their residential situation, either urban or rural. Selecting for environment where the wheelchair was used was thought at the inception of the project to be useful in exploring the problems with access and terrain.

Initially, the manager of the sports centre and the chair persons of the two social clubs were contacted by letter to introduce myself and the research and to request their assistance with contacting possible participants. The letters were followed up with a telephone call to discuss the study in more detail and to answer their questions. All those approached agreed to help. Having obtained their agreement to assist with locating possible participants the next step was to display a poster in the foyer of the sports centre explaining the study and asking volunteers to contact the manager in the first instance to express their interest. Some of the sports clubs published an article about the study in their quarterly newsletter and requested that volunteers contact the chair of the club if they were interested in knowing more about what volunteering might involve. Similarly, an article was published in the newsletters of the two social clubs approached. When a number of potential participants had been identified in the sports clubs and the social groups, I was invited by the chairpersons and manager to attend a group meeting to introduce myself and explain more about the study and what was expected of the participants.

All those who had expressed an interest had the opportunity to talk to me at the meeting. When all their questions regarding participation in the research were answered to their satisfaction all the volunteers were given a copy of the participant information leaflet. They were asked to take their time to consider whether they were able to participate in the study and, if they decided to volunteer, to complete the participant application form and return it in the stamped addressed envelope supplied. No timescales were put on this because the volunteers all needed different lengths of time to consider their applications. The selection of participants took place in parallel with interviewing and analysis during late 2007 and throughout 2008.

It was important that the volunteers did not feel coerced into being interviewed; I was anxious that that they volunteer because they were interested in sharing their experiences and to have their voices heard. They were fully informed about the study, my objectives in interviewing them and my intentions with regards to the information that they shared. They were under no obligation to participate.

One week after receiving the completed application form the participant was contacted by telephone to arrange an appointment for interview. Any further questions were answered at this time. Each participant chose where and when the interview would take place. In preparation, the participant was asked to think carefully about their wheelchair and what it represented to them.

5.7 Recruitment

I was seeking to interview people who had been wheelchair users for some time and therefore had extensive experiences to share. Previous research had already been completed with people who were new to wheelchair use and still undergoing rehabilitation (Oliver, 1988; Bates, 1993; Barker, 2004). I wanted to interview established and experienced users. Therefore, only participants who had been using a wheelchair for five years or longer were interviewed.

All the participants chosen were full time wheelchair users who were over the age of 18 and were living independently in the community. They were able to give informed consent and to read and understand the information sheet. The volunteers needed to be willing to participate in an in-depth interview that was to be recorded and transcribed onto paper. I indicated to the participants that the interviews were planned to last for approximately one hour. However, I was anxious that they take all the time that they required to fully explain their perspectives. Some did take considerably longer.

The participants agreed to the recording of the interview and its later transcription. They also agreed to the findings of the research being used in future publications. No-one who required the help of an interpreter or who used a communication device chose to volunteer to participate.

The decision was made not to include children in this study. Studies that report the perspectives of children who use wheelchairs and their families have been completed by specialist groups (Muscular Dystrophy Association, 2006, 2002). This study sought to explore the perspectives of participants with a breadth of experiences to share formed from many years of wheelchair use. This precluded the participation of children because of their age and relative inexperience particularly independently in the community.

Corresponding numbers of male and female participants were interviewed to ensure that the data would reflect any gender differences. This concern was informed by published research highlighting the difficulties reported by female wheelchair users in accessing aspects of healthcare (Buchanan, 1999). However, no reference was made to this issue by the participants in this study, and the data failed to suggest that the participant's gender was significant in shaping their perspective. The individual was understood to have formed their own unique view of the wheelchair

and its use influenced by their starting view point and their experiences as wheelchair users.

5.8 Consent and anonymity

Informed consent was ensured by providing a participant information sheet which all were encouraged to read and to ask questions in my presence. They took this and the participant consent form away and, if they wished to volunteer, signed the consent form and return it in a stamped addressed envelope provided. By my explaining my intentions to the participant, i.e. to record their experience of wheelchair use; collate and interpret these experiences and then to disseminate the findings to others associated with wheelchair supply through publications and lectures, and then asking them to take time to reflect on volunteering, I hoped to limit any feelings that the volunteer may have had of coercion.

I was careful to ensure that each participant signed a participant consent form. However, whether this is sufficient has been questioned in the literature (Rancharon and Cutcliffe, 2001; Simons, 2009). It has also been suggested that consent may vary with participants who have degenerative conditions. As their health status changes some individual's may change their mind about their willingness to participate in research. As participation in this study was over a short period of time this concern did not arise. My sensitivity to the data developed as the study progressed and so I returned to some participants to explore emerging issues. It was necessary to check that their consent had not changed over time (Simons, 2009) and the participant was able to decline their consent to further interactions. Moreover the participants were made aware that their consent to the use of previous interview data could be withdrawn at any time. All participants were offered the opportunity to read the transcript of their interviews and to reflect on whether their narrative accurately conveyed what they were trying to say. No concerns were expressed.

The participants were assured that I would endeavour to prevent their identity from being revealed in the thesis and any publications. A number of strategies were put in place to ensure this. These included the use of pseudonyms that were allocated before the interview began so that no one other than researcher was able to identify them. The use of pseudonyms has been challenged in the literature (Kushner, 2000). This device, it has been suggested, might be considered as denying the participant an identity. This is a political issue that has been explored by those writing about disability research (Oliver, 1990; Fincklestein, 1980; Barnes, 1991). In relation to this study I considered who preventing the identity of the participant from being known would benefit (Kushner, 2000). My position was that by making the participants, the area in which they live, the wheelchair dealers and the district wheelchair services mentioned in the findings of the research anonymous I ensured that anyone reading the thesis would be able to relate to the issues expressed but be unable to identify personalities. This thesis was never intended to be a critical review of services. However, all those concerned with delivering wheelchairs experience similar issues. Equally the participants' privacy and confidentiality is paramount and must be protected at all times to avoid embarrassment. I wanted to facilitate a free and open conversation about the findings which, I anticipated, would be widely read and discussed following presentations and publications in the future.

Every participant was offered the opportunity to check their interview transcript to satisfy themselves that their privacy had not been violated and that their narratives were accurately represented and captured their intended meaning. No amendments proved to be required. During the writing of the thesis, quotes were taken from transcripts verbatim to provide evidence to support my interpretation of the participants' narrative. These were not altered in any way and so the participant on reading the thesis may recognise their words; however, they should not be able to be identified by others from the content of the thesis.

5.9 Researcher participant relationship

In carrying out this research I was ideally placed to access participants for interview being employed in the NHS wheelchair service. However, as a researcher I needed to be aware of the possibility that the dual roles of therapist and researcher may conflict. The question of role confusion is an important one (Padgett, 1998). The research may have been jeopardised if there had been confusion about the difference between the therapeutic encounter and the participant–researcher interview. I conducted the interviews as a student of the University of Brighton, a physiotherapist with a keen interest in wheelchair provision.

It is suggested that familiarity with the area under investigation could enable the researcher to draw out pertinent information (McCracken, 1998). However, the literature advises caution as being too close to the area under investigation may limit the researcher's ability to be impartial (McCracken, 1998). The issues may be considered from the standpoint of insider and outsider research (Kushner, 2000; Simons, 2009). Working closely with wheelchair users I had formed opinions that may have affected my perspective of the data. However, I do not consider that this was insider research as I argue this from the position that I am not a wheelchair user. I am therefore unable to do more than reflect on a participant's situation and create my own understanding of something that I have not experienced. Schatzman, (1991) supports the researcher having a perspective at the start of the research as this is helpful in forming a basis for exploration. People have many roles that affect their perspectives and it is impossible to separate these (Kushner, 2000). My understanding was that in being an outsider with some practical knowledge of some of the issues enabled me to establish rapport with the participants. By ensuring that the data was constructed through co-working with the participant and that the findings emerged from this data without forcing, the credibility of this study would be strengthened. Critical self- reflection was applied throughout the study to ensure that the findings had credibility and rigour.

It has been suggested that participants respond better to researchers who know little of the subject under investigation (McCracken, 1998). The reporting of experiences may be constrained if the participant thinks that their opinions are too basic. However, in this research I was not attempting to measure the participants' knowledge of wheelchairs. My understanding of the wheelchair helped to establish rapport with the participants, but they were understood to be the experts in wheelchair use. I wanted to understand their perspective of what they had experienced and, influenced by an ontological and epistemological position that these perspectives were individual and changing, I approached each interview with one question and was open to all that was divulged.

The participants were considered as holding the power in the interview relationship and encouraged to make the decisions about venue and time of the interview. Ensuring that the participant was relaxed and comfortable with their surroundings was essential. All the interviews took place either at the participant's home, at the centre where their group meeting took place, or in the case of one participant, in a residential facility where they were staying temporarily. The essential feature of the interview situation was that the room was quiet and we were undisturbed. All physical barriers between the participant and researcher were minimised by careful arrangement of furniture. Interruptions were prevented by switching off the telephone, where possible, and by applying "do not disturb" notices where appropriate.

5.10 Interviewing

Once the participant was comfortable I commenced by checking that they had read the participant information leaflet and that they were happy to proceed. I reiterated that the interview was to be recorded so that a transcript could be produced by another person. I explained who would be doing this and who would see the data that was collected. The possibility of the participant reading the account of their

interview and making comments and checking that it accurately reflected what they had intended was discussed. Verbal consent was then sought to proceed.

I turned on the recorder and began by explaining that I wanted to collect their views about wheelchair use by having a conversation, rather than asking them questions. I entered the first interview with just one open ended statement:

“Please tell me about your life as a wheelchair user”.

The interview that followed was able to proceed in a natural manner. My input was guided by my previous explorations of the literature. As an inexperienced researcher I had prepared a sheet of subject areas to refer to if the conversation became awkward or stilted (Bryant and Charmaz, 2007). However, with no previously devised questions to ask I was able to be responsive to unexpected disclosures in order to explore experiences as they were revealed. The literature supports this approach (Burgess, 1984; Kvale, 1996) and it was found to be helpful.

The interview guide, Appendix 5, demonstrates how initially my focus was on the experience of the participant inside their home and using a wheelchair outside in the community, particularly how they coped with environmental barriers. After analysis of the first four interview transcripts my perspective changed and new aspects of wheelchair use became of interest. How the wheelchair was introduced into the participant’s life, their age at this time and their individual circumstances were explored. This gradually moved my perspective into enquiries about the participant’s perceived independence and autonomy. Finally, my enquiries focused on how the participant thought that using a wheelchair had changed them. The interview guide developed throughout the interviewing process and so I had to return to some participants to theoretically sample their perspectives as the focus of my analysis changed.

I left some interviews concerned that I had failed to remain on the subject area. However, as will be explained in chapter 6, these were some of the most influential interviews that were carried out as they provided new concepts that had previously not been considered.

Establishing rapport was important, and had been developed at meetings and telephone calls before the interview date. The building of an understanding of the subject area was approached as a partnership between the participant and interviewer (Rubin and Rubin, 1995). My approach at the interview was to listen attentively and respond supportively using prompts where necessary to maintain the flow and the focus of the conversation. It was the experiences that were most important to the participants that I aimed to collect. I wanted to capture their perspective of wheelchairs. Therefore, minimal questioning and direction was used anticipating that an uninterrupted flow would allow the participant to take the conversation where they wanted. This increased the richness of data and minimised researcher bias from affecting the narratives. My reflection on the first interview informed the second and the guide was revised as my understanding improved.

The interviews were recorded to ensure accuracy of the account and to allow the interviewer to concentrate therefore I did not take notes during the interview. It is suggested that taking notes may be a useful device to allow a break in eye contact to occur (Simons, 2009); as an inexperienced interviewer I wanted to concentrate on the participants' accounts and rely on the digital recorder to capture the content for transcription. In the whole data collection process no major technical difficulties with the recorder were encountered. Immediately upon leaving the participant I recorded my initial reflections in a research diary. I thought that it was useful to record my initial reactions to the interview. Was the information collected relevant? Had I been able to maintain a professional researcher demeanour when conducting the interview and managing the recorder? Did the participant seem relaxed and to be

enjoying the opportunity to relate their experiences? How might I conduct the next interview differently?

Ten interviews were completed between September 2007 and June 2009 and selected participants were returned to a second time as analysis and writing progressed to ensure that the data were complete.

5.11 Participant sampling

Participants were initially selected in terms of age, occupation and place of residence all this data was collected when the participant consent form was returned with a phone call to the volunteer. Participants were either young, middle age or older, and their place of residence was either urban or rural. The biographical information of the wheelchair users helped to sample the most diverse group of participants possible. Purposive sampling was used in the selection of the first four interviews. Thereafter, theoretical sampling (Glaser and Strauss, 1967) of participants was carried out. Later, sensitised to the issues by analysis of initial interview data, I selected for gender to ensure that numbers were equal and then for how the participant had become a wheelchair user. I did not ask for medical diagnostic information on the participant consent form as I wanted to interview a wide range of wheelchair users and was not interested in their diagnostic categories at the start of data collection. However, why the participant adopted wheelchair use was quickly identified as of significance and so was added to the selection of the next participant from the fifth interview. Once sensitized to the possibilities contained in the data I returned to the first four participants in order to check information on their medical condition and when and how they started to use a wheelchair.

As new issues emerged a second round of interviewing with some participants took place in order to fully explore their perspective of developing areas of interest and check that my interpretations of the data were accurate (Charmaz, 2006). This was theoretical sampling to inform the developing theory and allowed me to add

properties to the dimensions that were becoming prominent in altering my thinking as analysis progressed.

5.12 Data analysis

Dimensional Analysis (Schatzman, 1991) suggests that analysis be carried out in a number of stages and for the purpose of this thesis these are described sequentially. However, in practice, each stage formed part of a continuous cycle of reading the transcripts of the interview recordings, analysing the contents from a starting perspective, turning to the literature to increase theoretical sensitivity and then returning to the primary data to explore from a new standpoint. Repeated cycles of analysis took place each from a different perspective as my understanding of the data increased.

5.13 Dimensionalising

The first stage of analysis was to identify dimensions with properties from the socio-biographical data collected at the start of each interview. These data were tabulated as shown in Tables 7, 8 and 9 and indicate my starting perspective.

Table 7 - Gender, age, ability to walk

DIMENSION	PROPERTIES
Gender	Male / Female
Age when interviewed	Young / Middle Age / Older
Ability to walk	Never walked/ gradual deterioration/ sudden loss of walking
Age became full time wheelchair user	Young / Middle age / Older

Table 8- Schooling, employment, marital status and care needs

DIMENSION	PROPERTIES
Schooling	Special School / Mainstream / Both
Marital status	Married / Single / Divorced
Care requirements	Formal / Informal/ None
Employment status	Student/ Employed/ Un-employed / Retired

Table 9 - Wheelchair provision

DIMENSION	PROPERTIES
Choice of wheelchair	Manual / Powered
Appropriate accommodation for wheelchair use	Full / Partial / Un-adapted
Supplier of wheelchair	NHS / Private / Charity

The initial perspective taken towards the data in this first cycle of analysis informed the dimensions described which were socio-biographic. These were participants age, gender and mobility history, environment and wheelchair details. Also noted were the employment, education, social and care status; and home adaptations to accommodate the wheelchair that were identified from the data. These concrete dimensions and properties provided the starting point for the development of an understanding of the area of interest. These were data that were familiar to the working therapist and were identified early in the analysis and used as the foundations of the analytical structure that was to be built. Patterns could be determined from these data. Married participants relied on their spouses to provide much informal caring. Home adaptation, to accommodate their wheelchair, was a subject that certain participants addressed and others did not.

Having recognised these data and begun working with them I was then able to move on to labelling data segments from the interview texts. Each transcript was analysed as soon as it was available. This took place in parallel with the selection and interview of the next participant. Transcribing of the digital recording was carried out by a third party for speed and accuracy and was completed within one week of the interview.

The text of each interview was read whilst listening to the digital recording. This allowed the conversational nuances that the text alone could not convey to be appreciated, assisting with my understanding. This process was carried out several times, with each reading revealing something new that had not previously been identified.

A reflexive review of each interview was then written. This was facilitated by using the following questions:-

- Had I understood the participant's perspective and were the properties that I had labelled accurately reflecting their stories?
- How was the data relating to the area of interest of the research?

These questions were modified from Glaser (1978, p. 57). In the writing of the reflexive account of the interview, new questions arose that informed the approach to the next interview.

Each interview text was broken down into analytical building blocks with which to work and these were labelled. This was done as shown in a portion of one interview text provided below. This process promoted interaction with the data and facilitated understanding of the texts as data chunks rather than an individual's story.

The way that this was done is demonstrated below:

*"I'm in a bit of **a different position to some disabled people** because, I don't know whether you know, but I've got cerebral palsy. **My ability is defined as cerebral palsy. Cerebral palsy is a lifetime disability so I've not known how it is to be able bodied in any way, shape or form. Therefore, all my mobility from school age upwards has been dependent either on crutches, callipers or now, for all intents and purposes, a wheelchair.** In the early days, and you can go back 30 years or more because I'm now 53, it was a matter of if my parents wanted me to go and wanted to take me somewhere they had to make the **effort to overcome the obstacles, i.e. stairs and lack of access were overcome by the fact that my father was a rower and therefore quite strong and fit physically.***

Malcolm

From the text above, different analytical components were identified. These were tabulated as shown below and were considered to be the initial building blocks of the analysis. Dimensional analysis is built on the premise that by labelling all of the components the full extent of what is contained within the data is revealed (Kools, 1996).

As each text was labelled, the dimensions noted were compared and contrasted with the texts of the other participants. Each provided properties of dimensions already identified, or the participant’s different perspective informed the writing of new dimensions.

Table 10 - Example of how dimensions were named

<u>Dimensions that were written from the text above</u>
<i>“I’m in a bit of a different position to some disabled people.....”</i> Differences acknowledged to other wheelchair users.
<i>“My ability is defined as cerebral palsy.”</i> Diagnosis shared
<i>“Cerebral palsy is a lifetime disability....”</i> Understanding that this was a lifetime disability
<i>“Mobility from school age upwards has been dependent either on crutches, callipers or now, for all intents and purposes, a wheelchair.”</i> Mobility always dependent on equipment

The second aspect of dimensional analysis is that the dimensions identified are without form until the researcher adopts a viewpoint on the data (Schatzman, 1991). Initially, my perspective was concrete and led by my social history and training. However, through working with the data and increasing my theoretical sensitivity by searching the literature, my perspective altered and the nature of the dimensions and properties identified within the data changed. The first perspective was the exploration of the socio-biographical data, which took place from the standpoint of a therapist. The initial dimensions that were labelled in the data were from a functional and environmental perspective. Following further reading, I was able to understand the data differently, and dimensions with greater abstraction were revealed (Examples of Dimensions – Appendix 1 and 2). These allowed the differences between the participants to become clearer. The data were then explored

from the perspective that wheelchair users all expressed different attitudes towards their wheelchairs. It was these differences that informed my understanding of their concerns.

This abstraction from the data and recognition of new concepts is demonstrated in the analytical memo below:

Table 11 - Analytical memo

Working Hypothesis: Special schooling provided an accessible environment for wheelchair use and skills training.

Analytical Memo: *The data indicate that special schooling gives the individual confidence. At first this was identified as being due to learning wheelchair skills and socialising with others with similar disabilities. However, I now understand this differently. Was this education teaching enablement and was this why the participant was confident and independent?*

Was this provided for other wheelchair users who did not attend special school? How did they learn skills and did confidence in wheelchair use affect their general well-being?

This should now be explored in relation to the wheelchair users who were able to walk for some period of their lives.

Each new interpretation prompted a return to the data to reread the texts and to explore the new concepts. New dimensions and properties were identified. However, the relationship of these was yet to be understood.

The next question was, what more were these data describing and to identify the main concerns of the participants? The reflective summaries of each interview were reread from the revised viewpoint and understood differently. This led to a return to the data and my identifying new dimensions and properties.

5.14 Managing the dimensions

As the number of dimensions labelled grew, in order to track and organise them an extensive spreadsheet¹ was used (Example of spreadsheet Appendix 3). This was drawn up with the participants' pseudonyms down the columns and the dimensions across the top. Each participant's response or lack of evidence was recorded in the cell thus created and were understood to be the properties of the dimension. The use of the spreadsheet allowed me to see patterns in the data and to expose absent data, and gave insight into alternative perspectives as it highlighted the common views and made transparent idiosyncratic opinions.

The spreadsheet was populated with all available dimensions and properties, gaps were noted and patterns were observed. Certain participants' columns referring to how wheelchair use was adopted were incomplete. This prompted the writing of a memo recording this analytical observation.

¹ 18 pages of Excel spreadsheet

Table 12 - Analytical memo identifying groups by adopting wheelchair use

Analytical memo: **Wheelchair users are a group of people who are unable to walk.**

Initially, the participants were considered to be one group of people who were all unable to walk, which necessitated the use of a wheelchair. However, it transpired that for some, their differences needed to be stated by them, at the start of the interview, immediately putting them into a different group to other wheelchair users. All of those who were born with a physical impairment and had never walked felt that it was important for me to understand this at the outset of their interviews. This may be a starting point for exploring groupings in the data. Two groups are immediately apparent – those who have walked and those who never walked without equipment. Why does this matter? What is it that the lifelong wheelchair users are trying to explain? Becoming a wheelchair user is the starting point for each participant's personal journey. However, only some participants discussed this. How did each participant begin to use a wheelchair? Return to transcripts and explore this.

The transcripts were reread and additional properties added to the Excel spreadsheet. Returning to the transcripts it was possible to understand how wheelchair use had been adopted from all but one of the participants' interview transcripts. This participant was contacted to identify the circumstances of their adopting fulltime wheelchair use. This was an example of how theoretical sampling was used to saturate the data in defined areas.

The study showed that permanent wheelchair use was adopted either naturally as a developmental stage, or through a life event leading to loss of walking, or due to gradual decline in the ability to walk. The importance of the reason for wheelchair use became clear as the data were analysed. The dimension **loss of walking** allowed the participants to be grouped for comparison. The use of a wheelchair for all mobility was then understood as having the twin dimensions of **decision to use a wheelchair** and **change to functional walking**. These were thought to be co-dependent.

Groups of participants were then identified. The lifelong wheelchair users were first grouped together and the dimensions that they shared were explored. Each had started to use a wheelchair naturally as a developmental stage and they also shared the same property for the dimension: **age when wheelchair use adopted**.

The next group identified **suddenly** acquired physical impairments later in life that prevented them from walking through accidents. Wheelchair use was therefore **enforced**, through **sudden loss of walking** and they were all **young when wheelchair use adopted**.

A third group, with slowly worsening physical conditions, were able to make a **decision when to use a wheelchair**. They were described by the dimensions **pragmatic adoption of wheelchair use** through **gradual loss of walking**. The age of this group when adopting wheeled mobility, in all but one case, was in **middle age**.

For clarity these dimensions and properties were brought together in the Tables 13 and 14 below.

Table 13 - Decision to use a wheelchair

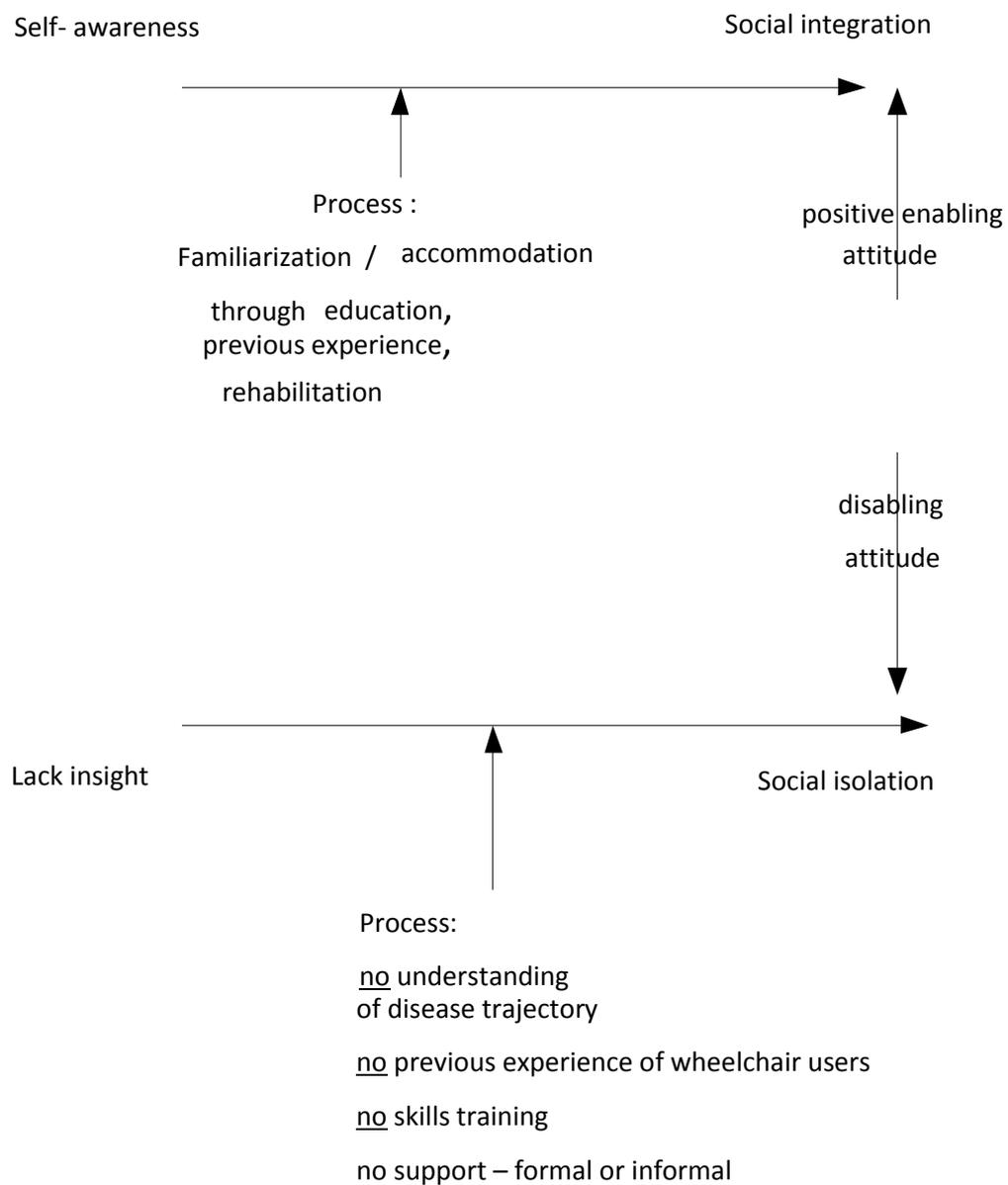
Dimension	Properties
Decision to use a wheelchair	<p>Enforced</p> <p>Informed by:</p> <p><i>...without it on the floor</i></p> <p><i>...always been used to having a wheelchair</i></p> <p>Pragmatic</p> <p>Informed by:</p> <p><i>...use it when you need it</i></p> <p><i>...purely pragmatic</i></p> <p><i>... a safer way to move around when tired</i></p>

Table 14 - Change of functional walking ability

Dimensions	Properties
Change of functional walking ability	<p>Never walked - <i>Natural progression when walking was never possible</i></p> <p>Sudden loss of walking - <i>Sudden loss of walking due to accident</i></p> <p>Gradual loss of walking - <i>Gradual loss of ability leading to use of walking equipment, occasional use of wheelchair then fulltime and permanent use</i></p>

Possible relationships between dimensions and properties were then explored. A case report for each of the three groups was written and compared to the reflective summaries of each participant’s interview. The way that participants described their lives moving forwards following the introduction of the wheelchair was then understood as a process of behavioural change that facilitated incorporating the wheelchair into their lifestyle. In order to understand the relationship between dimensions, decision trees (Appendix 4) were used to provide a visual portrayal of each conceptual group. These were considered to be analytical memos as they moved my thinking on to ask new questions of the data. One such is shown in Figure 1.

Figure 1 - Self-awareness to social integration or social isolation



5.14 Change in perspective

The dimensional analysis method recognises that the selection of the dimensions is influenced by the researcher's perspective towards the data and that this perspective will change as the process of analysis continues (Schatzman, 1991). A change of perspective took place when I identified from the Excel spreadsheet that there were gaps in the matrix of two participants. Closer exploration of the interview texts of these two revealed that they had both gradually become wheelchair users following many years of deteriorating mobility. Their circumstances had not changed in response to fulltime wheelchair use in the same way as others in the same conceptual group. This accounted for the gaps in the data. However, why this was the case was not clear at this time.

Further analysis identified that change was significant. Properties relating to different types of change were noted: change of occupation, change of accommodation, altered life choices. New dimensions were named and added to the spreadsheet.

The understanding that the data revealed a process of change taking place led to a return to the transcripts to reanalyse them from this new perspective. This cycle of analysis resulted in some dimensions being strengthened, others becoming less influential and new dimensions and properties being created. The Excel spreadsheet was revisited and modified accordingly. An example of the developing spreadsheet is provided in Appendix 3.

As analysis progressed the dimensions were expanded and refined to include the new dimensions and properties identified. Memos were used to record change of analytical direction and to reflect on progress. These memos were consulted later in the analysis when the writing of the explanatory matrix was taking place.

Table 15 - Analytical memo for the sudden adoption group

Individual contextual conditions: Sudden loss of walking leads to wheelchair use without preparation. However, all of these participants were hospitalised following their accidents and received protracted rehabilitation. They had professional assistance with understanding their new physical limitations; choosing the best wheelchair; learning wheelchair skills; making decisions about adapting their living space. In addition, a rehabilitation centre environment is associated with: mixing with others with disabilities; learning coping strategies; support from peers; support in exploring the environment as a wheelchair user; building self-confidence as a wheelchair user. Each participant in this group had access to rehabilitation however, they all presented very different stories. Is this due to individual factors?

Recognition that different groups of participants reacted in different ways to becoming permanent, fulltime wheelchair users led to revisiting the data to explore how the manner of adoption and their future independence were related. Theoretical sampling of selected participants was necessary to explore these issues. This indicated new dimensions, these included:-

- Wheelchair promoting independence
- Feelings of enablement with right wheelchair
- Feelings of being in control of own life in wheelchair
- Wheelchair's effect on social interaction.

However, it also became apparent that for each individual in the adoption group, natural, sudden or gradual, it was the unique factors appertaining to them that influenced their resulting independence and autonomy and that this was unrelated to their level of disability. The concept of the consistency or disruption to the participant's life style, caused by adoption of wheeled mobility, was then explored

for each group identified. Some participants had a continuous story while others had experienced disruption that they were unable to overcome.

The dimensions and properties for each individual relating to the participant's biographical disruption on becoming a wheelchair user were revisited. These were then compared and contrasted between all the participant interview texts. The data revealed that some had developed an alternative map, following biographical disruption on loss of walking, others had not. Why was this? This prompted the memo:

Table 16 - Analytical memo

Analytical memo: *There seems to be little consistency within each of the groups in the area of moving on after adopting fulltime wheelchair use. Some users have developed new life maps and are positive about the future. They have adjusted their lifestyles accordingly, others less so. This seems to relate to other dimensions such as adaptations to home and the choices that were being made regarding the type of wheelchair used and the lifestyle adopted.*

Further exploration of the data led to the conclusion that the level of acceptance of wheelchair use was affected by disruption of life map rather than the age at which the participant entered a wheelchair. Participants who had not formed a life map prior to full time wheelchair use, or who were able to continue with their previously formed life map, accepted wheelchair use and became independent autonomous individuals..

If the participant experienced disruption of their life map and was unable to create a new life map lower levels of acceptance were observed.

Therefore, disruption of life map was thought to lead to the wheelchair being fully accepted only if an alternative was developed and fully embraced by the wheelchair user. This is illustrated in Table 17.

Table 17- Analytical memo –Matrix of the dimensions associated with stage of life/ age when permanent wheelchair use adopted/disruption to life map/acceptance

<p>Working Hypothesis: The stage of life at which the participant became a full time wheelchair user is important as an indication of their ability to accept wheeled mobility. Analytical Memo: Could the age of the participant when permanent fulltime wheelchair use becomes necessary be indicative of the level of acceptance of wheeled mobility that results? Does the disruption to their life map and subsequent building of a new life map affect this?</p>				
Group A: Always a fulltime wheelchair user				
Participants	Age entered wheelchair	Life map disruption	New life map embraced	Acceptance of Wheelchair
Malcolm	0	No	N/A	Natural Accepted
Joshua	0	No	N/A	Natural Accepted
Kathryn	0	No	N/A	Natural Accepted
Group B: Younger when fulltime wheelchair use became necessary				
Participants	Age entered wheelchair	Life map disruption	New life map embraced	Acceptance of Wheelchair
Matt	19	Yes	Yes	Fully Accepted
Jeffrey	25	No	N/A	Fully Accepted
Chantelle	15	Yes	No	Partially Accepted
Di	13	Yes	Yes	Fully Accepted
Group C: Middle age When fulltime wheelchair use became necessary				
Participants	Age	Life map Disruption	New life map embraced	Acceptance of Wheelchair
Sue	40	Yes	Yes	Fully Accepted
Group D: Older When fulltime wheelchair use became necessary				
Participants	Age	Life map disruption	New life map embraced	Acceptance of Wheelchair
Patrick	60	Yes	No	Reluctant Accepted
Maeve	55	Yes	No	Reluctant Accepted
<p>Working Hypothesis: What enabled some participants to form and embrace new life maps where others were not able to do so? What were the other contributing factors? Return to data.</p>				

The observation that the creation and consistency of a personal life map were central to the participant’s ability to move forwards and establish a level of independence required further exploration. The data indicate that some participants made fundamental changes to their lifestyles that maximised their independence. The data

were explored once again from the perspective of demonstrating change and accommodation of wheelchair into lifestyle. New dimensions were incorporated into the spreadsheet. No further development of the range of dimensions was considered to be necessary. The analysis then moved on to the stage of differentiation.

5.15 Differentiation

The next stage was to amalgamate the dimensions from the cycles of analysis in a process called differentiation. The dimensions were brought together and then organised into groups. The potential of each dimension to assist in understanding the phases of the process of change being explored was assessed and in so doing memos were written that recorded the analytical thinking at that stage.

The dimensions were then organised into matrices, each one provided a different perspective on the data and suggested a new analytical insight. Each dimension was elevated in turn to the position of the central organising perspective. Other dimensions were then arranged with reference to this. In this way dimensions that were central to the developing explanation became apparent and others were considered as more peripheral to the unfolding story. An example of this is that correlation between selection of wheelchair and adaptation of home environment was addressed in participants who were similar in other respects such as age when wheelchair use was adopted and social circumstances.

A number of questions were then asked of the data:

- Why had participants reacted differently to wheelchair use?
- How had their reactions affected the user's perceived level of independence?

An example of the formation of a matrix is shown below. Age when adopting wheelchair use was elevated to the organising perspective and other dimensions arranged relative to this.

Age when adopting permanent and fulltime wheelchair use:

- Adapted home for wheeled mobility
- Receiving support/formal /informal
- Taught enablement /skills training/rehabilitation
- Managing barriers
- Planning lifestyle around wheelchair
- Wheelchair mobility providing independence
- Maintaining and developing social interactions
- Implementing an alternative life map.

Each matrix was then compared and contrasted with the others to understand their inter-relationship (Kools, 1996). Writing the matrices facilitated new levels of abstraction by understanding the data in an alternative way. The perspective that was adopted to guide the matrix lent a different viewpoint to the story that was unfolding.

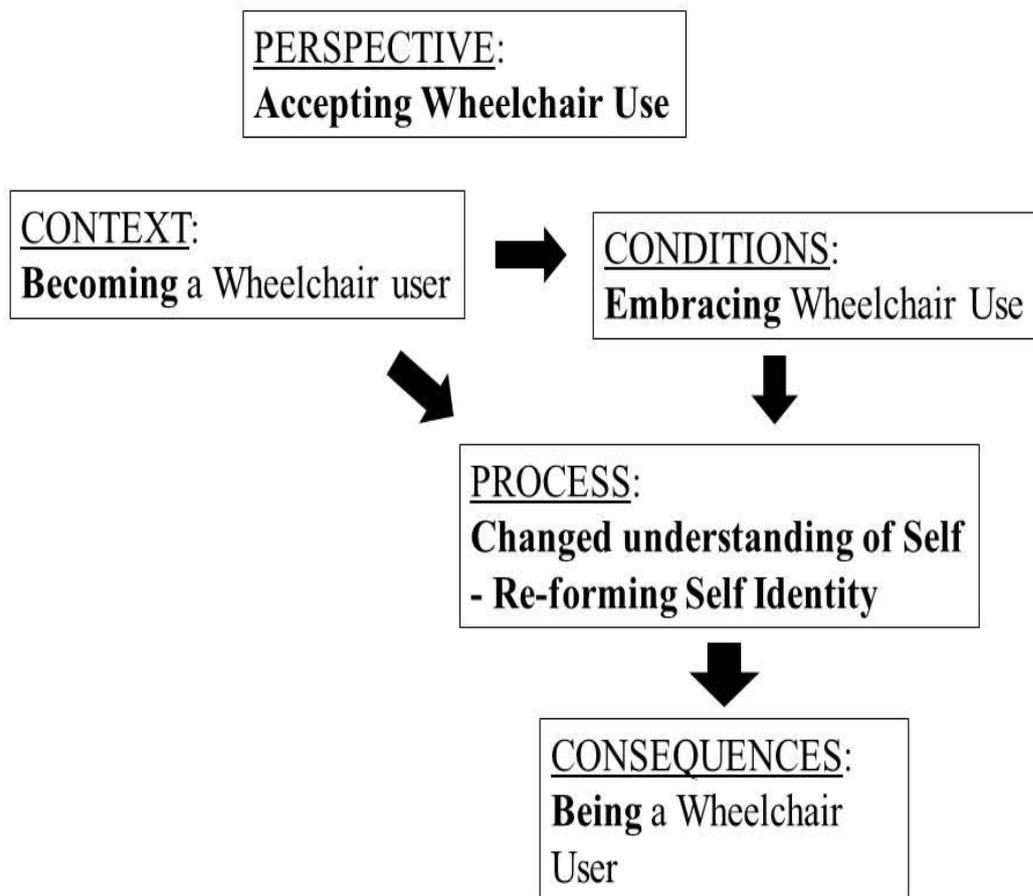
The memos that addressed analytical decisions or theoretical possibilities that were written during the analysis were reviewed at this time. This culminated in the matrix that provided an over-arching explanation of the process of change contained in the data becoming the explanatory matrix. A new round of data analysis was carried out to ensure that the data supported the structure of the explanatory matrix.

5.16 Construction of an explanatory matrix

The final explanatory matrix takes the dimension 'accepting wheelchair use' as its central perspective. This was understood to be a change in behaviour described in different ways in the data, which involves a movement from walking to wheelchair use. The dimensions were organised to support the concepts becoming a wheelchair user, embracing wheelchair use and being a wheelchair user which indicates a change of behaviour. This culminates in the participant altering their understanding

of themselves and their world. The reorganisation of the dimensions to support the explanatory matrix led to some dimensions being elevated to positions of greater importance and others becoming less relevant to the developing story. An overview of the final explanatory matrix is shown in Figure 2.

Figure 2 – Overview of explanatory matrix



5.17 Integration

Once the final explanatory matrix was formed writing began to explain the findings and develop the theory. Writing deepened understanding and prompted further abstraction. This stage in Dimensional Analysis is called integration and is a process of abstraction and interpretation that is never finished (Schatzman, 1991). Writing and revising continued until the thesis was completed.

Schatzman (1991) argued that by using dimensional analysis it is possible to produce an understanding of a basic social process that has theoretical validity. Without these

foundations the findings of research studies may become mere descriptions. It is the researcher, using a symbolic interactionist theoretical lens, who interacted with the data to develop unique meanings (Robrecht, 1995). This interaction impacted on the selection of significant dimensions and influenced the formation of the final explanatory matrix. The researcher's own perspective was therefore "embedded" (Bowers and Schatzman, 2009, in *Developing Grounded Theory: The Second Generation*; ed. Morse, J.M.; p. 86) in the analysis. The researcher deductively developed an understanding of the process that emerged from the data, a theory was then developed that explained what had been discovered and this was then tested, inductively, by returning to the data to confirm or refute the explanation that was being revealed.

5.17 Writing

Schatzman (1991) believed that writing was the key to the development of theory, and throughout this period writing organised thinking and the exploration of new ideas. In returning to the data to test linkages, the final matrix demonstrates both inductive and deductive reasoning. An understanding of the social process was formed through interaction with the data. The different perspectives taken with regard to the data were influenced by exploring the associated literature. Sections of the data became illuminated once my theoretical sensitivity was heightened. Many of these ideas, whilst analytically interesting, became less relevant as the formation of the matrices continued. Having constructed many matrices through writing, another level of abstraction became apparent. This required re-ordering of the dimensions to provide a more comprehensive explanation of the data. By rearrangement of the dimensions to support this developing explanation of the process some dimensions, which had previously been considered important because of their saturation, became side-lined. The data were reanalysed using this new knowledge and perspective to produce the explanation of the social process of accepting wheelchair mobility that is described in the next chapter. In the writing of

the thesis further integration of ideas continued throughout up to hand-in. This is in keeping with Schatzman's (1991) stance that grounded theory is never complete.

5.18 Theoretical sufficiency

Once the overarching explanatory matrix had been decided a return to the data allowed the conceptual linkages of the theory to be tested and ensured that theoretical sufficiency (Charmaz, 2006) had been achieved. Strauss and Corbin, (2008) suggest that in a Grounded Theory saturation may never be achieved. Rather that the researcher will reach a point when new data does not change the major categories or the relationship between them. This was found to be the case in this study. Once the explanatory matrix was fully developed and tested, collection of new data was not progressed. The data collected had provided an understanding of the social process and further data collection was not required. Theoretical sufficiency was concluded to have been reached.

Theoretical sampling then took place to test my theory with selected participants. The result of these encounters was that the explanation that had been developed was consistent with their experiences. The findings were presented at the local research forum where like-minded colleagues discuss their studies, and were well received. No further data collection was thought to be required.

5.19 Summary

This chapter has sought to explain how the research was carried out by exploring the decisions that were made regarding the design of the study and how participants were accessed and selected for interview. Data collection methods and the way that the data were analysed were all addressed. How Dimensional Analysis was used to understand the data is presented. An overview of the formation of the explanatory matrix is presented. The final explanatory matrix is presented and explored in Chapter 6.

Chapter 6 Findings

6.1 Introduction

Data analysis led to an understanding that the participants were describing a process of change. A final explanatory matrix, Figure 3, 6.2, was created that had as its central organising perspective **accepting wheelchair use**. Once this was discovered all other relevant dimensions were able to be arranged to support this structure and increased confidence in the theory that was emerging from the data.

Accepting wheelchair use was understood as a social process that was conceptualised as a phased transition consisting of three stages. This described the participant's passage from walking, to adopting wheelchair use termed **becoming** through a period of environmental, functional and emotional change called **embracing** wheelchair use. The final stage, **being**, found the participant describing themselves as a wheelchair user. The chapter explains that this is a process that is triggered by loss of functional walking and is altered for each participant by their **individual contextual conditions**.

Throughout the writing of the findings I have referred to the literature that sensitised me to the possibilities within the data. This is acknowledged to be unusual in the completion of a findings chapter. However, as theoretical sensitivity and returning to the literature throughout the research process is a cornerstone of the chosen methodology the use of this device was felt to be justified.

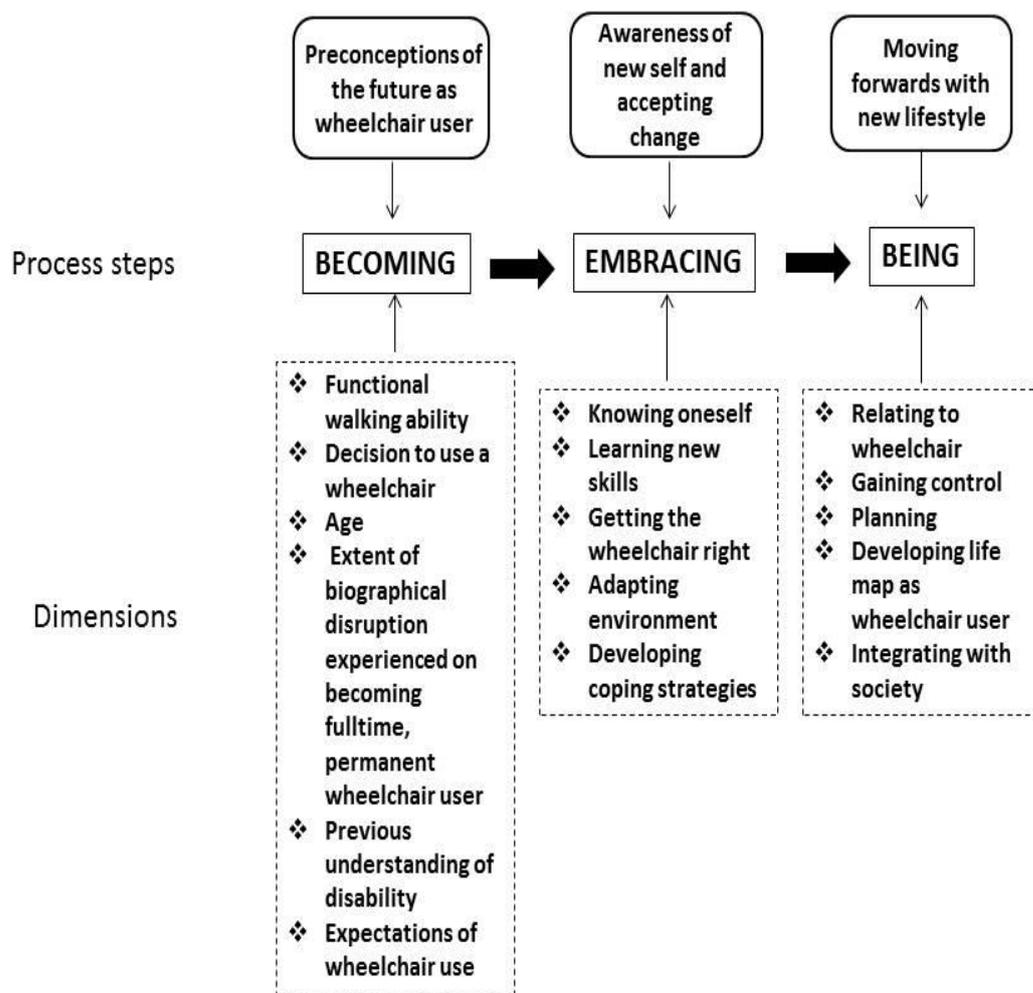
6.2 The explanatory matrix

Each participant had a different story to share. The experiences of all of the participants were compared and contrasted. The dimensions were ordered and reordered and an understanding of **accepting wheelchair use** was formed. This was conceptualised as a phased process of change, the completion of which led to autonomy and independence as a wheelchair user. The participant's behaviour was shown either to facilitate their acceptance of wheeled mobility, to delay the process, or as blocking their accepting wheelchair use. However, becoming a wheelchair user

was found for some participants to be a developmental process that was different to the other wheelchair users interviewed, as walking was, for them, never an option.

The explanatory matrix, Figure 3 shows the individual's progress from **becoming** to **being**. For this to be achieved a series of adaptive tasks must take place that move the user from becoming to embracing wheelchair use. In accepting wheelchair mobility and accommodating the wheelchair into their lives the participant is facilitated to develop a new life map and activities in partnership with their chair.

Figure 3 – Explanatory matrix



6.2.1 Phased transition to accepting wheelchair use

On becoming a fulltime and permanent wheelchair user, the participants entered a period of transition. This is conceptualised as a process, moving from left to right, (Figure 4). It is a linear representation of a complex web of adaptations that the individual makes to accept wheelchair use.

Figure 4 - Phases of transition



The data described the participants as passing through three stages to **accepting wheelchair use**. These were **becoming**, **embracing** and **being**. Each phase was altered by the individual contextual conditions of the participant as wheelchair use was adopted. In response to the change in their function, practical, organisational and behavioural alterations to the participants' lives, or **embracing** wheelchair use, were necessary. This was adaptation that brought behavioural change, which facilitated the physical inclusion of the wheelchair into their lives and promoted psychological and emotional modifications. Embracing wheelchair use had consequences for the participant's autonomy and independence. The final phase, **being** a wheelchair user, describes how for some participants, having accepted wheelchair use, they were able to **move forwards with a new lifestyle**. The participants then described themselves as **being** a wheelchair user. They developed a new life map or continued to follow the existing one with practical modifications being implemented to allow this to take place using a wheelchair for all mobility.

Seven participants in this study experienced a change to their mobility, from walking to wheelchair use. Their perspectives were different from those expressed by the three participants with lifelong conditions, who naturally adopted a wheelchair as their natural and only practical form of mobility.

To explore what was happening in the data, the framework of phased transition described in the previous section was applied. However, each participant was found to be at a different phase of this transition. For some of the participants the process was complete and for the others transitional changes were still taking place. Some had become stuck at a certain phase, and moving forwards to write a new life map was yet to be achieved. This interpretation of the data is now explained, using excerpts from the transcripts of the participant interviews combined with their socio-biographical data.

6.3 Becoming

The first stage in the transitional process is **becoming** which is informed by a number of different elements itemised in Table 15 5.14. The process of becoming a wheelchair user was conceptualised as consisting of six different aspects:

- The participant's experience of walking and its loss – **change in functional walking;**
- The nature of their decision to use a wheelchair - **decision to use a wheelchair;**
- The participant's age when loss of walking occurred - **age, young, middle aged, older;**
- The degree of biographical disruption experienced due to adopting wheelchair use – **biographical disruption;**
- The participant's experience of illness and disability - **previous understanding of disability;**
- How the participants anticipated wheelchair use - **expectations of wheelchair use.**

Table 18 – Becoming

Main category	Dimensions and Properties
BECOMING	Change to functional walking Sudden loss Gradual loss Never walked
	Decision to use a wheelchair Enforced Pragmatic
	Age Age range 5-50
	Degree of biographical disruption experienced on adopting wheelchair use Biographical consistency/disruption
	Previous understanding of disability Nature of previous exposure
	Expectations of wheelchair use Nature of expectation

These concepts are now explored using quotes from the participants' narratives.

6.3.1 Change to functional walking

The starting point for understanding the process of accepting wheelchair use was to recognise that each participant had become a wheelchair user in a unique way. However, three different groups of participants were identified from the data: never walked; sudden loss of walking and gradual loss of walking.

6.3.1.1 Never walked

The first group identified were those who became wheelchair users as a natural developmental stage, having never walked. In all of their interviews these

participants talked about being different to other wheelchair users, forming a discrete group.

"I've always been, like pretty much the majority of cerebral palsy, have always been used to having a wheelchair." Joshua

"My disability is defined as cerebral palsy...which is a lifetime disability so I've never known how it is to be able bodied in any way, shape or form. Therefore all my mobility from school age upwards has been dependent upon a wheelchair." Malcolm

"I'm a quadriplegic cerebral palsy, my four limbs are affected, so in my manual chair I can't do anything for myself, totally dependent on other people, but in my powered chair I'm pretty independent." Kathryn

The participants who were born with lifelong conditions were never able to walk. They all described their medical condition at the start of their interviews and considered themselves to be different to other wheelchair users. Their understanding of the world was formed from the perspective of the wheelchair being their natural way to mobilise, and their ontological perspective had foundations built on continuity. They had not experienced the disruption to their life maps that the change of mobility caused to all of the other participants in the study.

6.3.1.2 Sudden loss of walking

Those who experienced a sudden life event changed from wellness to patient, walker to wheelchair user in an instant. Individuals' responses to this change are reported in the literature to be more dramatic where the transition is marked and when the adversity is greatest. However, the more severe the misfortune the greater the acceptance of the changed circumstances is likely to be. This has been shown to be the case for the actor and also their significant others (Allen and van de Vliert, 1984, p. 54). Three participants lost the ability to walk following accidents. This meant that they entered a supervised pathway from walking to wheelchair use through

their extended hospitalisation and rehabilitation. These were all younger people, which was understandable as spinal cord injury is more prevalent in the younger population². The event removed walking suddenly. Matt described how he remembers the experience and his reaction to this.

“When people around you start getting some use of their legs back, for about six or eight weeks I thought well it might happen but if it doesn’t I’m not bothered. It makes no difference to me if I can walk or not. That’s the only thing I can’t do now that I could do before. I can do everything else apart from walk.” Matt

The other participants who experienced a life event that suddenly removed the ability to walk did not discuss their injuries merely alluded to “*the accident*”. Sensitivity to their feelings prevented further exploration of this difficult subject as it was the participant who controlled the areas explored at the interview.

6.3.1.3 Gradual loss of walking

Participants with slowly worsening conditions had time to become accustomed to wheelchair use before loss of all walking occurred. Initially, this group of participants obtained a chair for occasional use out of doors, and, as their physical abilities declined, the length of time that the chair was used each day and the places where it was used changed. The four participants all came to permanent wheelchair use following a protracted period of decline in their ability to walk. This was due to an active disease process or to weakness remaining after an acute illness that worsened as they aged. This was graphically described by Patrick:

“By that time I was walking with one stick, no callipers, but a spinal jacket, but then my knees started as I have no quadriceps as such so walking meant that I hyperextended at an appalling angle. I just couldn’t do it any longer.” Patrick

² Spinal cord injury affects over 40,000 people in the UK (<http://bestpractice.bmj.com> accessed 02/07/2013). Motor vehicle accidents account for 48 per cent of the cases. Other causes include falls (21 per cent), sports injuries (14 per cent), and gun-shot injuries (15 per cent): 82 per cent of patients are male, with 61 per cent being between 16 and 30 years of age (mean age 19 years).

6.3.1 Decision to use a wheelchair

Adopting wheelchair use was found to be dependent upon the way that wheelchair mobility became necessary through loss of walking. This happened in a number of ways. For three participants, wheelchair use was **enforced** through lifelong conditions that prevented their ever walking. Wheelchair use was naturally adopted as this was their only form of mobility. For three participants who experienced a sudden life event, the possibility of walking in the future was permanently removed and they too found wheelchair mobility to be enforced. The remaining participants all had deteriorating health, and gradually, over a protracted period, became fulltime, permanent wheelchair users. These were **pragmatic** wheelchair users.

The category decision to use a wheelchair enforced where no decision was made or pragmatic, when the participant had time to slowly become accustomed to the change in their mobility and to organise for future permanent wheeled mobility, were compared with change to functional walking. In 6.3.1.1 and 6.3.1.2 the participants in the enforced group describe their experiences of becoming wheelchair users. These contrasted with those detailed by the pragmatic group of users who gradually lost the ability to walk.

The group of participants with gradually acquired disabilities each reacted differently to the need to use a wheelchair. It was these reactions to wheeled mobility compared with the sudden adoption group that allowed me to understand the process of transition that was being described in the data and the adaptations required to succeed in accepting wheelchair use.

The decision to obtain a wheelchair was difficult for some. Sue described how she took time to come to the decision.

“I remember it clearly, my husband and son and daughter had been to the Tower of London for the day and I hadn't gone [she had used work as an excuse] I knew that I wouldn't cope. I got in touch with the local health centre and from there it didn't take very long to get a wheelchair [with small wheels that someone had to push] We kept it in the boot of the car and from then I was always there on family outings...The first wheelchair was a way of

breaking the ice and getting used to it for long walks out of doors or in crowded places at first, and then it was used progressively more often and for longer periods...I'd get tired and basically it was a lot easier. It's like trying to pat your head and rub your tummy at the same time...then I had this eureka moment...I realised that I was missing out on family outings because I couldn't walk and so I thought 'use the wheelchair'.. after that it became part of our life..my son was 5 or 6 at the time and when I wasn't in it he was." Sue

Jeffrey also decided to use a wheelchair when the time was right for him. However, he did not find this decision difficult and it was not mentioned in his first interview. He was contacted a second time to explore this matter. He described it as a "pragmatic decision" made for reasons of expedience at the age of 25 when working as a house officer. He was confident that wheelchair use would improve his life as it allowed him to respond faster when on call at the hospital than attempting to walk with crutches and callipers, as he had done for many years. Having made this decision his life continued largely undisrupted. He described accepting wheelchair use as enabling him to "get on with life". Jeffrey and Sue, initiated wheelchair use themselves and thought that it enhanced their lives by allowing them to have the mobility that they required for independence and autonomy.

Maeve and Patrick, although similar in many respects to Jeffrey and Sue, reported that they were introduced to wheelchair use by medical professionals. They described their introduction to wheelchair use as follows:

"one knee started to give me trouble and the local doctor, who was a family friend, said you need a wheelchair and so we had one from the NHS..." Patrick

"When I first got it I thought it was heaven. She [the therapist] said sit in the wheelchair and I sat back and couldn't believe how easy it was to make a cup of tea. [Maeve had previously described how difficult it was for her to manage her everyday tasks before she had a wheelchair] That proved to me that I was ready for a wheelchair." Maeve

Both agreed that the wheelchair had been a help, initially. Later in the chapter, 6.6, the differences that individual participants who gradually adopted wheelchair use

found in their levels of independence and autonomy are discussed. These were instrumental in informing their perspectives on their wheelchair and its use.

6.3.2 Age

The ages of the participants on adopting permanent and fulltime wheelchair mobility were provided in Table 3, Chapter 3, accompanied by their socio-biographical data. The age of the sudden adopters was between 13 and 19 years. The gradual adopters may have had a wheelchair for many years before they became permanent and fulltime wheelchair users and so were older. Jeffrey was the youngest at 25 years of age. The others in this group were in their forties at the time that wheelchair use became their only way to mobilise. This whole group of participants, being older when interviewed, were of a different generation to the other participants.

Differing generational attitudes to wheelchair use were underlined by the reactions of Patrick and Maeve, who were theoretically sampled later in the collection of data to explore emerging ideas. They were chosen because Jeffrey and Patrick shared the same medical diagnosis and had been using walking equipment since childhood. Similarly, both Sue and Maeve had gradually deteriorating neurological conditions whose walking had become affected in their thirties and forties, Table 3, Chapter 3. All adopted fulltime, permanent wheelchair use following protracted chronic illness leading to a gradual decline in their walking ability. However, they each described different experiences of wheelchair use. The manner in which the wheelchair was introduced into their lives was discussed in 6.3.2. The way in which they are dissimilar is in their respective ages when fulltime and permanent wheelchair use was adopted and their previous experience of disability.

Jeffrey's occupation (medicine) and impairment following polio at three years of age had made him familiar with disability issues from a young age and he accepted the use of equipment to improve his mobility. He described the decision to use a wheelchair as being:

“merely a safer way to move around when tired.” Jeffrey

Sue, a nurse, also had professional knowledge and familiarity with disability and the loss of mobility. These factors may have made their decision to use a wheelchair easier.

Maeve and Patrick were the oldest participants interviewed. Wheelchair use was adopted later in their lives and they had little previous personal experience of disability. The period in which they grew up may have influenced their attitudes, as disability issues were rarely reported or discussed in the media and it is reported that some older people find accepting using a wheelchair even for short periods to be impossible (Barker, 2004).

6.3.3 Biographical disruption

Three of those who gradually adopted wheelchair use were middle-aged when the decision was made to use a wheelchair all of the time. This was captured in Table 3, Chapter 3. Loss of walking, therefore, caused disruption to their established life maps. Jeffrey has already been described as adopting wheelchair use to facilitate his continuing with life as he had planned. However, Patrick explained that he changed his occupation because of the wheelchair.

“as a qualified teacher I taught in [xxx] for 3 years. The problem then was extended standing as a teacher. It was just getting too much so we looked around and ...joined a company in the organisation and methods department (a sedentary occupation)”. Patrick

In changing his profession, he alleviated the problems with standing as a teacher, rather than use a wheelchair all of the time, which may have been difficult due to access many years ago when this happened. It is also true that this was before the Disabilities Discrimination Act (1995), so that his employers may have been less helpful in accommodating him into the staffroom and school than would now be the case.

The experiences of Maeve and Patrick, being the oldest participants interviewed, were compared with the findings of Barker et al, 2004 who reported on acceptance and meaning of wheelchair use in senior stroke survivors (Barker et al., 2004). This was part of a larger study that addressed the practical performance issues of the study group from the wheelchair user and their care givers' perspective. However, it was one of the few studies that reported the lived experience of wheelchair users who acquired disabilities later in life. The paper comments that at that time, 2004, no research into the impact of wheelchair use on biographical disruption to those with chronic illnesses and the effect of continuity of life on the acceptance of mobility equipment was found. In the study by Barker et al (2004) data were collected by semi-structured interviews. The report of the study stated that an inductive approach using constant comparison process was adopted. In addition the researchers utilised a qualitative computer software programme, QSR NUD*IST4, (1997) to assist in coding. The findings of their research provide a system of categorisation of acceptance of wheelchair use. The wheelchair was reported by the participants to be a necessity, a great asset or "part of me". These views were modified by the participant's reluctance to use a wheelchair, grateful acknowledgement of the assistance provided by the wheelchair or their complete acceptance of wheeled mobility or internal acceptance. These categories may be usefully applied to the data from the present study and comparisons made. The older participants in this research both demonstrated "*reluctant acceptance*" (Barker et al, 2004, p. 224). They agreed that the wheelchair was a help, however, if they had an alternative they would rather not use a chair. Whilst they felt positively about the wheelchair's assistance they did not speak at length about it.

Barker et al (2004) concluded that the participants of the 2004 study understood the wheelchair as a tool for continuity of activities that brought meaning to their lives. This finding was not confirmed by the two oldest participants in the present research. These two, Maeve and Patrick, described their chairs as preventing them

from participation in activities outside the home. One never went out and the other, at his interview, listed what the wheelchair prevented him from doing. This corresponded with the findings of Barker et al. (2004), a “*reluctant acceptance*” group, who talked most about activities that they were prevented from attempting by the presence of their wheelchair. However, this reluctance was linked with time spent as a wheelchair user in the Barker 2004 study. It was argued that emotional acceptance of the wheelchair occurred gradually over years of use and was linked to the level of acceptance expressed. It was also suggested that these were not necessarily static categories of acceptance, but could evolve gradually.

Gitlin et al. (1998) also addressed acceptance of wheelchairs in an elderly population following stroke. This paper reported that patients expressed anxiety about social acceptance and personal identity with regard to wheelchair use, even though they agreed that the equipment provided the opportunity for independence.

In the present study, those who experienced illnesses in childhood, leaving muscle weakness and necessitating the use of callipers and crutches when attempting to walk, Jeffrey and Patrick, formed their identities based upon a consistent level of disability but not wheelchair use. However, their acceptance of wheeled mobility was different. The data in the present study suggests that this is due to individual contextual factors that change the participant’s reaction to wheeled mobility. This finding is supported by others (Iwama, 2009; Mumma, 2000; Rush, 1997). It was concluded that individual contextual factors altered the participants’ reactions to the introduction and fulltime use of a wheelchair that the data described.

The participants who had undergone a gradual change in their physical abilities that triggered the use of a wheelchair, when walking was no longer possible, were understood to have experienced disruption to their life map and associated biographical disruption. The disruption was heightened for participants who came to wheelchair use in their middle years and were established professionally and socially. This had advantages in that they had a stable social situation, a degree of

financial security and support from significant others. However, they were least likely to have formed positive attitudes towards disability due to their age, history and the biographical disruption that they experienced, which may have been greater than for younger less established participants.

The participants who suddenly came to permanent wheelchair use in this study were all in their teens, as shown in Table 3, Chapter 3, when their life event happened. Their age when fulltime wheelchair use was adopted was thought to be significant in changing the way that wheelchair use was incorporated into the lives of the participants. The amount of biographical disruption experienced by each of the participants in this group, who suddenly became wheelchair users, was affected by their relative youth when wheelchair mobility was adopted. Participants were in their early (two) or late (one) teens when their accidents happened. The degree of biographical disruption described was therefore limited as none of this group was married with families to care for or established careers. Their youthfulness was found to be a helpful factor in their rehabilitation that facilitated flexibility, the ability to learn new skills and so their **embracing** wheelchair use.

The sudden adopters of wheelchair use were all teenagers living at home with parents at the time of their accidents. Di returned home after her rehabilitation and continued her education at the same school, which she described as "*luckily*" having "*reasonable access*" so that in order for her to use her wheelchair nothing major had to be changed. The other two sudden adopters of wheelchair use were helped to settle into adapted accommodation in the community by rehabilitation professionals. The way that they reformed their life maps following the introduction of wheelchair mobility is discussed later in this chapter, 6.5.4.

6.3.4 Previous understanding of disability

The data indicated that the level of each participant's contact with and understanding of disability on becoming a wheelchair user themselves affected their perspective of their wheelchair. These experiences were varied. The younger

participants were more aware of disability issues through contemporary media coverage. They all had assistance with becoming wheelchair users through school or rehabilitation centre professionals. The participants in the gradual adoption group received no such professional assistance in adapting to wheelchair use.

Those with medical backgrounds, Jeffrey and Sue, had less difficulty adopting wheeled mobility. However, for Maeve and Patrick little previous understanding of disability issues was indicated. Patrick described his perspective thus:

“to use a wheelchair when you wanted it was my philosophy but when you didn’t need it keep doing what you could do because I’d seen so many people who refused to go in a wheelchair and in the end when they were in the wheelchair they were in it. They never walked again. I had staff in the office, two who had MS, who refused and in the end we had to pension them off and they were in a wheelchair and they never walked again. I kept on saying use it when you want to, keep the muscles going.” Patrick

6.3.5 Expectations of wheelchair use

A range of different perspectives were expressed by the participants of their expectations of wheelchair use. The wheelchair was described as:

“The wheelchair’s always been a help to me” Maeve

This was conceptualised as the wheelchair providing assistance. Alternatively, Jeffrey thought of wheelchair use as providing safety 6.3.3. His expectation of his wheelchair was that:

“once you’ve got it organised you don’t think about it” Jeffrey

For Sue, the wheelchair meant inclusion in family life.

“I was always there on family outings” Sue

For others, the mobility that a wheelchair provided gave independence and autonomy for the first time in their lives:

“it was a lot easier in my powered chair and I’m pretty independent”. Kathryn

“mobility from school age upwards has been dependent upon a wheelchair.” Malcolm

The expectations expressed were varied and were not found to relate to the relative independence and autonomy expressed by the individual.

6.4 Embracing

The participant's reaction to the transition process, **embracing** wheelchair use, led to the wheelchair being incorporated into the user's life-style. The dimensions informing the concept are:

- Knowing oneself
- Learning new skills
- Getting the wheelchair right
- Adapting the environment
- Developing coping strategies

These are demonstrated in Table 19, which describes the physical and psychological adjustments that the participant makes in order to change their behaviour. These are all interdependent and moderated by individual circumstances.

Table 19 – Embracing

EMBRACING	DIMENSION
	Knowing oneself Understanding disease trajectory/ assessing capabilities
	Learning new skills Level of training received
	Getting the wheelchair right Knowing what you want and how to obtain it
	Adapting environment Level of adaptations to home
	Developing coping strategies Nature of strategy

6.4.1 Knowing oneself

Experiencing a change in physical abilities was different for each individual. Knowing oneself was the cornerstone of getting the wheelchair right and promoting independence. Self-knowledge leads to an understanding of what is required to facilitate independence and interaction. The participants with lifelong conditions considered the wheelchair to be an essential part of this process. Life without their chairs was described as something that was unthinkable. Joshua described his day thus:

“it is a case of getting out of bed in the morning into a chair. I don’t think that even I appreciate the level of dependence that I have on this chair because you never think about being without it...[without the wheelchair] you’re stuck on the bed all day.” Joshua

The wheelchair had been introduced at an early age and was part of their lives as they grew to adulthood. They understood the presence of their wheelchair as positive. It facilitated mobility, which, for them, was impossible; and the wheelchair was described as contributing to the participant’s image.

“I think that the wheelchair is about projecting the right image. I’ve always compared it to having a new pair of trousers.....you manage what other people think. I’ve got enough confidence in my own disability to know that it’s not something that I could ever change, but a nice brand new piece of equipment that you are proud of, it’s a major thing. It would be nice to think that everyone immediately looked beyond the wheelchairit is a massive factor, it’s what I do 24/7.” Joshua

Image was a significant feature of the narratives of younger participants in response to choosing a wheelchair. This feature was unconnected with the type of chair or the extent of the user’s physical limitations. In the same way that clothes and cars have to be right when you are a teenager or young adult in order to maintain a desired social identity in the world, the wheelchair also has to meet the user’s exacting

requirements. This is discussed later in the chapter, when wheelchair users with acquired disabilities are addressed.

6.4.2 Learning new skills

The lifelong wheelchair user learns wheelchair skills experientially as they grow and is taught enablement by their family and through their education. The three participants who never walked all spoke positively about their experiences at special school. They learned practical skills that allowed them to maximise the assistance that their wheelchair provided for them to access all areas.

"I'd never known what it was to be able bodied in the first place, so I knew if I wanted to do something I had to use the wheelchair and in order to do that I had to know how to use a wheelchair to the best of my ability." Malcolm

Their confidence in their abilities as wheelchair users was a pre-requisite for successful integration into their communities, as the built environment presented constant barriers to access and reminders that they were different.

Their education at special school was described as a process of **taught enablement**.

This was illustrated by Malcolm's statement:

"I started school when I was five...it was a special school. Once we started school the attitude to disability was that disability didn't really matter. We were taught to be people first and disabled afterwards. That meant that we were quite forceful characters, we wanted to try and do things despite the fact that we were in wheelchairs, which created in us a demand to learn the skills to use the wheelchair to the best possible advantage and that manifested itself in ways that modern physiotherapists might frown upon. We learnt to do back wheel balancing, which is now not so important because of all the ramps that are available...it was necessary to be aware of what the wheelchair could do, which gives you confidence to do things in the community."
Malcolm

The experience of enablement that school provided was shared by all those participants with lifelong conditions. The younger of these participants attended special school within the last 10 years. Malcolm, who was older, attended special

school 30 years ago. However, they shared the same attitudes about the advantages of special schooling. The younger participants had the opportunity to attend both special and mainstream schools. Kathryn considered that special school did not push her academically; however, it enabled her to develop, as Malcolm had stated, as a “person” by providing friendship and stability as she went out into a world where she stated that she was different.

“It was through my special school that I had an indoor/outdoor chair... when I went to mainstream I was at home all the time. My special school was my safety net. I had physio and I met my friends each evening. At special school we weren't treated differently we were all in wheelchairs, we all had disabilities but we were treated the same...when they see me have a spasm they try to act normal because they know that I'm feeling a bit...sometimes it's funny especially when you're in class and your teacher says do you want to say something...all your classmates start laughing.. 'Kate it's not time to put your hand up', so you don't feel abnormal...you do the same things that able bodied people do.” Kathryn

Self-awareness and an acknowledgement and acceptance of their differences to others, to this group of participants, meant that being unable to walk was not perceived to be a loss, their disabilities were a fact of life. An insight into their perspectives on disability is presented below.

“I have always been confident ...but I think that my disability has helped in terms of levels of determination. To live with a disability is extremely difficult and you have to have unbelievable levels of determination....the right wheelchair enhances my confidence.” Joshua

“We really have to get over this idea that you can separate the wheelchair from the person...events dictate, everything has to fit together...” Malcolm

Joshua indicated that he considered his disability had made him a stronger and more determined person. Malcolm explained that his wheelchair was his starting point in understanding the world. His interactions with significant others and the society in which he lived were influenced by the presence of his chair. He came to understand the world and himself as a wheelchair user. His identity, seen through the eyes of

the community, was that of a wheelchair user and this was how he understood himself.

Other participants, who came suddenly to wheeled mobility following spinal cord injury were taught wheelchair and coping skills at rehabilitation centres. However, the gradual adopters reported that they were offered little or no assistance with managing the transition to wheelchair use, see 6.4.3.

“I got in touch with the physiotherapist at the local health centre and from there it didn’t take long to get a wheelchair” Sue.

Jeffrey had strong opinions about this issue.

“it is completely essential that you should be given a lifetime’s advice...it can come from any moron as long as you’re given it!” Jeffrey.

6.4.3 Getting the wheelchair right

Acquiring, what the participant considered the best wheelchair, one that would facilitate their mobility and function, was something that all of the participants in the lifelong user group stated was important. The plethora of wheelchairs on the market makes selection difficult. However, choice from the NHS wheelchair service may be restricted, and many users prefer to obtain a chair privately or from a charity. In embracing wheelchair use, these participants demonstrated many different skills. They were able, through a lifelong understanding of their physical impairments and an educated approach to wheelchair use, to modify their wheelchair as required to meet any change in their physical abilities and to facilitate maximum function. Choice of wheelchair extends not only to the features of the chair but also to the provider. Two participants in this group used NHS wheelchairs. Both were satisfied with the equipment that had been supplied. The third participant was young and living in university halls of residence that were wheelchair adapted. The outdoor terrain on campus was not ideally adapted for wheelchair use, and for this reason Joshua felt that a powerful chair was required that was not available through the

NHS. He had chosen to have his wheelchair supplied by a charity, which gave him greater control over the choice of chair.

“I’m used to going along with what the public wheelchair service is saying. This cushion is right or this chair’s right. It was only when I came to Action for Kids and found out there was another way that I realised how inadequate and inappropriate my chair was....I have never felt in a position to say I feel this chair is not suitable for me”. Joshua

The wheelchairs chosen by these participants were either manually propelled by the occupant, using the large rear wheels, or controlled by the occupant steering an electrically powered wheelchair. Malcolm chose not to use a powered wheelchair. However, he was able to self-propel strongly and he also drove a car. This may have affected his attitude towards powered wheelchair use. Malcolm explained,

“I do have the belief that the public concept of a disabled person is a young fit male with a back injury propelling themselves gracefully down the road...a powered chair [gives the impression that its occupant] is past their physical prime and is considered to be elderly... the flat where I live, in order to accommodate the powered chair because of the difference in physical stature of the chair, I would have to change several things in my home.” Malcolm

Malcolm indicated that he does not want a powered chair, but suggested that this was because of his housing situation, he made a compromise and chose to use a smaller manually propelled chair rather than alter his home to accommodate a large powered chair. However, for the other two participants who were lifelong wheelchair users, powered mobility was essential. The NHS will only supply a powered chair to those who are unable to self-propel due to upper limb weakness. This included Kathryn and Joshua, for whom manual self-propulsion was never an option because their condition affected at least three of their limbs, which meant that they were unable to coordinate their arm movements sufficiently well to manually self-propel a wheelchair. Powered wheelchair use was introduced when they were very young to replace their baby and toddler buggies, and provided them with independent movement for the first time in their lives. Joshua considered the

powered chair that he had chosen to be superior to the NHS chair that he was offered as it was both more powerful and better looking.

“The chair having a certain amount of style that’s the main thing. Able bodied people seem to have this unbelievable mystique when it comes to a brand new powered chair and when I say that a Storm costs £9,000 they’re very surprised, as you can get a middle of the road banger car for £900 they want to have a go with it and you have to explain it does have a sense of appeal for a while but try being in it 17 hours a day.. the appeal wears off. ..let there be no doubts whatsoever that I’m not in it because I want to be...every feature is entirely necessary, not a piece of Buzz Lightyear equipment”. Joshua

These were features that he considered to be important. For Joshua the charity had given him the choice to select a wheelchair with many additional features, not available through the NHS, which allowed him to participate fully in university life. Joshua illuminated this whilst thinking about the dichotomy between his attitude to his powered wheelchair and his manual. He was unable to functionally propel the manual wheelchair himself and required assistance when he used it. He described how his dependence on his powered wheelchair was highlighted when he was forced to be without it.

“going to a party I know that I am going to have to spend time in my manual chair simply because the person’s house isn’t accessible for an electric chair...in your manual you’re just reducing your capacity to participate so hugely that it’s not worth being there because you can’t move around, mingle, interact” Joshua.

Kathryn remembers getting her first powered chair.

“When I first got it, it was just amazing... I can actually move on my own, without having to think no I can’t do that.. my world was opened up.. it made my life so much easier and comfortable because I could go out [on her own] I could go to the cinema, I could get on Dial-a-ride.” Kathryn

The importance of her powered chair, expressed by Kathryn, was that it allowed her personal autonomy. This was removed in her manual chair, which she was unable to move herself and made her dependent upon others for help.

“Without the [powered] chair I get frustrated. I won’t do without it....I get upset. I have to rely on somebody else. That is really hard for me. It’s silly things like making myself a drink. I can’t move round... I just want to go back and I can’t. I just get really snappy.” Kathryn

This reflected similar attitudes to Malcolm, who earlier described how loss of his wheelchair would affect not only his mobility but also his personality.

The lifelong wheelchair users were all well informed, active people who were integrated into their communities and valued their independence. In order for the wheelchair to promote independence, the participants had to incorporate their wheelchair into their lifestyle and develop strategies to facilitate its use. The steps necessary to **embrace** wheelchair use have been captured from the perspectives of the lifelong users. The steps include adapting the home environment to accommodate the size of the optimal wheelchair selected by the user. Kathryn illustrates how as she grew her needs changed and her family’s role in embracing wheelchair use.

“I did a bit of walking and stuff in physio but I’ve always been in some kind of chair. I had a buggy when I was younger but as you get older your cerebral palsy changes and you need a better chair. My parents had to fund two electric chairs; one for indoors and one out, the golf club helped, they brought one... That was the problem, I can’t transfer on my own so my parents were in a situation. As I got older I got heavier, when I was 14 my Dad said it’s really getting difficult, whisking you in and out, in and out. And my parents worked as well so it was difficult...That’s when I got my Harrier [indoor and outdoor powered chair combined to allow use of one chair not two] it made my life so much easier and comfortable because I wasn’t being transferred all the time. Easier on my family because I could go out and then I went to college where you can’t be late just because you can’t get along as fast as others.” Kathryn.

Knowing how to acquire the best wheelchair to meet their needs either through the NHS, a charity or privately purchased through a dealer, was essential for this group of active independent adults. They each chose different ways to access the chair they required. Kathryn had financial support in purchasing a wheelchair, from the local

golf club. Joshua chose to approach a charity to supply a more powerful and better looking wheelchair than the NHS provided. However, Malcolm was satisfied with the NHS provision.

The chair should be the most appropriate for each user. It should provide a level of assistance commensurate with their physical impairments. Jeffrey discussed this issue,

“you’ve got to have the right chair. It’s quite hard finding the right one..they’re either poor or you need a lot of help with them...once you’ve got it organised you don’t think about it until it goes wrong.” Jeffrey

However, it should also suit their lifestyle. Jeffrey described his perspective.

“electrically powered chairs are very heavy...if you want to charge them you need a garage, you have to have flat access to your house. It’s a whole lifestyle thing. You’ve got to decide what your lifestyle is and then get the chair for that lifestyle...I go to Naidex [the major equipment exhibition in the UK] every year to keep an eye on all the equipment...I am careful to know about all the equipment for sale, anything that might help me.” Jeffrey

Jeffrey had become an expert on wheelchair design and the products available. However, he emphasised that he chose his lifestyle and then a wheelchair that would blend with this. Jeffrey had assessed whether a powered chair would be helpful, as his upper limbs were weakening, and decided in order to suit his lifestyle to settle for a manual chair with an additional driving pack.

“I have one wheelchair in my car, two wheelchairs downstairs and one wheelchair upstairs. I have a stair lift to connect me between the different wheelchairs. My serious wheelchair has been adapted with a Yamaha motorised hub kit. I have spent a lot of time getting the right chair you can declutch it and then you have a mechanical chair or it’s a fully electric chair...you couldn’t get it on the NHS.” Jeffrey

Those who attended rehabilitation centres had assistance with choosing the correct wheelchair and learning how to use it. The lifelong wheelchair users were taught to be independent and competent wheelchair users at special schools. However, the gradual adopters did not have access to either of these opportunities and for them learning to be a wheelchair user was experiential. The participants' significant others, family and formal carers, may affect the participants in this as they are often willing to take over roles that might be managed in an alternative way if their help was unavailable. An example of this is the actions of Patrick's wife,

"my wife and family are always with me, they push me...the car I've got at the moment the wheelchair has to stand upright, not lay down, so somebody has to lift it in and out..we are retired my wife is always with me." Patrick

Patrick's wife assisted him to transfer into his car, which he drove with hand controls. She then lifted his chair into the boot. She pushed his chair when they were in the community, despite his ability to efficiently self-propel.

"Now I've got no choice because I've deteriorated...I'm lucky I've got my arms...my wife was pushing me and we went across a cobbled road and as we came to the other kerb the front wheel stuck in the cobbles and I shot forwards and tipped completely out onto the cobbles." Patrick

There was no discussion about alternative ways to manage his disability and to enable him to have greater independence and autonomy. This might have been achieved by him obtaining a powered wheelchair, acquiring a wheelchair accessible vehicle and adapting his home to accommodate the chair. He chose to manage in a different way, thus Patrick did not embrace wheelchair use or change his behaviour.

Matt is also a wheelchair enthusiast. He explained:

"I've got 4 wheelchairs and a hand bike. One of the wheelchairs isn't a lot of good anymore because my condition has changed since I left hospital. I want a different chair for different things: one's for sport, one's for shooting, the other's for basketball..and my handbike is excellent for exercise. I'm often taking things apart... I sit on the sofa and pick it up and start taking it apart. I play around with it....I am able to do it." Matt

Support from professionals in making the transition is reported to be helpful, but in short supply. Sue stated:

“it was an OT who helped me with the first two wheelchairs...I think that there was a sense that people were being compassionate..about your needs, there wasn’t a financial benefit to them.. but she hasn’t been in touch since.” Sue

Rehabilitation and wheelchair professionals only manage the provision of NHS chairs, and so once the user moves outside the District Wheelchair Service equipment range they are no longer involved. The participant’s ability to choose the right chair will be affected by the availability of help with purchasing the correct chair and by their financial resources.

“my mother brought me an electric wheelchair. This was a good experience as we didn’t have to go through an agency to fight for it, but it was a bit of a blow to realise that the chair I brought is a bit too heavy for the standard constraints for cars. I should have chosen one that was a little less all singing and dancing....when you buy a wheelchair privately I really felt that I was a customer and they were trying to sell me a product..any sense of caring about my needs or how it might affect me wasn’t there at all...this was a financial transaction and they wanted to make a sale.” Sue

Sue underlines that the problems with choosing your own wheelchair and the shortage of independent support available outside the NHS.

The gradual adopters, who did not have access to rehabilitation, had little access to assistance with wheelchair acquisition.

“I tried to get an electric one but they want proof I can see. I hit the doorframe, I couldn’t see it ..I’m alright now I’ve got this eye patch I went away with a black patch on that eye nothing on the other and I was fine. That was all I had to do. Like Sinbad the sailor. With this [the manual chair] you’ve got to get hold of this and wheel yourself if you can manage to steer it [the wheelchair] and push yourself around, all is not lost and it’s hard work. It’s becoming more and more hard work.” Maeve

6.4.4 Adapting environment

For successful mobility the right wheelchair for the occupant has to physically fit into their home. This often requires major adaptations to provide flat access and widened doors. Often additional small items of equipment are provided like rails or ramps, which may be aesthetically wanting.

Jeffrey stated,

“Most adaptations are poorly conducted. Council bathrooms are revolting..so if you don’t want your wife to feel miserable you keep away from council adaptations. I have a wet room, to blend in with the family [the equipment] must be aesthetically acceptable. There is no reason why all the equipment couldn’t be designed to look domestic and nice. Some are trying, but the purse won’t buy it they are very expensive.” Jeffrey

Space is required to manoeuvre the chair and this is greater if a powered chair is used. Flat access, which is helpful if a manual chair is used, becomes essential when a powered chair is considered.

“I was OK in the mornings and then as the day wore on and I got tired at night and the push to the bedroom, with all the facilities so I don’t have to go upstairs, was too much I found that I was staying in the bedroom at 9 o’clock rather than going back because I’d been to the loo... so my mother brought my Beetle [electrically powered wheelchair].” Sue

The structural adaptations to her home already in place allowed Sue to introduce a powered chair without difficulty when she required one.

However, two participants with deteriorating conditions had no adaptations to their homes to facilitate wheelchair access. A powered chair may become necessary if the wheelchair user is no longer able to propel a manual, and understanding and accepting the trajectory of their disease process is a vital step in the participant ensuring that the wheelchair they use is the most appropriate. Those participants who have adapted dwellings are noted in Table 10. The two participants whose

homes were not adapted for wheelchair access, Patrick and Maeve, would not be able to use a powered chair.

Through embracing wheelchair use, the lifelong wheelchair user ensured their independence and social integration. From the data previously presented in Table 3, Chapter 3, it was observed that all the participants in this group lived in fully adapted homes with space for the optimal wheelchair to facilitate their mobility and independence. This was a feature of wheelchair use that had been part of their life experiences from birth. As they grew, so the equipment became more difficult to accommodate into the family home and car. The need to make allowances for their wheelchair was understood by this group of lifelong wheelchair users.

Those in the sudden adoption group were facilitated in settling into the community by rehabilitation professionals in the acute and sub-acute hospital environments. They were therefore able to function from the level of their wheelchairs immediately on discharge from hospital.

6.4.5 Developing coping strategies

Fulltime wheelchair use means learning new behaviours for everyone involved in the participant's life. The reactions of employers, family and friends to the use of a wheelchair by the participant affected their approach to change. The participant changed their behaviour, and those around them were required to change also. Once using a wheelchair, the experiences of the user were affected by the reaction to those around them, their significant others, and also by their experiences in the wider community.

"We were in Tesco's and we were going round and somebody said that looks very like Marjorie...oh it is you, where's Patrick? And I was by her side and they hadn't even seen me." Patrick

Patrick's perspective was that the wheelchair was an invisibility cloak that made the man disappear as the wheelchair took over. The independence and autonomy that the other participants describe a wheelchair providing was not how Patrick experienced wheelchair use. Sue also described the experience of being "unseen".

"Fewer people tend to talk to the people pushing you than they did [in the past]..people don't notice me in a wheelchair because you're out of eye line, and a number of times in shops people walk into me.. we have a few collisions.. they crash into me...it doesn't really worry me but I think that my background as a nurse has helped." Sue

Her personality was able to cope with the difficulties that she experienced when out in the community.

"there are some people who will always gawp at you and be totally insensitive... in the supermarket people will say excuse me and then push you away so that they can get by...it's me and the wheelchair against the world.... but people are doing more diversity training in the workplace." Sue

The expectations of significant others, relatives and of staff and other patients in the rehabilitation centre altered the reactions of the sudden adopters. Becoming a wheelchair user involves many complex interactions. The influence of others is always an issue because the wheelchair is visible and an ever present sign of disability. One example of this was the failure of Patrick's employer to make the adjustments necessary to accommodate use of a wheelchair into the working environment. His changing physical abilities resulted in this teacher leaving the profession.

The participants' reactions to becoming wheelchair users decided their future independence and autonomy. Only if the participant was able to embrace wheelchair use could they move on and establish a new life map and self-identity. Acknowledging that walking is no longer possible is a considerable change in

circumstances and would be expected to be accompanied by emotional turmoil. This was discussed by Matt who said:

“it just shows that they’ve never got over it... never come to terms with it, they’re governed by it... to me it just makes no difference, me being in a wheelchair. I can do everything else except for walk.” Matt

“I tend to make a statement. I am quite an extrovert sort of person so it doesn’t really matter to me and I guess if you were shy and didn’t like to be noticed, then you would find it very difficult.” Sue

The personality of the participant was pivotal in their acceptance of wheelchair use and their ability to make the transition of role into being a wheelchair user. All the participants who were lifelong wheelchair users had emphasised that to be a wheelchair user required confidence and perseverance. This was supported by others who had walked before becoming a wheelchair user.

The older participants who came to wheelchair use in their middle years were established professionally and socially. Jeffrey, although younger, had excelled at school and was recognised by the community as a high achiever, being a qualified doctor when he made the decision to use a wheelchair all of the time. He had confidence and status. His life map was established and he accepted wheelchair use in order to facilitate his lifestyle. The importance of establishing a life map and having purpose in life will be discussed later.

Sue, similarly, had a professional background and a stable home life when in her forties she accepted wheelchair use, pragmatically, as a confident mature person who was anxious to continue being socially integrated and independent within the community.

Matt described himself as obstreperous, a person with the confidence and belligerence to strive to be recognised. He demonstrated by describing his management of taxi drivers who fail to provide a good service.

“taxi blokes just shake their heads at me because they can’t be bothered to get out and pull the ramps down at the side of the taxi...but they’ve always given us a lift because I’ve gone and sat in front of the taxi until he opened the door and [...] done it” Matt

Jeffrey, an outgoing person, copes with the community through engagement with others. He related how he manages his chair by asking for help.

“I just say hello can you help me with my wheelchair...if you ask for help someone will say ‘my Aunty was in a wheelchair for years you know’. More and more people are using them now and it’s part of life.” Jeffrey

Personality and confidence are foundational to the participant’s ability to devise coping strategies. Jeffrey and Matt continue with everyday life. However, for Maeve, taxi drivers had quite the opposite effect and she rarely leaves her home except on charity buses with thoughtful volunteer drivers/carers or on ambulances.

“For some unknown reason he came down forwards...the wheelchair ran away with him and I smashed my feet into the brick wall and he couldn’t have cared less...I’ve long given up on buying things in shops...it’s not for people like me.” Maeve

Motivation to succeed was encouraged in Matt’s case by the discovery that he could become a world class sportsman following his spinal injury. He found purpose in his life, which enabled him to embrace wheelchair use and to form a new self-identity, one where his sporting success brought a sense of purpose and achievement that he had not experienced before his accident.

People who use wheelchairs for mobility are discussed in research papers as chronically sick. However, for the lifelong users this was incorrect, they have lifelong

differences. Those who gradually come to wheelchair use having walked are more likely to be in declining health and less physically able to make changes to their lives to incorporate wheelchair use. Their journey is marked by losses and their withdrawing into their homes. Maeve's interview detailed a number of losses. She no longer went out shopping or continued with her voluntary work.

"We have to make do with ordering things from a catalogue, ordering something and hoping it fits.. I've got my own hairdresser who comes every weekas you get worse you drop things...my hands are not strong enough...some people like to be waited on hand and foot. I don't...now I just sit. Sitting here that's what I do" Maeve

Similarly, Patrick talked of losses. He had given up his career in teaching, had struggled to avoid wheelchair use and now his leisure activities were becoming curtailed. He would like to swim but thought that this was no longer possible.

"I haven't swum for three or four years ...I would love to but I've got little ability to lift my bottom off the seat to dry myself." Patrick

The lifelong wheelchair users interacted with society and were influenced by the cultural conditions that prevailed at the time. These have changed during Malcolm's lifetime. Access was an obstacle to Malcolm when he was growing up, as this was long before legislation to ensure access for wheelchair users in the community (Disability Discrimination Act, 1995; Community Care Act, 1999).

"Because I was a twin it was necessary to my parents that my brother and I went as many places together as possible...my brother was able bodied. He was burly fit and physically healthy and cognitively able to go to a normal school...the physical effort involved by my parents to overcome obstacles, they were determined because I was a twin, in some cases my Dad had to carry me on his back...in other cases they carried the wheelchair upstairs to get me to a place that I needed to go." Malcolm

It was this determination that Malcolm's parents demonstrated in insisting that their twins be treated equally, despite one having a physical impairment, that has influenced Malcolm's perspective and resolve to succeed.

Despite legislative reforms to ensure inclusivity for all in our community, (Disability Discrimination Act, 1995; Community Care Act, 1999) many environmental barriers still exist today. Joshua explained how he was unable to drive his powered wheelchair to parties in his student friends' houses because they were too small for his large powered wheelchair or had no flat access to allow him to drive straight in.

"In terms of actually physically propelling there's just no way so you'd have to have somebody with you helping you out. It doesn't come up very often...but I don't like it because I'm so used to being in my electric [wheelchair] that any time I'm in my manual it's like coming out of your comfort zone...reducing your capacity to participate so hugely that it's almost not worth being there." Joshua

He described going to parties in his manual chair only because he had a friend who was willing to push the chair. This was an example of a coping strategy that this group of wheelchair users, and their parents, had always been required to use to manage the social and environmental barriers that existed from the outset of their wheelchair use. To be fully integrated into their family and beyond, the lifelong wheelchair users developed strategies to facilitate their access to the built environment, where many obstacles to wheelchair mobility remain. Because the wheelchair was central to the planning and execution of their lives, coping strategies were second nature to this group. These skills were learned naturally as they grew and throughout their education, where they had the opportunity to learn enabling strategies in a protected environment.

Legislation having gone some way to address the physical limitations of the built environment, wheelchair users are now better able to interact with the wider community even though restrictions to free access to all areas remain. However, once the physical barriers are removed there are new barriers to overcome, these are

attitudinal restraints. Kathryn who was independently mobile described her experience.

“One bus driver wouldn’t let me on... he made me cry. He said you can’t come on here and I said why I’ve been using the bus for ages...[this was because] he had to get out of the bus to pull the ramps out and pull the seat down. I was so frustrated because I had waited for 45 minutes for one bus and this didn’t have ramps so I had to wait for the next one, then he was like, ‘I’m going to be late you’re not coming on my bus’.” Kathryn

Coping with these attitudes requires confidence in your own abilities and the fortitude to ensure that fair treatment is received. A secure sense of self was central to Kathryn’s interpretation of the situation and her actions.

The perspectives of the participants (with lifelong disabilities) were formed from a standpoint of acknowledgement of their difference to others and acceptance of wheelchair use from a young age. This led them and their families to naturally **embracing** wheelchair use as a part of family life as they grew.

6.5 Being

The data demonstrated how, on completion of the phased transition, the participant viewed the world from a changed perspective. Having made changes in their home and lifestyle, the participant had maximum independence and autonomy. Their life map was rewritten from an alternative ontological viewpoint, that of **being** a wheelchair user.

The title of the substantive theory here is *accepting wheelchair use*. On exploring the meaning of the word *accepting* many different alternatives were suggested. Accepting was severally described as enduring, tolerating, bearing, as well as recognising, understanding and agreeing. Accepting therefore covers a range of reactions and emotions, from reticence to knowledge that leads to compliance. The data were the experiences of wheelchair users, and their interviews explored all of

these elements. It is acknowledged that for each individual the introduction of a wheelchair happens at a different time in their lives and in a unique way. However, for all wheelchair users a transitional process takes place. If the series of adaptive tasks is completed then environmental, functional and cognitive changes take place that prepare and promote the individual's use of their wheelchair. The final element of the process is an emotional change that allows the individual to identify with **being** a wheelchair user. This change of self-identity emerged as foundational to the wheelchair user's continued wellbeing. The substantive theory captures this transitional process, incorporating all elements of the change that each individual experiences on becoming a wheelchair user.

Table 20 – Being

BEING	Dimensions
	Relating to wheelchair Attitude expressed
	Gaining control Wheelchairs effect on independence
	Planning life including wheelchair Nature of interactions
	Developing life map as wheelchair user Life map continuous /disrupted/reformed
	Integrating with society Nature of integration

6.5.1 Relating to the wheelchair

The way in which the participant related to their wheelchair was indicative of their transition through the process of acceptance. Exploration of the data identified that the participants explained their attitude towards their wheelchair in a number of different ways. These were labelled:

Embodiment

Adornment

Image

Detachment

Embodiment

The lifelong wheelchair users all described their wheelchairs as part of them. Those who naturally adopted wheelchair use described closeness to, or seamless union with, their wheelchair. This was termed embodiment. They explained their perspectives using statements such as:

“we really have to get over this idea that you can separate the wheelchair from the person; it is with you all the time...so you have to make it part of you. The whole person is me and the wheelchair...a manual chair can physically become part of you. Malcolm

“it’s part of me...your whole body, because it’s just to me it’s, it is my body It’s not my legs it’s the whole of me it’s who I am.” Kathryn

These participants talk about their wheelchair as an extension of themselves, almost part of their bodies. They considered it to be something far removed from a piece of equipment that you sit in. None of the other groups of interviewees described their wheelchairs in this way. However, this group, who naturally adopted wheelchair use, shared no sense of loss associated with using a wheelchair. Having never walked, they accepted that the wheelchair was a necessity, part of them and their lives were built around its use, they were unable to contemplate being without it.

The other participants talked about their chairs in a more detached way. The wheelchair was discussed as a separate and distinct entity. They mentioned sitting *“in the chair”* or *“on”* it. In all seven cases the wheelchair was understood to be a separate item of equipment that was considered in a number of different ways.

First and foremost the chair replaced a function that was lost to them i.e. the ability to walk. All of the participants had fully intact lower limbs; they were, however, no longer able to use them for walking. They describe their wheelchair as an adornment that contributed to their self-image. For others it was a hobby, described in 6.4.3. These participants were constantly striving to achieve the best performance possible from their wheelchair and they spent time and money reconfiguring the equipment to meet their clinical needs and exacting standards.

The participant’s relationship with their wheelchair was that of an adornment, part of their self-image or as a hobby. The wheelchairs were variously described thus:

“It’s just a substitute for your legs. It should take no more of your attention than your legs. It’s more like shoes really” Jeffrey

"it's you that are going to be sitting in it for a number of hours not someone else. It's another part of me. Because my legs are not working this chair has to be my legs" Chantelle

The different perspective of those who had walked for a period of their lives may be due to the wheelchair **replacing** a function. The chair was described as having **"to be"** my legs. This way of describing the chair is markedly different to the perspective that the wheelchair **"is"** my legs (**embodiment**) described by the lifelong wheelchair users.

Adornment

The analogy of wearing items of clothing was used to describe the approach to the wheelchair that was described by those who had walked for a period.

"it's like wellies for the garden, sandals in the summer kind of approach" Patrick

"it's the same as my trousers" Jeffrey

"it's like your glasses" Di

Alternatively, the wheelchair was part of the participant's image and the statement that it made to the world.

Image

Di stated that her wheelchair was an adornment and also that it was part of her image.

"it matters to me, because it's also an image thing. It's like clothes. You always want to look good, so you want the chair to fit the clothes, which is why I now go for neutral coloured chairs." Di

"it changes other people's perceptions of you as well, because if they see you in, like, an NHS chair, it's just another disabled person. I've had people come up to me and say I've got those wheels on my bike." Di

"I think that people don't notice the chair so much because it sort of merges in with you...you just happen to be sitting down" Di

Matt described his wheelchair as:

“an extension of the ego...you don't want something that looks horrible it's got to look good...it's like a flash set of wheels on the car”. Matt

These wheelchair enthusiasts spoke from a position of interest and knowledge. They understood their clinical needs and were able to select a wheelchair that provided performance with the appearance that was required. The look of the chair is very important. The enthusiasts have the self-knowledge and the wheelchair skills to commission custom made wheelchairs to meet their specifications. However, they each became wheelchair users at a young age; were sudden adopters and received wheelchair skills training. Jeffrey similarly considered his wheelchair to be a hobby, see 6.4.3. He was younger when he chose fulltime wheelchair mobility and he had specialist knowledge due to his occupation (medicine).

Detachment

Detachment is a feature identified in those who had not completed the transitional process to being a wheelchair user and is described later in the chapter when individual responses to wheelchair use are discussed.

6.5.2 Gaining control

The wheelchair means that the individual has control over their lives. This is described by Sue:

“The chair is an enabler really ...the opposite of disabler...because it enables me to do things that there is no way I could do without it. I go to ---- regional meetings and I am a voluntary chaplain at the cathedral” Sue

For Chantelle her powered wheelchair provides autonomy in a life where she is rarely alone (having 24 hour care) and finds exercising her independence difficult to manage.

“I just feel happy that I can control one part of my life. I can go anywhere, do anything. I just like being as independent as possible.” Chantelle

Disability means that the individual is reliant on others to perform functions that they are unable to complete for themselves. The wheelchair is regarded as facilitating their controlling one part of their lives.

“it’s difficult to quantify the difference that having a wheelchair makes...with a wheelchair I can do virtually everything that an able bodied person can do without it I would be on the floor..I don’t think that I could consider not having a wheelchair” Joshua

6.5.3 Planning

As Malcolm described earlier in the chapter, to successfully use a wheelchair in the community requires planning. Sue talks of how she checks out the physical environment and then decides which wheelchair she needs to use that day.

“We knew it was level access I could use the toilet and get around all over the place (in my powered chair). We have been to two weddings this year one was at a golf club and the other a country hotel. One was level access but the toilet facility was lousy ...and the other I was transferred onto a stair lift and the wheelchair had to be carried up the stairs. There was no way I could use my powered wheelchair”. Sue

6.5.4 Developing life map as wheelchair user

It is the way forwards after embracing wheelchair use that ensures the user has social integration and quality of life **being** a wheelchair user. Reforming or rewriting their life map was a key feature of this. Meaningful occupation was possible for those who, like Jeffrey, were able to continue with their previous map having accepted wheelchair use. Di had become a wheelchair user when young, and so having recovered from her accident she returned to school and completed her studies. Her plans for the future included her wheelchair as she now understood herself as **being** a wheelchair user.

“My chair is an extension of me. Just like you with your glasses you want them to look good...I went on a university field course to Spain and when we landed Spain hadn’t told Gatwick that I was on board so we got there and there were steps down. Someone had left a 24-pack of Stella on board so my friends were like why don’t we just pick it up..there wasn’t enough people to carry both I don’t drink beer so we left the Stella.” Di

Her attitude was light-hearted, as this quote illustrates. She reformed her life map and to go to university and then out to work, which required enormous determination on her part to overcome the barriers. Di explained that one such barrier was her mother's anxiety about her living away from home.

"My mother keeps trying to get me to go down and stay with her at the moment and I say I'm not going...I won't go I like living here now this is where I live..but my mum just wants all three of us safely together." Di

Purpose in life moderated the participants' perspectives of wheelchair use. For some the wheelchair was acknowledged to have allowed their life map to continue unhindered, as was the case with Jeffrey. To others, the wheelchair brought new opportunities. Matt developed a new and more rewarding life as a wheelchair user.

"It made me do things that I wouldn't have probably done before... after my accident I was lucky enough to be picked for the inter-spinal games and that's where I found out about it. I used to do it before just for fun but I didn't know where the clubs were or how to join...someone said would you give up your gold medal to have your legs back so you could walk again I said I would keep my medal." Matt

6.5.5 Integrating with society

Both of the participants above regard the wheelchair as enabling them to be socially integrated. However, if no new life map as a wheelchair user was established the participant became progressively more withdrawn, as happened to Maeve who rarely leaves home. Her story is described in 6.6.

An essential part of **being** is described by Sue who thinks of her wheelchair as helping her to be socially included.

"a group of people came from a Vitalise Centre on holiday to look around the Cathedral and I was the duty chaplain...it really was a lovely encounter, there were people who could communicate well and others with problems and I felt that as I was there as a wheelchair user

and as chaplain it was really good for them... to relate to somebody who probably knew what it was like.. Sue.

Others also mentioned how the wheelchair helped to break down barriers by providing a talking point with strangers (Jeffrey 6.4.5). The consequence of each participant's personal reaction to their change in mobility governed their future independence. The data describe a variety of reactions to fulltime and permanent wheelchair use. Some sought advice, undertaking wheelchair skills training and changing their environment to accommodate their wheelchair. Others resisted change and failed to act to embrace wheelchair use and became dependent and isolated.

Either the participant changed their behaviour and embraced wheelchair use or resisted this change. Some accepted the new self-identity, that of a wheelchair user, and rewrote their life map embracing wheelchair use. This maximised their independence, facilitated their social interaction and autonomy. The ontological perspective of those with lifelong conditions was that of a wheelchair user because they had never walked. This was illustrated by Malcolm who explained:

"my view on the world is from a different level to yours. I view the world from this angle."
Malcolm

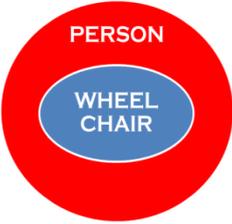
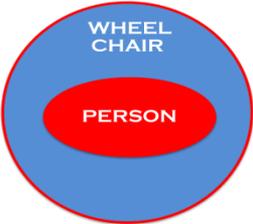
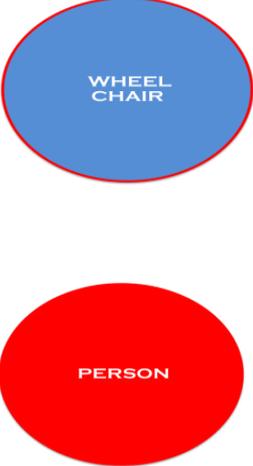
Whilst this seemed to be referring to his eye level he was actually trying to explain, at interview, that his wheelchair gave him a different perspective on the world to mine. Malcolm explained that the difference was because his wheelchair was his starting point in understanding the world. His interactions with significant others and the society in which he lived were influenced by the presence of his chair. He came to understand the world and himself as a wheelchair user and his identity seen through the eyes of the community was that of a wheelchair user. With it they were able to "*overcome*" their disability. Malcolm described this:

“so if you were to separate my physical body from the wheelchair perhaps my personality wouldn’t change but my ability to interact with people would be severely restricted and if this went on for any length of time then you might find a personality change” Malcolm

For others, the change in behaviour required was impossible. Emotionally they were unable to accept wheelchair use and ontologically they continued to take a perspective on the world that was formed when they were walking. Hence, they attempted to continue with their previous behaviours, which produced ontological dissonance. The wheelchair was then understood as being responsible for their increasing dependency and isolation. The findings show that these participants experience disproportionately greater disability and dependency than their peers with similar physical impairments. Those participants who failed to progress through the transition process or who became stuck were unable to accept wheelchair use. A discussion of these participants’ is found in 6.6.

Table 21 demonstrates the way that participants relate to their chair and how this affects their response to wheelchair use and their level of independence or dependency.

Table 21 - Responses to ways of relating to wheelchair user

Relating to wheelchair	Explanation of concept	Factors leading to participant being in category	Response to wheelchair use
 <p>EMBODIMENT Integration of wheelchair and participant.</p>	<p>User relates to wheelchair as mine.</p> <p>Describes Embodiment of equipment</p>	<ul style="list-style-type: none"> • Lifelong condition have never walked • Developmental adaptation to wheelchair use reinforced through special schooling • Positive self-image • Positive attitude 	<ul style="list-style-type: none"> • Normalization/ Developmental stage • Independence • Self confidence • Self-actualization • Life map continuous
 <p>Wheelchair understood as:</p> <p>ADORNMENT IMAGE HOBBY</p>	<p>Wheelchair provides mobility contributes to self-image.</p> <p>User describes sitting in or on the chair. Relationship is positive. W/C seen as a facilitator.</p>	<ul style="list-style-type: none"> • Able to accept that a wheelchair is necessary for function • Able to accommodate to wheelchair use. • Able to plan future. 	<ul style="list-style-type: none"> • Accommodation • Independence • Self- reliance • Positive self-identity • Life flow restored or maintained • Disrupted life map revised
 <p>DETACHMENT Wheelchair considered to be an external entity.</p>	<p>The user feels they are put into the chair and it is seen as a barrier to social integration.</p> <p>Contributes to a negative self-image.</p>	<ul style="list-style-type: none"> • Inability to move forward • Increasing isolation • Cannot envision disease trajectory • Denial • Blame attributed to the chair. • Invisibility 	<ul style="list-style-type: none"> • Conflicted • Increasing levels of dependency • Failure to accommodate • Chair stigmatises • Reinforces negative self-image • Life flow disrupted • Horizons increasingly diminishing • Unable to establish new life map

6.6 Individual transitions

In comparing the stories of the participants in the sudden adoption group with those who gradually adopted wheeled mobility an understanding of **accepting wheelchair use** as a process of transition was revealed. Accepting wheelchair use was conceptualised as a phased journey, represented in Figure 3. These three phases of change, **becoming, embracing and being** are incorporated into Figure 4 to provide an illustration of the journey experienced by all seven of the participants who came to wheelchair use after having walked for a period of their lives. The stories of these participants are marked by disruption. The data showed that the decision to use a wheelchair was unreliable as an indication of the participant's future independence and autonomy when wheelchair use became permanent and fulltime. The reasons for this are now presented using individual cases to explore the issues.

The participants were at different stages in the transitional process to accepting wheelchair use and this was found to be unrelated to the length of time that they had been a permanent wheelchair user, detailed in Table 3, Chapter 3. Constant comparison across all of the data led me to an understanding of the reasons for the differences described. It was found that the individual contextual conditions, different combinations of which were experienced by each individual, affected their journey to being a wheelchair user.

The journeys of the participants to acceptance of wheelchair use are illustrated in Figure 5.

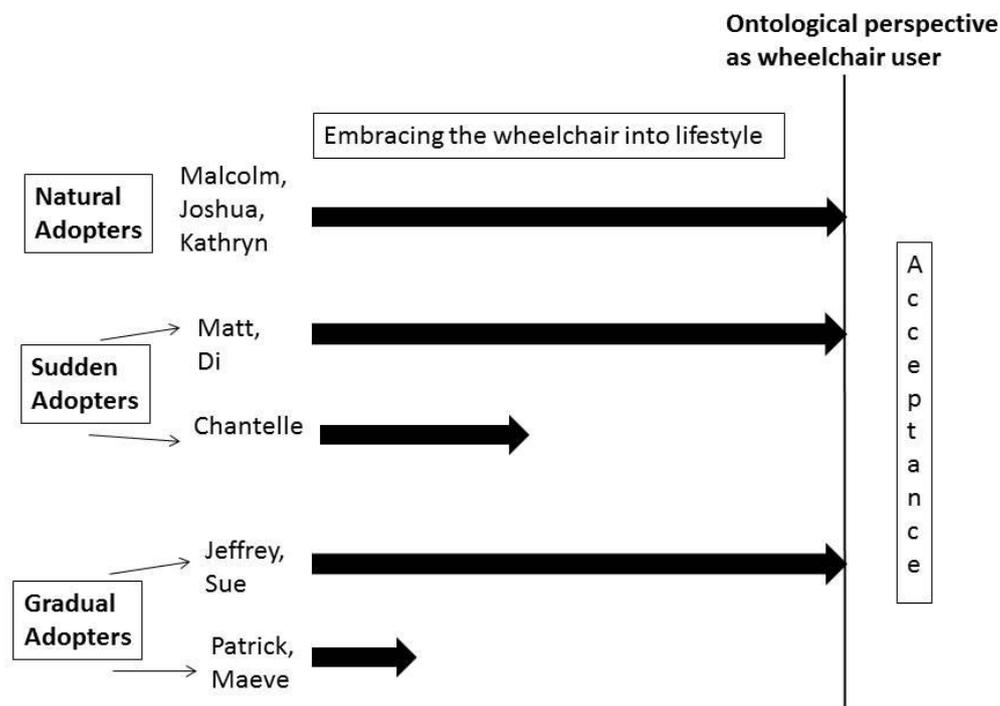
6.7 Individual contextual conditions

The individual, on **becoming** a wheelchair user, was forced to address the need to make changes at a number of levels: functional, cognitive and emotional. This has been conceptualised as a process of transition.

The data indicate that each phase of the transition process was altered by the individual contextual conditions of the participant. These facilitated, delayed or blocked change in behaviour. The conditions are multi-faceted. The socio-biographical contexts of the participant when adopting wheeled mobility were instrumental in promoting or blocking the process of change required to accepting wheelchair use.

Figure 6 illustrates individual participants' levels of completion of their journeys, from **becoming** to **being** a wheelchair user. It can be seen that Patrick and Maeve do not progress to embracing the wheelchair into their lives, and that Chantelle is still undergoing transition. These atypical cases are now discussed. Their circumstances are compared and contrasted with other participants who were thought initially to be similar in many respects such as age, decision to use a wheelchair and social situations.

Figure 6 – Individual acceptance of wheelchair use



6.8 Patrick and Jeffrey's stories

Both Jeffrey and Patrick experienced illnesses in childhood that left them with weakness and necessitated the use of callipers and crutches when attempting to walk. Each had formed their adult identities based upon a consistent level of disability, but not wheelchair use. Jeffrey had continued to physically weaken in the same way as Patrick throughout his life. However, Jeffrey's professional experience and previous familiarity with wheelchair users (Furnham and Thompson, 1994) prepared him to accept the use of one himself. In addition, he reported that he chose to use a wheelchair: he had developed and maintained what Charmaz (1987) might conclude was a **super-normal identity** based on his intellectual abilities and high socio-economic group status. Jeffrey spent little time in his interview talking about himself or his work. He responded to my initial question by describing all of the wheelchairs that he owned and providing a brief summary of their advantages and

disadvantages. Jeffrey's opinion was that the wheelchair, once he had it set up to suit his needs, should take up no more of his time until it went wrong. All alterations that Jeffrey may have been required to make, to accommodate changes in his muscle strength or pain levels, were possible because of his training and cognitive ability to make renegotiations in his lifestyle, environment or wheelchair by using his intellect. By applying Charmaz (1987) criteria, with each exacerbation of his illness Jeffrey's identity level was likely to have dropped from **supernormal** down the **identity hierarchy**. However, his preferred identity was regained rapidly once he was able to find a way to overcome any functional weaknesses; usually by adapting his wheelchair to meet his new physical constraints, e.g. adding a powered hub to improve his propulsion speed when his arms became weaker. In this way he preserved his desired level of mobility and ensured that he maintained his sense of self-esteem and identity. This sense of well-being was reinforced by a supportive family and he was financially able to maintain his lifestyle. Although Jeffrey was retired when he was interviewed he described a stimulating and busy life. He had **meaningful occupation, autonomy and independence**. Patrick's story was very different and he demonstrated all of the features of a "*salvaged self*" (Charmaz, 1987, p. 287). Throughout his interview he chose not to talk about his wheelchairs but talked of himself, his educational achievements, and a previous self that no longer existed. He had no meaningful occupation, no home adaptations to accommodate his wheelchair that would facilitate its use. He never went out without his wife, who lifted his chair into the car and who pushed his chair wherever they went.

6.9 Emotional adaptation

In order to become independent and have autonomy as a wheelchair user, the participant has passed through a number of stages. Initially, they meet the challenge of their inability to walk with **denial** which was described by Sue 6.6.2. However, she was able to make the emotional and psychological transition and adopted **coping strategies** indicated by her adopting wheelchair use in a timely fashion and

adapting her home so that when she required powered mobility she was able to accommodate the larger chair into her environment thus promoting continuation of her chosen life style.

In understanding their changed physical abilities and acknowledging their disease trajectory practical alterations were carried out. Moreover the psychological and emotional adjustments that promoted wellbeing and allowed autonomy and independence were completed. The self-identity was adjusted to incorporate the wheelchair and a new social identity was pursued. Some develop **maladaptive coping strategies**, acknowledging that their walking is affected, however, choosing to lessen the impact of this realisation by developing ways to avoid making the changes that are required to embrace wheelchair use. The participant admits some of the facts and experiences the emotions that accompany them.

Chantelle has moved some way towards accepting wheelchair use by living in an adapted dwelling and selecting a wheelchair that she considers assists her with living. However, she has been unable to establish a new self and social identity and continues to shop and go out in the evening with her previous friends as she used to before her accident. She has no meaningful occupation and is upset by this. She exemplifies that the coping strategies devised have been unhelpful because of her inability to see the whole picture. Maladaptive strategies may push the user into a situation demonstrated by Maeve. She is further disabled by now having to use her wheelchair fulltime and permanently inside a home where access and egress was no longer possible Table 10, Chapter 5.

Throughout her interview Maeve spoke in a detached way about her wheelchair. She was having difficulty coping with her gradual loss of her function. Her use of language when referring to her wheelchair was indicative of her feelings. She spoke of her carers "*putting you in it*" and the wheelchair as "*this bloomin' thing*". However, her most striking comment was:

"mustn't let the wheelchair be your be-all and I would never let it defeat me." Maeve

Maeve was over 65 years of age and was struggling to present herself positively. She lived alone and was turning her negative feelings about her life into animosity towards the wheelchair. However, she acknowledged that it helped her in some ways. At the time that I interviewed her she had been a permanent wheelchair user for many years and self-propelling was no longer possible. She wanted a powered wheelchair from the NHS. However, she had been rejected. She explained:

"I don't really go out many places. My hands are not strong enough...with this you've got to get hold of this [the push-rim on the large wheel] and wheel yourself and it's hard work. It is now becoming more and more hard work. I need an electric one but they want proof that I can see." Maeve

She thought that her horizons were diminishing and considered that a powered wheelchair might prolong her existing lifestyle. Maeve gradually became a wheelchair user due to a progressive neurological condition. She was unhappy with her wheelchair from the NHS for a number of reasons. She became unable to walk later in life and did not receive any training in wheelchair use or help to anticipate the physical impairments that her disease was to cause and so make the changes to her lifestyle and her home that were required to facilitate fulltime wheelchair use. She had no close family to support her with these adaptations and her contact with rehabilitation professionals had focused on the provision of small items of equipment within her home to help her to manage as caring for herself became progressively more difficult. She did not demonstrate that she had been enabled to envision the trajectory of her disease process and in consequence had not forecast her future wheelchair and housing needs. Maeve, like Patrick, lived in a home that had no structural alterations to allow space for wheelchair use. She had not embraced wheelchair use and this had led to her being unable to live with a powered wheelchair in her home even if she had acquired the equipment that she

wanted. However, when describing her experiences outside her home her perspective changed. She spoke of her trip to church each week thus:

“the congregation have made a space that fits the wheelchair.... there is a hole there for me”

Maeve

Her physical abilities have deteriorated since receiving her NHS wheelchair and at interview she explained:

“if you can manage to steer it (the wheelchair) and push yourself around all is not lost you don't have to break down and cry because you are in a wheelchair”

Her final thoughts underline her situation, which was of increasing dependence on others.

“I've learned the hard way...as you get worse you drop things...I can't pick up a kettle now...I needed a hot drink yesterday badly and there was no one about.” Maeve

6.10 Transition leading to ontological dissonance

When the participant was no longer able to functionally walk and wheelchair use became fulltime and permanent this triggered a process of change. There was a cascading effect on all aspects of life. However, for some this was discussed as a starting point for the interview and for others the reason and nature of the decision was not addressed. For those who gradually adopted wheelchair use, making the adjustment in their self-identity to being a wheelchair user was able to be avoided when the wheelchair was used occasionally. When it was the only form of mobility open to them they were unable to make the change in perspective required to embrace wheelchair use. Their acknowledgement that walking was no longer possible produced ontological dissonance for some participants. For those who still thought of themselves as being as “walkers” making the psychological transition that being a wheelchair user required involved a change in their self- identity.

Wheelchair use was considered to be a loss by most participants, although this was questionable in the case of Jeffrey, whose pragmatic approach to the transition may have been influenced by the difficulty that he had always experienced with walking using callipers and crutches, which cost him valuable time out of his working day and required great physical effort. Permanent wheelchair use could not have been anticipated by any of those in the sudden adopters group. It is suggested that the degree of change in behaviours expected will affect the transition and that anticipating the change limits the effects (Allen and van de Vliert, 1984). For all those in the sudden adoption group there was no warning of the change that was to happen and so no cushioning of the effects that the strain caused.

6.11 Trapped at an early phase of the transition

The wheelchair user's route planning (Frank, 1995) may become permanently disrupted and so they are unable to move on, which was the case with Chantelle. The age at which she became paraplegic was important in this context. She had yet to leave her family and develop her independence as an adult. She was, at the time of her interview, struggling.

All the participants talked of independence associated with wheelchair use. However, Chantelle went further and discussed being able to control one little part of her life only with the help of her electrically powered chair.

"I just feel happy that I can control one part of my life I can go anywhere do anything."

Chantelle

Chantelle related how she and her friends go out to pubs. They all sit at low tables together. However, a key feature was that she described how she managed if all the low tables were occupied and the group of friends had to use high stools.

"I just raise up my chair so that I'm on eye to eye level with my friends" (this is done with a special feature on the powered wheelchair that allows the user to bring the seat height up by 9–12 inches, independently). Chantelle

Her opinion conflicted with Malcolm's perspective. His viewpoint on the world was from the seated position. He had no reason to come to the eye height of others as he fully accepted his disability and as his wheelchair was a seamless part of him he functioned from it at the height of a seated person. Matt had a similar opinion to Malcolm.

"I've rarely had any problems accessing anywhere. A few years ago it might have been different but I don't mind I just stick my head up over the counter...it's person relating to person." Matt

Jeffrey's perspective was that his needs were met by a standard wheelchair without a riser function. When out socially he never worried about being at a different eye level to his friends for him wheelchair use had other advantages.

"That doesn't bother me. If you're stuck up on a high wheelchair it spoils all social interaction. I've never seen it work people just think gosh that's odd ..you meet friends in restaurants and houses when you're all sitting down anyway and the grandchildren can just climb onto my knee." Jeffrey

Those participants who had fully accepted wheelchair use were comfortable with adjusting their viewpoint. For Chantelle it was important to be on the same level as her friends, to become a part of the group who were "walkers". She had yet to create an identity for herself in the same way as Matt and Di as being a wheelchair user. Although the literature on spinal injuries indicates that the time that had elapsed since the accident was an important factor in acceptance of changed life circumstances (Bates et al., 1993) Matt had been paraplegic a much shorter time than

Chantelle. However, he had established a new life map and excelled in his new role, and his acceptance of wheelchair use was complete.

The age at which Chantelle had her accident may have been crucial. She was at the time of her accident a young adult who had yet to establish her independence. At a time in her life when plans were being formed and opportunities explored her mobility and life were disrupted. She had been unable to move on with her life and form a new plan. Complete autonomy was therefore impossible for her as others had a large part in shaping all her decisions. The decision, that she was able to make for herself each day, was whether to use her powered or manual wheelchair. Chantelle explained her perspective on powered wheelchair use changed when she was with friends that she met at the rehabilitation centre:

“friends of mine that I met when I was in hospital and they’re paralysed as well, a lot of them would say that I’m lazy to use an electric wheelchair. But I mean at the end of the day that chair gives me more independence.” Chantelle

Her level of independence was enhanced by her powered chair. Throughout her interview, she talked of a constant irritation with her manual chair which she was forced to use when her powered chair broke down. However, the breakdowns, experienced by the powered chair, she reported to be mainly due to “her misuse” of the equipment. This could be indicative of her frustration. She was unable to move on and to form a new life map and she had not sought professional help to assist her with this and meaningful occupation in her life was missing.

Patrick was resistant to making the transition to understanding himself as a permanent wheelchair user. His story was one of a constant battle to maintain walking using callipers and sticks as his condition changed. He continued to walk to his car every morning, whilst using the wheelchair all day. However, at interview he stated that it was the size of the factory that he was required to walk around each

day that forced him to use his wheelchair. He was unprepared for permanent wheelchair use and when it became necessary because of his lack of acknowledgement of his disease trajectory he was unable to accommodate the wheelchair in his family home. In this way his story corresponds with that of Maeve.

6.12 Unable to embrace wheelchair use

Patrick and Maeve were theoretically sampled and their data confirmed the theory of transition to accepting wheelchair use that was emerging. Patrick's start in life was similar in most respects to Jeffrey's. He was ill at the age of 15 and from that time could walk only with the aid of callipers and crutches. He returned to school and was an able student qualifying as a teacher. However, the similarities between Jeffrey and Patrick disappeared once they became adults. Patrick developed an identity and self-worth based around intellectual success. However, as his health deteriorated he was forced to give up teaching because he could no longer stand for the extended periods of time that were required. He was forced to renegotiate his life map. He described from this point on his life as a series of losses from which his self-esteem had never recovered. The key feature that would explain Patrick's loss of self-worth and his changed identity level was his reluctance to become a wheelchair user. He was willing to change his occupation and make considerable alterations to his lifestyle in order to avoid what, for Jeffrey, was a purely pragmatic decision to maintain functional mobility and to use a wheelchair all of the time. Patrick was unable to make this major change, even though the decision was his in terms of the timing of this change. As his condition worsened he was forced to become a fulltime wheelchair user. However, his approach to wheelchair use was one of ambivalence and detachment. Patrick's reticence to use a wheelchair may have been due to his age. He had no experience to inform his decision and limited knowledge of disability issues. Patrick had similar social support and circumstances to Jeffrey. However, he could not adapt his self-image to that of a wheelchair user. His self-identity prevented him from choosing wheelchair use as a pragmatic solution to his

deteriorating physical condition. The need to use his wheelchair on a permanent and fulltime basis promoted ontological dissonance for Patrick. He was detached from his wheelchair. It was something that he was advised to use by his doctor, something prescribed. It was not embraced, and the trajectory of his disease was not understood to include wheelchair use. He was a walker and saw no requirement to adjust his identity. His position was one of dissonance.

6.13 Formation of identity as a wheelchair user

The ontological perspective of the participant, informed by their successful formation of a new self-identity as a wheelchair user, was foundational in the process of acceptance. The findings show the importance of self-awareness. Only by understanding their disabilities was the participant able to accept and embrace wheelchair use to gain continued independence. Through accommodating the wheelchair into their lifestyle the participant promoted their social integration by facilitating access to the wider community. Lack of insight led to a progressively disabling attitude, gradual withdrawal from activities outside the home and increased social isolation.

The need for individuals to renegotiate their social and personal identities has been researched extensively. However, much of this work was based upon a medical model of disability and the premise that recovery was possible (Parsons, 1951 cited in Frank, 1995). This renegotiation becomes increasingly more difficult when chronic illness or accident is concerned (Frank, 1995). In understanding the life changes and transitions of the participants of this study, two theories were of assistance. The first was that of Role Transition (Allen and van de Vliert, 1984) and the other Identity Levels of the Chronically Ill (Charmaz, 1987).

The theory of role transition (Allen and van de Vliert, 1984) provided an example of a transition from one set of behaviours to another. The adoption of permanent, fulltime wheelchair use may not be understood as a role change. However, the

change of role from wellness to chronic ill health, active worker to retired, carer to receiving care illustrate the change of roles that may be associated with the onset of wheelchair use – or grounds man to elite athlete. A change of role was experienced by few of the participants of the present study on adopting wheelchair use; however, change of self and social identity took place for most (Charmaz, 1987).

Allen and van de Vliert (1984) provided a conceptual framework that enabled the findings of the present study to be understood in the context of a transition from one set of life circumstances to another. However, some of the participants of this research demonstrated that they had moved beyond a change of function and role to rewrite their life maps and move forwards with a revised understanding of who they were. Their self and social identities were changed by the constant presence of their wheelchair. Charmaz (1987) suggested that those with chronic illness seek to establish meaning in their lives. Her work examples how chronically ill people create “*preferred identities*” (Charmaz, 1987, p. 283) for themselves and that as their illness progresses they may alter these moving up or down an “*identity hierarchy*” (Charmaz, 1987, p. 284) as their health and function changes. Further exploration of Charmaz’s theories will be presented in the following chapter as will identity theory.

All of the individuals who lost their former ability to walk, were forced to revise their life maps, and with this for some came the formation of an alternative identity. Charmaz (1987) described this process developing from the individual “*outlining plans and assessing prospects*”. The wheelchair has to be included in this renegotiation of self. However, the data suggests that for some of the wheelchair users it is the wheelchair that is regarded as being the cause of this readjustment rather than the illness. Others view their chair as merely one aspect of the overall revision to their life map.

6.14 Summary of findings

The findings suggest that only by forming a consistent ontological perspective, as that of a wheelchair user, was the participant able to become fully independent and to accept wheelchair use. Physical and emotional adjustments were necessary and if completed the participant was able to move on with their lives, rewriting their life maps from the new perspective.

Independence and social integration were found to be dependent upon how the wheelchair users understood themselves. The nature of this understanding was critical. The wheelchair user who embraced wheelchair use felt independent. In being a wheelchair user the participant adjusted their perspective and this facilitated their autonomy and social integration.

Accepting wheelchair use was found to be dependent upon the ability of the user to change. This was based on exploration of the perspectives of those who had lifelong conditions and had never walked. Their approach to life and integrated identity formed from a position of ontological consistency was central to their ability to accept wheelchair use. For those who had come to wheelchair use later, following disruption to their lives through loss of the ability to walk, learning about themselves and reforming their self-identities in the context of their new mobility was essential for their future wellbeing and independence.

Chapter 7: Discussion

7.1 Introduction

Theoretical sensitivity was informed by exploration of wide ranging literature and formal theories that guided my thinking and decisions during analysis. The substantive theory of accepting wheelchair use suggests that the self-identity of the wheelchair user is altered by completing a transitional process leading to change. The understanding of this process and the formation of the substantive theory was influenced by work on human adaptation. Adaptation explains how participants respond to make sense of their world and manage threats to continuity of their life style. The data in this study were considered from this standpoint and adaptation understood as an individual's psychosocial response to loss of walking (Roy and Andrew, 1999:p.35).

A conceptualisation of change was found in the Theory of Role Transition (Allen and van de Vliert, 1982). This theory provided a model of individuals altering their behaviour within a social system associated with their place in that system and their expectations. Role transition was used to inform the substantive theory by providing a conceptualisation of social behaviour and identity change. Identity change was one result of reactions to strain placed on the individual through change of circumstances and altered expectations of their behaviour. The theory of Social Constructionism (Berger and Luckman, 1967) informed understanding of the multifocal nature of influences on individuals through their cultural and historical backgrounds that was considered as part of the transitional process of accepting wheelchair use.

The data led me to theories of identity, which were first developed by Mead (1934), acknowledged to be the originator of theory concerned with the self, and modified by Cooley, Thomas, Pierce, James and Dewey, who were working at the same period in sociology, psychology or philosophy. Giddens (1991, 1992) developed this work

by adding a theory of reflexivity and a general theory of self, which needed to be established for use when addressing the self in both personal identity theory and social identity theory informed by the work of Stets and Burke (2000).

Charmaz (1987) seminal work: "*struggling for a self: identity of the chronically ill* " was revelatory in suggesting that the self and the social identities of the chronic sick were separately developed. These theories are now explored in the context of the findings of the study.

This chapter presents a substantive theory of the process of *accepting wheelchair use*. This is an explanation of a social process that is grounded in the data presented in Chapter 6. Accepting wheelchair use was conceptualised as a series of adaptive tasks that takes the individual from loss to ability. If the tasks were completed the wheelchair user described a life of autonomy and independence. In completing the process the individual changed all aspects of their life and behaviour, and ultimately a revision of their self-identity took place. This transformational progression from walker to wheelchair user was presented in the preceding chapter and described within the context of an explanatory matrix. In this chapter the substantive theory of accepting wheelchair use is presented and discussed with reference to formal theories and present knowledge. The impact on practice is then explored from this new understanding of wheelchair acceptance.

Reflection on my experience of the research process follows, including what has been learned from the study and suggestions for future work exploring different aspects of the research findings. Finally, the chapter concludes by addressing the research in the context of the NHS wheelchair service and explores how wheelchair provision in England and Wales might use the framework to place the individual user at the centre of wheelchair provision and improve their experience of the supply process.

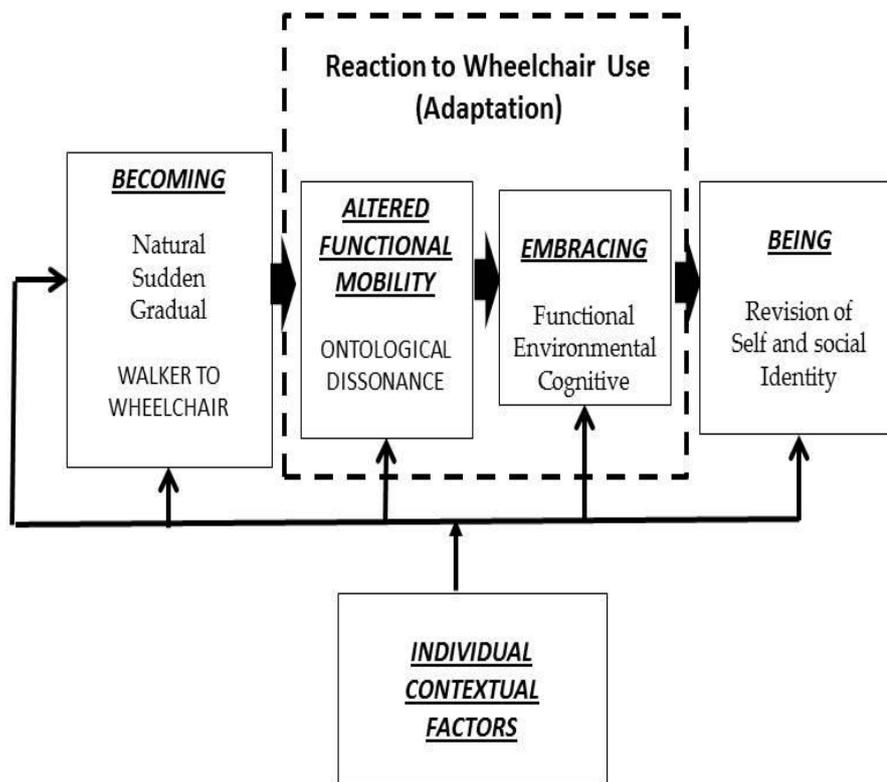
7.2 A theory of accepting wheelchair use

A model of the substantive theory of accepting wheelchair use is presented in Figure 7.1. It captures the transitional process that incorporates wheelchair use into lives and changes each individual's understanding of themselves and the world from the viewpoint of walking for mobility to describing themselves as **being** a wheelchair user. The data indicate that this affects all aspects of the wheelchair user's life. It is not just a change in functional mobility: changes are required to the homes and lifestyles of the fulltime, permanent wheelchair user. Practical changes are accompanied by cognitive adaptation, emotional reactions and culminate in a revision of the individual's understanding of themselves and of their identity.

The substantive theory of this research takes as its starting point the way that wheelchair use is introduced. This experience is unique to each individual. However, the process of transition that follows takes a similar course irrespective of the manner in which wheelchair use is adopted. It is the individual's response to **becoming** a wheelchair user, described in Figure 3, that affects their progression through the transitional process leading to independence and autonomy. The theory suggests that in completing these stages labelled, **becoming, embracing and being** discussed in Chapter 6, it is the self-identity of the user that crucially is altered.

Figure 7 - Substantive theory of Accepting Wheelchair Use

Model of the Transition Process to Accepting Wheelchair Use



The substantive theory combines practical, emotional and cognitive changes for the individual that are collectively described as **embracing** wheelchair use. These are transitional tasks that are required to accept wheeled mobility and to incorporate the wheelchair into every aspect of life. Understood within the framework of adaptation these tasks are coping strategies developed not only in order to manage altered function and maintain a desired lifestyle, but also to enable the user to psychologically adjust to a change in their mobility.

If these transitional tasks remain incomplete, barriers to independence and autonomy will exist that lead to increasing dependency and social withdrawal. The data demonstrated that those who were unable to complete the transition process

were unable to move on with their lives. As their life map remained the same as it was before permanent and fulltime wheelchair use was adopted these individual's understood that it was the chair that was preventing them from being independent and having personal autonomy (Chaves et al., 2004). If the individual continues to understand themselves and the world from the perspective of walking and arranges their life from this viewpoint then the wheelchair is the focus of their frustrations and distress.

The data in the present study showed that the resultant loss of function, access to the community and personal wellbeing that was experienced when the development of coping strategies was delayed or not addressed was unrelated to, and disproportionate with, the individual's level of physical impairment³.

The substantive theory describes how successful task completion (Maidment and Merry, 2002) using a wheelchair is just one feature of embracing wheelchair use. It is the accompanying change of understanding of self that enables the individual to make the wheelchair a seamless part of their lifestyle. Describing the wheelchair as an integral part of themselves, or embodied, was unique to those with life –long conditions, presented in 6.4. Others suggest that they achieved a closeness that allowed them to forget about the chair and therefore concentrate on life this was discussed by Jeffrey in 6.7.3.

The literature concerning chronic illness suggests that the main concern for the individual is related to unachieved goals and narrowing horizons (Charmaz, 1987). The data of the present study found that those who had walked for a period of their lives were helped to move on, to review their options and to reconstruct their life maps by fully accepting wheelchair use. Through this process a revision of their self-

³ Comparison may be drawn between the independence and autonomy of Joshua and Kathryn both of whom have 3 out of 4 limbs affected and are unable to use a manual wheelchair and Patrick and Maeve who have similar or less physical impairment who have limited independence and rarely go out of their homes.

identity took place and the individual came to refer to themselves as **being** a wheelchair user.

The substantive theory of accepting wheelchair use suggests that the self-identity of the wheelchair user is altered by completing the transitional process. Although practical changes may be in place, it is only through altering their approach to mobility and lifestyle that autonomy and independence may be maximised. The evidence for this is presented in 6.8, where different cases are presented to compare and contrast individuals' experiences of permanent and fulltime wheelchair use and their reactions to this.

The emerging theory is now related to and integrated with existing theories and literature in the subject area (Urquhart, 2013). The formal theories that informed theoretical sensitivity and shaped the writing of the substantive theory are now discussed.

7.3 Change

Foundational to the substantive theory is the change in human behaviour in response to a threat, a life event, or in this research, an illness that precludes walking for mobility. For some, the introduction of a wheelchair normalises and ensures continuation of a way of life, and little physical or cognitive change is required to maintain the status quo⁴. For others, the process of change had not been completed. This change was the individual's experience of adopting wheelchair use and was, therefore, considered in a micro-sociological context. However, the process might also be applied from a macro-sociological perspective, where the change would be understood as adaptation to disability in a group of wheelchair users.

Human adaptation was explored through social functionalism as outlined by Spencer and Durkheim in the early years of the twentieth century and later was

⁴ This was demonstrated by Jeffrey and the younger spinal injured participants Matt and Di.

further developed by Parsons in an attempt to explain the parallels that social scientists at the time were drawing between changes in societies and biological organisms (Fulcher and Scott, 2011). The concept combines functional needs that may be met from the environment, and emotional changes that are then generated within individuals. Whilst the language has changed throughout the decades since the theories were first documented, the process remains relevant. The individual will make the changes that are required to facilitate maintenance of their role within their social group. This integration was described as the meeting between human and environment which results in adaptation (Roy and Andrew, 1999). Society is understood from this perspective as having a framework of norms that define the expectations of individuals and shape their behaviour (Fulcher and Scott, 2011). The processes that individual's go through may be explained in a number of ways dependent upon the stance taken towards disability.

On adopting fulltime wheelchair use a change of mobility may be accompanied by a role transition (Allen and van de Vliert, 1982). Role transition theory provides a model of changing expectations of individuals' behaviours within a social system associated with their place in the social system and expectations. For some, wheelchair use indicated a change of role from breadwinner to patient⁵ or manual worker to elite athlete⁶. In role transition theory a similar process is described as in the substantive theory: identity change is the result of reactions to the strain placed on the individual through change of circumstances and altered expectations of their behaviour. In role transition and the substantive theory of accepting wheelchair use identified in this study, the difference in expected behaviour is moderated by the context in which the change takes place and the personality of the experiencing individual. The substantive theory suggests that a wheelchair user's continued

⁵ See Patrick's experience of change so disruptive that he no longer propels his own wheelchair (6.7.4).

⁶ See Matt who through his rehabilitation team was able to develop as an athlete through their knowledge of training opportunities (6.12.2).

independence and autonomy requires a change in self-identity of the wheelchair user.

The changes that are required to complete the process to accepting wheelchair use are only able to take place if the user is able to review their self-identity, suggesting that the process may be considered as a feedback loop. A small change in function leads to the development of a coping strategy that promotes greater independence.⁷ The amount of difference in expected behaviour is so great and all enveloping that only by understanding oneself as having changed fundamentally, to **being** a wheelchair user, can the individual review their options and move forwards with their lives. The change of identity that has been suggested in the present study leads to autonomy and social inclusion for the individual. An alternative perspective has been researched that considered individuals' transitions as

“a creative process of re-embodiment by physically disabled adults who become wheelchair users” (Papadimitriou, 2008, p. 691).

Papadimitriou (2008) described wheelchair use in a single diagnostic group, individuals with spinal injuries, and conceptualised their journeys as those of re-enablement through making the wheelchair part of their embodied existence. Disability was conceptualised as a state of being that was all encompassing. It is acknowledged that an alternative approach to research accepting wheelchair use might be from a psychodynamic perspective. In that case the formation of coping strategies and the individual undergoing a transitional process to accepting wheelchair use might be considered as occurring through emotional and psychological adaptation. However, in the present research study a psychosocial approach was adopted that addressed behavioural change in individual's who had previously walked and become wheelchair users latterly. The experiencing

⁷ Jeffrey modifies his wheelchair as his condition worsens to maintain his chosen life style and self-identity (6.8.1).

individual was understood to change at multiple levels practical, functional and cognitive. From the data emerged the need for coping strategies to be developed that facilitated the transitions that the users were required to complete in their evolution to that of **being** a wheelchair user. Development of coping strategies occurs at many levels. In this study, practical strategies that physically changed the individual's environment to accommodate selection of the right wheelchair to meet their clinical needs was a starting point. However, the literature suggests that differing theoretical underpinnings lead to alternative perspectives on strategies to assist in the development of coping strategies. Coping has been termed a "*psychological strategy to decrease, modify or diffuse the impact of stress generating life events*" (Livneh and Antonak, 2005). Many different intervention strategies are available to assist individuals to adapt. These include cognitive-behavioural, psychodynamic and interpersonal (Livneh and Antonak, 2005; Waller and Gilroy, 2000). These are beyond the scope of the present study. However, it is acknowledged that psychological change may be facilitated using different therapeutic approaches and that further research on facilitating acceptance of wheelchair use may focus on this neglected area.

7.4 Identity

The concept of self is central to the substantive theory and was a foundational tenet of identity theory. In sociological terms, the idea of "self" was first developed to move concerns from the wider society to the individual or from macro-sociology to micro (Brown, 1979). There is, however, an overlap with the psychological concepts of personality and character (Stryker, 1977). This research study explored the acceptance of wheelchair use through interaction and the understandings that individuals formed about themselves as wheelchair users through their experiences. Their perspectives were discovered by the researcher joining the participants in their chosen environment and jointly creating interpretations of their lives and

perspectives through their narratives. It is therefore taking a micro-sociological standpoint, where the self is central to the theory that emerged.

The self, is understood in this study, to refer to the individual's understanding of who they are. Self-identity is defined by the way that things have significance for individual's (Taylor, 1990).⁸ Out of which, an image of themselves is created that they want to project to others (Goffman, 1959). This is the concept of self within the wider society. Goffman described self as a performance. One has a number of roles that are played out in numerous situations on a day to day basis. From the feedback provided by others, a public self is understood that the private self knows underpins identity and "*the continuity of respect and trust in routine social interactions*" (Elliott, 2013, p. 38). Mead (1934) is acknowledged to be the originator of theory concerned with the self. His perspective was that the self is a response developed in the mind of an organism by interaction with its environment. It is a process of social interaction (Fulcher and Scott, 2011). This was later extended into a theory that presents the self as being constructed through interaction and comparison with others, social constructionism (Berger and Luckman, 1967). Cooley, Thomas, Pierce, James and Dewey were working at the same period in sociology, psychology or philosophy (Elliott, 2013) to create understanding of identity in micro and macro settings. Giddens (1991, 1992) developed this work by adding a theory of reflexivity to what was previously known. This theory addresses the important part that reflection on life and its possible trajectories plays on what people do and how they do it.

Central to post-modern thought in this area is the theory of interactionism (Blumer, 1983). The wheelchair when considered through a symbolic interactionist lens, is understood as a symbol that conjures up meaning not only for the individual but

⁸ Jeffrey and Sue have previous experience of wheelchair use and disability through their work and their attitudes to becoming wheelchair users are markedly different to those who had little contact with disability prior to adopting wheeled mobility. Jeffrey in 6.25 says that once you have the wheelchair right it is not thought about again until it goes wrong.

also for others with whom they come into contact (Blumer, 1983). According to Mead, language is at the heart of self (Elliott, 2013) and the self is the medium through which one makes comparisons with others.

Perspectives on wheelchairs and their use are present before the individual loses the ability to walk and requires equipment for mobility. These pre-existing attitudes influence acceptance of wheelchair use (Furnham and Thompson, 1994). Despite increased awareness of disability and changes to the built environment to provide greater access for wheelchairs, it is reported that “*stigma*” is still attached to use of a mobility aids. Stigma in this case is understood to be the “*discrepancy between what society expects and what is seen*” (Rush, 1997, p. 9). This has affected the attitude of both those in society and the wheelchair users themselves towards the equipment in some instances.⁹ The perspective about wheelchair use that the individual brings to wheeled mobility is shaped by their past experience,¹⁰ and may be changed by incidents with others in society, by individual contextual factors and also their progression through the adaptive tasks necessary to accept wheelchair use. Rush (1997) explored use of mobility aids in her elderly clients from a nursing perspective. Her findings concur with perspectives related by certain wheelchair users of a similar age.¹¹ The wheelchair is a visible symbol of disability and in a society that is concerned with productivity the wheelchair may be considered by some to be an outward sign of altered autonomy and dependency. This, it was reported in Rush (1997) resulted in withdrawal from society into domiciles. The individual was then able to control their self-identity to a much greater extent. As discussed previously, this was identified to be the case with the two oldest participants in the present study 6.8 ; 6.11.

⁹ See Kathryn’s reference to attitudinal barriers in 6.5.4

¹⁰ Patrick brought negative attitudes to wheelchair use discussed in 6.11

¹¹ The progression of Maeve and Patrick was related in part to their age when coming to wheelchair use, 6.6.2.

The presence of the wheelchair can therefore be understood to have implications on social processes for the individual at both micro and macro sociological levels. A general theory of self needed to be established for use when addressing the self in both identity theory and social identity theory. Stets and Burke (2000) argue that these two theories have similarities and overlaps that are not apparent because of use of different language. This is demonstrated by the use of "*categories or groups*" in social identity theory and "*roles*" in the case of personal identity (Stets and Burke, 2000 p. 224).

Application of identity and social identity theory may then be considered together, and in linking these two theories a fully integrated view of self may be understood (Stets and Burke, 2000). The self has been described as reflexive (Giddens, 1991,1992), forming labels in relation to social situations. Identity is part of the self that is developed by the individual to explain the roles that they undertake. This concept is acknowledged in both identity theory (McCall and Simmonds, 1978) and social identity theory (Turner et al., 1987). Charmaz (1987) suggested that the self and the social identities of the chronic sick were separately developed. The findings of the present study indicate that it is the mismatch between the wheelchair user's self-identity and actual functional ability that prevents accepting wheelchair use. Failure to reform one's self-identity leads, through inaction at the optimal time in the disease trajectory, to social withdrawal. This is caused in part by a mismatch between the home environment and the wheelchair. If the environment is not suitable for the type of wheelchair that would provide best function then maximum autonomy and independence is impossible.

Inability to complete tasks leads to a high level of dependency, loss of autonomy and gradual withdrawal from community activities into the home. In the present study, by remaining at home and limiting contact with others in the wider community the preferred self-identity of the user was observed to remain intact. This, preferred identity, was presented to the researcher at interview when a former life was

described that referred to a self that no longer existed. This finding concurs with that of Charmaz (1987) and Watson (2002), who describe how many people with chronic illness do not self identify as disabled. This viewpoint is at the core of the social model of disability. The ableist movement argue that disability is caused by social and environmental barriers (Shakespeare, 1996) that disable people not by the individual who has physical challenges. Whichever approach is adopted, the loss of contact with the wider community results in the wheelchair user having no requirement to revise their identity. The findings of the present study indicated that a self- identity based on wheelchair mobility may never be formed.¹² This resistance to change led to increasing dependency and isolation. This was found to be the case by Charmaz, 1987, who describes how for some, chronic illness leads to a continual battle to maintain self worth (Charmaz, 1987).

The substantive theory describes an evolving and changing identity through completion of social adaptive tasks. Accepting wheelchair use happens in parallel with identity change. However, Charmaz (1987) looked at chronic illness in a different way, choosing to talk of “*preferred identities*” and “*identity hierarchies*” (Charmaz, 1987, p. 283). Identity is understood to be influential in reforming the changing self because of its connection with past experiences and roles (Charmaz, 1987, p. 284). Whilst identity hierarchies were not systematically applied to the data, it was possible to understand some perspectives using this model as well as that of Barker (2004), whose model described acceptance of wheelchair use in senior stroke survivors. The important difference between these studies and the present research is that the data in this study were collected from individuals who had come to wheelchair use in diverse ways. Either their mobility had remained the same, as was the case with those who had lifelong conditions who had never walked, or their

¹² The data referring to Maeve and Patrick show that both have withdrawn into their homes and their narratives related to a former self.

mobility had changed gradually through chronic illness or suddenly following a life event. However, most of the participants did not consider themselves to be chronically ill and they rejected the sick role. This supports the finding of Charmaz (1987, p. 86) who reported rejection of invalidism in her participants. She explained that in

“attaining, maintaining or recreating a valued identity after an episode of illness was crucially significant..and failure to do so was a failure of self” Charmaz, 1987, p. 286.

The substantive theory may be applied equally to all wheelchair users. Charmaz (1987) devised the theories of preferred identities and identity hierarchies in the chronic sick. The data in this study supported these in part. Preferred identities were maintained by many individuals. Illness challenged these and the wheelchair user endeavoured to achieve their former identity having slipped down the hierarchy whilst unwell. For some this was relatively simple as they assessed their clinical needs and sought to acquire a new wheelchair or modified their existing chair to meet their changing needs. For others, gradual loss of abilities led to a change in identity level that could not be recovered and this led to functional losses. However, in this study the preferred and actual identities of the wheelchair user were understood to be dependent upon their individual contextual circumstances. The deciding factor in maintaining identity was completion of adaptive tasks that allowed acceptance of wheelchair use.

7.5 Locating the substantive theory

The substantive theory of accepting wheelchair use developed in this study brings together the many disparate issues related to loss of mobility into one succinct theory. It suggests how function and environment may be understood together with the individual's emotional response and change to their self-identity. The wheelchair is understood not only as a means of task completion, but in the context

of a changing self-identity. The completion of the transition process brings acceptance of wheeled mobility, with a reformed self-identity as that of being a wheelchair user.

To date there has been little research on the social and psychological effects to the individual of becoming a wheelchair user. There has been extensive social scientific research into human reactions to threats of all kinds that indicates psychosocial adaptation takes place with the development of coping strategies being foundational to the individual's response (Hamilton, 2009).

Some aspects of accepting wheelchair use (Barker et al., 2004; Gibson, 2006; Papadimitriou, 2008) have been explored in selected diagnostic groups. However, no studies addressing the process of accepting wheelchair use were discovered. The substantive theory developed here addresses this omission. It presents a model of the process of accepting wheelchair use that explains the behaviour of all groups of people who use a wheelchair for their mobility and it is applicable throughout the life of the individual. The limitations of the present study are discussed in 7.7.

Interest in the study area was initiated by a concern that some wheelchair service users reported dissatisfaction with the wheelchairs that were issued that could not be understood by applying biomechanical, functional or environmental assessment alone. No previous studies were found that linked and incorporated all these different facets of wheelchair use with the identity of the wheelchair user. The transitional process of change, to being a wheelchair user, devised in this research provides a way of combining all of these concepts into one substantive theory of accepting wheelchair use.

7.6 Implications for practice

The substantive theory developed here offers an alternative way of understanding wheelchair use not previously explored. It fills a gap in the literature by considering the experiences of the individual wheelchair user as a socio-behavioural process of

transition. The theory includes the functional aspects of wheelchair provision that are foundational to the present assessment and supply process presently in place throughout the NHS wheelchair service. The substantive theory is different and new as it draws these components together with previous work on emotional and psychological aspects of accepting disability (Livneh and Antonak, 2005; Papadimitriou, 2008) and combines these into one process of transition. Theoretical underpinnings relating to change including psychosocial adaptation to loss and identity transformation are then combined with the former framework. This theory will be helpful in understanding the transitions that individuals attending the service have made. If incorporated into the assessment process the transitional process might be used to indicate where assistance should be focused. This might include fitting a wheelchair correctly to the occupant, selecting a different chair with alternative features, arranging for assistance with home adaptations and outdoor mobility training or referring to other professionals for psychological assessment or counselling. This is the first attempt to provide such a model for use in connection with wheelchair provision.

The finding of this study that some users considered themselves a separate group (those who had never walked having been born with a lifelong condition), was revealing. The NHS wheelchair service is presently organised to treat each client in the same way, with no allowances made for the history or health of the user. If the three stages of accepting wheelchair use were to be incorporated into the assessment process then different levels of input could be offered accordingly.

The development of the substantive theory of accepting wheelchair use is timely as the Health and Social Care Act (2012) has implications for the future organisation of the wheelchair service. In 1.6 the issues that the wheelchair service had experienced since provision was incorporated into the NHS were explored. Users have reported dissatisfaction with the service and the wheelchairs provided. Variation in quality and provision across the country was identified by the DOH as an issue that needed

to be addressed, and the Health and Social Care Act 2012 was a first step in this process. The Act proposed to fundamentally change one of the founding pillars of the NHS, and has caused concern to be expressed by many different professional groups, including the Royal College of Nursing and the Royal College of Midwives, the British Medical Association and the Royal College of General Practitioners ([http://en.wikipedia.org/wiki/Health and Social Care Act 2012](http://en.wikipedia.org/wiki/Health_and_Social_Care_Act_2012) accessed 22/10/2012 12:56)

The Act proposes that any qualified provider may be asked to deliver services previously only undertaken by the NHS. The stated aims of the Act were to place patients at the centre of the NHS. This is to be achieved by changing the emphasis of measurement to that of clinical outcomes and to empower health professionals, in particular general practitioners (DOH, 2010). It is GPs who will become the fund holders for equipment purchase directed through Clinical Commissioning Groups. In terms of equipment provision this may see a return to commercial dealerships supplying wheelchairs. Quality indicators derived from research will be required to ensure that future provision of wheelchairs offers an equitable and excellent service for all users. The substantive theory of this research could be used as a framework to facilitate development of quality indicators and assist with the transition from the NHS to the private sector once more. This thesis may play a part in increasing understanding of the needs of the clients and improving their experience of future wheelchair provision.

7.7 Reflections

Reflexivity has been described as requiring the researcher to operate at the personal and the epistemological level (Dowling, 2006) in explaining their involvement in the construction of meanings in a study. Reflexivity concerns self-awareness, using reflection as a learning tool and personal reflexivity that implies action (Colbourne and Sque, 2004). This has been explained by placing reflection and reflexivity at either ends of a continuum (Finlay, 2002) where the researcher both influences the

research and is influenced by it (Hand, 2003). Explication of the processes of reflection and reflexivity provide credibility to the qualitative study and are an important element of a grounded theory.

Preparation for writing a reflective account of the research process was confusing and stressful. I had maintained a research journal and written numerous memos of different kinds throughout the study. However, inspiration to complete this part of the research process remained stubbornly elusive. Eventually, I happened upon Mezirow's seven different levels of reflection (Jarvis, 1995, p. 96), which I have used as a template for my comments.

The first important question in the research process was how best to explore an area of interest where no specific research question had been set. This was a speciality in which I had practiced for many years and had developed my own opinions. I wanted to explore the perspectives of wheelchair users, without focusing on the limitations of the wheelchair service, in the most effective way. From the data collection methods available, one-to-one interaction and collection of interview data was my choice. I wanted to develop a connection with the participants and to join them in their environments to interactively create and interpret data together.

I was aware that researcher bias and involvement in the research process were areas that needed to be considered and decisions made with regard to how to handle aspects of participant selection and researcher influence on the data collected. The use of grounded theory methodology enabled collection of wheelchair users' perspectives based on one simple question,

"Please tell me about your life as a wheelchair user?"

It is acknowledged that the in-depth conversation that followed was influenced by my responses, which encouraged as wide ranging a discussion as possible.

However, affective reflectivity meant that I was aware of the participant making their own assumptions about what I wanted to hear and the perceptions that they wanted to share. It was this melding of researcher, therapist and participant perspectives that I wanted to achieve. However, I was careful never to extend the interaction into the therapeutic milieu and no researcher–clinician conflict was experienced. I introduced myself only as a physiotherapist with an interest in wheelchairs. I enjoyed and was encouraged by these conversations with individuals, who offered valuable perspectives on a subject about which I considered that I knew only a modest part. I understood the interviews as allowing me to look into worlds that in my practice were never visible. I was aware that I had a difficult path to tread between therapist and researcher. I had age, experience, culture and professional training all influencing my judgements on the narratives that were being shared. On leaving some interviews I was aware that we had wandered off the prepared interview guide (Appendix 5) and was concerned that the time had been less than usefully spent. However, due to the methodology chosen I was surprised at how these were often the most fruitful texts to analyse as they suggested new areas of enquiry not previously identified as relevant. It was from the concerns of the participants expressed in the data that the question that needed to be answered became apparent (Glaser and Strauss, 1967).

Through use of grounded theory, emerged a theory of accepting permanent and fulltime wheelchair use, where none had existed before. At the outset of the project the literature was explored and it was found to be insufficient to develop an understanding of the social process and to develop theory. From the data, an understanding of adopting wheelchair use as a transitional process of social change emerged. The selection of the research methodology was foundational to the successful outcome of the study. A method that allowed theory to be built from the data with no preconceived framework or formal theories to follow. In choosing to use Dimensional Analysis, a second generation development of grounded theory

method, a structured theory building approach that provided an analytical framework for the novice researcher to follow was selected.

Other grounded theory approaches were explored before the decision to use Dimensional Analysis. Throughout the literature it was identified that the user's perspective on wheelchair use was an area that had formerly been overlooked in favour of research orientated towards equipment, task completion and measurement (Bates et al., 1993; Reid et al., 2002; Barker et al., 2004; Furnham and Thompson, 1994). This gap in the literature was an omission that needed to be addressed, as in practice understanding the service user's perspective and improving client experience is now of heightened importance as government policy is turning evermore to assessing performance in the NHS using client-centred measures. Therefore, this study was a timely intervention and the findings have already been helpful in providing an alternative perspective from which to approach my practice.

Reflexivity is an important element in research reports of this kind to facilitate the reader to understand the decisions that were made throughout the study. This is necessary as, in contrast to scientific research, it is not possible to replicate results.

The interpretive study relies on discriminant reflectivity (Jarvis, 1995). The decisions that I made about the narratives of the participants and my perceptions of the perspectives shared were possibly wrong or misguided: this is where the imperative to maintain an audit trail of my thinking and decision making as the study progressed was invaluable. This was done in order that the reader of the thesis could make judgements on the veracity of the work. However, in practice it allowed me to return to previous assumptions and decisions and revise these or discover a new way of understanding the data. It also allowed for value judgements to be reconsidered in the light of new material, and data that was disregarded at one time was reviewed and found to be relevant in a new context. In researching an area

closely associated with my practice I was aware that I brought to the research my own attitudes and values; for this reason a research methodology was chosen that acknowledged the existence of the researcher's starting perspective and that this perspective would change as the study continued. I realised that I had formed opinions through experience and that it was impossible to not bring these to the research milieu. My interpretation of past experiences, modified by professional, social, cultural and historical influences, shaped the practitioner that I am today and were brought to the research study.

The next concern was accessing participants for the study. My position within the wheelchair service would have allowed access to wheelchair users without difficulty. However, I was uncomfortable with combining the role of therapist and researcher. The researcher needs to be aware of the possibility that these dual roles may conflict, particularly when the supply of equipment is involved. The question of role confusion was an important one (Padgett, 1998). I therefore chose to move outside my geographical area of practice and the wheelchair service and searched for participants in other areas of life. The decision was to approach social groups and a sports centre designed for wheelchair sportsmen and women. I was surprised and pleased with the response to my request for help in completing this study. The participants gave their time freely and with enthusiasm, clearly thinking that this was an opportunity to make their voices heard, and I hope that the study that I have completed justifies their confidence in me. However, the limitation of this study is that I interviewed a group of almost entirely British citizens from a small geographical area. It is therefore difficult to know how the theory created would generalise with a wider participant base in this country. It is impossible to anticipate its applicability in another country, where wheelchair provision is different or non-existent for some citizens. Limitations were therefore identified in participant selection. Within this grounded theory the data were bounded by the participants interviewed. In exploring a process with the NHS wheelchair service at its heart,

variation in those targeted to recruit for the project is limited. Those outside the system were not excluded, but access to them may have been limited by my selection of venues to find volunteers.

The data were interviews with a group of participants. I participated in their world, at a time and place of their choosing in order to enter their reality.¹³ This was because interaction between the researcher and the participant, in order to understand the individual's perspective, was at the core of the study. Limitations due to the use of words as symbols, or through mutual interpretation of what was sought were put to one side in the excitement of discovery. I would not choose to change the method of data collection.

When analysis of the data of the first four interviews commenced, I learned how eclectic the nature of the narratives collected was because of the open nature of the conversations recorded. In my enthusiasm not to be prescriptive in the information collected I failed to recognise the challenges that this might present. I had collected a mass of text from which I had to conceptualise and abstract, to compare and contrast in order to make sense of all that the data contained. Dimensional Analysis (Schatzman, 1991) gave me a template to work with. The research journal notes my relief on finding this method of analysis, which provided a method of moving from the text to understanding these as data. The interview text was organised into data segments, which were then brought together and arranged and rearranged many times before revealing an understanding of what the data contained. The process was far from easy and constant repetition was the key. I felt that I knew the interview texts by heart at some points of the study.

¹³ In the case of the two people who do not evidence a transition the place that they chose to be interviewed was their homes. This demonstrated that they had withdrawn and this is reinforced by the statement of one confirming this in 6.8

One key feature of Dimensional Analysis is that Schatzman advises that memos of all types – analytical, theoretical and at some points frankly miserable – are written throughout the analysis to note changes of direction and sometimes the researcher’s mood. These were reviewed and used during the writing of the thesis. Completing the writing of the thesis was challenging as I found little helpful literature to direct my efforts that resonated with the study that I had completed.

On reflecting on the concepts that were identified from the data it is acknowledged that in a grounded theory the findings are never completed. New understandings may be seen as iteration takes place and there is no right or wrong interpretation. Analytical misfiring led to days of work that ended in disappointment often prompted by making judgements on the basis of limited data. Whether the concepts identified justified the conclusions drawn was also an issue. This was where participant verification of the work as it progressed was helpful. By returning to selected participants, invaluable help was given in understanding the processes being explored and confirming my assumptions. Also the opinions of other professionals were sought to help to unravel analytical knots.

Theoretical reflectivity refers to the value of analysing one set of perspectives collected at one moment and then using these in building an explanation. This is a limitation of this study, however, no claim is being made that the substantive theory may be generalised other than in the population presently under exploration, wheelchair users from the south-east of England. Confirmation of what is referred to as grab and fit (Glaser and Strauss, 1967) of the theory will only be possible when it is used in practice to understand the clients who present at the wheelchair service. Using the theory in a clinical setting is anticipated with enthusiasm as this will confirm or contradict the thesis.

The help of others was vital in sustaining me during the work, what was emerging, providing insight into how the process could be changed, and just keeping me going. The local research group and knowledgeable friends made a significant contribution, as did the steadfast belief of my supervisors that I could do this.

In completing the research study I developed as a practitioner. My interventions are now more considered and reflective. They are based on a newfound understanding of service users' experiences. The research experience has enriched my practice and enabled me to empower clients through greater understanding of their perspective.

With hindsight, it can be seen that in completing this study and thesis I have undergone adaptive tasks at each stage. It has been a journey of discovery and cognitive and professional change that will have a continued influence.

7.8 Recommendations for further research

This study explored the perspectives of a diverse group of wheelchair users and from this emerged an understanding of accepting wheelchair use as a transitional process. This would be considered a "*low level theory*" that emerged from micro-phenomena (Urquhart, 2013, p. 129). Glaser and Strauss emphasise the importance of a substantive theory as a "*strategic link in the formulation and generation of grounded formal theory*" (1967, p. 79). The substantive theory developed out of the data from understanding that wheelchair users need to complete the three steps, **becoming, embracing and being** in order to accept wheelchair mobility, needs to be tested in different populations. These would be populations of wheelchair users in different geographical situations and at different times in the process of adopting wheelchair use. The theory may have resonance with others with acquired disabilities that have to use equipment such as prosthetic devices. Further research may apply the theory in association with concepts such as maintaining community access, promoting social integration and securing and maintaining employment as a wheelchair user.

However, it may also be explored when considering other groups where there is a causal relationship between environment, function and identity. Such areas as those changing their place or country of residence, contracting a terminal illness, accepting disability, and changing status from single to married or employed to unemployed.

The theory may be used in future research into different ways of identifying individuals who require assistance with assimilating equipment use into their lives. The findings of the present study confirm that a number of individuals had received limited or no help with aspects of equipment use such as promoting social integration. Part of this was a lack of wheelchair skills training. A study of the provision of this outside of the rehabilitation setting and the effect of such an input would be a helpful addition to the literature.

Research into service users accepting greater control of the wheelchair provision process is also indicated. The findings of the study indicate that some users are confident to take a lead in equipment provision. However, the extent that this could be generalised should be explored before the sentiments of many government reports¹⁴ promoting involvement in decision making and choice can be fully adopted in the wheelchair provision process.

¹⁴ A full list of these is provided in 1.6 and 1.7 Table 2.

7.9 Summary of chapter

This chapter set out the substantive theory of accepting wheelchair use that emerged from the data. This suggests an alternative way of understanding the experience of accepting wheelchair use. This theory is then discussed with reference to the formal theories that provided theoretical sensitivity throughout the research process. The substantive theory, having been located within the existing literature, is then applied to practice and suggestions made for changes to the provision process.

Reflection and reflexivity are cornerstones of a grounded theory and how this was undertaken in this study was then explored. From this suggestions are made as to further research that could apply and extend the substantive theory into new populations and environments.

Concluding statement

“The wheelchair’s not working.” Anon.

This statement was the starting point of my journey to complete this research.

Initially, it seems to be an innocuous observation. However, all too often it proves to be an impossible problem to solve. The therapist makes a systematic assessment. First the mechanical state of the wheelchair is inspected. Then its suitability to meet the clinical requirements of the user are addressed. The wheelchair and user are assessed for successful completion of tasks and finally the environment in which the chair is to be used is explored. If all of these parameters are found to be satisfactory then what else is there to check? The substantive theory suggests an alternative way of approaching wheelchair use.

The emergent substantive theory of accepting wheelchair use takes the transitional nature of the experience of becoming a wheelchair user as its starting point and

seeks to explore the factors that influence the user's satisfaction with their wheelchair. This is the first attempt to link different aspects of wheelchair use and combine these into a theory of a social process of identity transformation.

The substantive theory of accepting wheelchair use acknowledges that for each individual the experience was different. The context in which the wheelchair was introduced was unique for each person. However, the process of adaptive tasks was similar.

The researcher too was required to complete a process of adaptive tasks to carry out the research and complete this thesis. Change was the foundation of the undertaking. A transitional journey of development required a change from clinician, whose concerns were of equipment and service provision, to methodological explorer, interviewer, objective analyst and researcher capable of abstract thought. The process was far from easy and there were many barriers along the way. These required that I adapt to be able to conceptualise the problem and develop coping strategies to deal with the issues.

At a time when the NHS wheelchair service is under threat, the substantive theoretical model of accepting wheelchair use is offered to others who wish to understand their clients' perspectives in an alternative way and to provide quality indicators for providing an excellent service. Attention is drawn to the fact that wheelchair provision is much more than supplying equipment. A wheelchair is understood by the user to be of greatest assistance only when they have shed the concept of being a walker and put on the mantle of **being** a wheelchair user. This emotive and complex activity was found to be foundational in the individual's accepting wheelchair use. Fundamental to the social process that the substantive theory details is the understanding that a change of identity is required of the user. Without this on the part of the user no wheelchair will ever work.

Accepting wheelchair use requires that the individual leave behind the self-identity of a walking person and become a wheelchair user. Similarly in writing this thesis I was required to leave behind the therapist and put on the mantle of researcher. The following quote sums up succinctly the sentiments and main concern of this study.

“All the art of living lies in a fine mingling of holding on and letting go.”

Henry Ellis. In: iMinds Pty Ltd, 2009, Quoting Life

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Appendices

Appendix 1 - Example of Dimensions - 1

- GENDER
 - BORN WITH OR ACQUIRED DISABILITY
 - SCHOOLING
 - MARITAL STATUS
 - AGE BEGUN TO USE WHEELCHAIR
 - REQUIRES CARE
 - EMPLOYMENT STATUS
 - TYPE OF WHEELCHAIR PROVISION
 - LIFE PLAN
 - Self — AUTONOMOUS BEHAVIOUR
 - EMOTIONAL CONNECTION TO CHAIR
 - HOW W/C CAME INTO USE
 - HOW THE CHAIR MAKES ME FEEL
 - W/C IMPROVED MY LIFE
 - W/C PROVISION
 - LIVES ALONE
 - W/C ADAPTED ACCOMMODATION
 - HAD CONTACT WITH PEOPLE OF SAME DISABILITY
 - HAD CONTACT WITH PEOPLE WITH DISABILITIES
 - W/C AS FREEDOM/LIBERATOR
 - MOVING ON
- Σ
- W/C AS HOBBY
 - W/C AS 'TOOL'
 - BEING INVISIBLE
 - PROMOTES INTERACTION WITH SOCIETY
 - CULTURE W/C SUITABILITY
 - W/C RELIABILITY
 - W/C USER'S VIEW ON SOCIETY
 - SOCIETY'S VIEW ON W/C USER
 - PERSONIFICATION OF W/C
 - COLOUR OF W/C
 - PEOPLE WANTING TO HELP
 - PEOPLE BEING INCONSIDERATE
 - W/C IMAGE
 - PERSONAL CONFIDENCE WHEN IN W/C
 - COMPARISON WITH ABLE-BODIED
 - UK GOVERNMENT ISSUES
 - SELECTION OF W/C FOR LIFESTYLE
 - LEARNING THRU' LIVING
 - CONTEXT
 - KNOWLEDGE
 - FINANCE
 - RESEARCH
 - EXPERIMENT
 - AFFORDABILITY
 - ADVICE/TRAINING
 - FAMILY SUPPORT NETWORK

- ENVIRONMENTAL BARRIERS IN STREET/HOME
- CAR DRIVER
- CAR AS OUTDOOR MOBILITY
- USES TAXI'S OR BUSES
- ABLE TO SELF PROTECT
- CONFRONTS ISSUES
- FINDS SOLUTIONS
- LIVES WITH FAMILY
- LIFE PLAN NOT DISRUPTED
- W/C PART OF ME
- W/C IS MOBILITY
- W/C ALLOW CONTROL OF ONE'S LIFE
- SELF IDENTITY - CONTINUOUSLY REFORMED
- SELF IDENTITY - REFORMED FOLLOWING ILLNESS OR ACCIDENT
- PERSPECTIVE
- SECOND NATURE
- YOUNG
- FLEXIBLE - ABLE TO CHANGE
- PUBLIC / PRIVATE SUPPORT
 - ↳ FORMAL / INFORMAL

- VIEW WORLD FROM DIFFERENT PERSPECTIVE
- SYMBOL OF LOSS
- SIGNIFIES CHANGING PLACE IN WORLD
- WITHDRAWAL
- SHRINKING HORIZONS
- OTHERS IGNORE USERS
- SEE BEYOND THE CHAIR
- W/C + ENVIRONMENT
 - ↳ USAGE
- CONSPICUOUS
- INSULARITY
- resentment expressed.
- I hate this chair.
- understanding self.
- understanding requirements of chair
- acceptance of own limitations
- with a chair there are no limitations
- a self identity
- w/c is elephant in the room.
- ice breaker.

Appendix 2 – Example of Dimensions – 2

- Disrupted identity
- Point in life map when walking became impossible

❖ **Occupation**

- Employment
- Meaningful activity
- No structured activities
- Sense of Well Being

❖ **Social situations**

- Family and relationships facilitating w/c use
- Family relationships inhibiting w/c use
- Lifestyle Choices
- Image

❖ **Experience in the wider community**

- Interaction built with environment
- Invisibility cloak
- Barriers to communication
- General publics approach
- Education
- Familiarity with Wheelchairs i.e. previous contact with wheelchair uses
- Level of personal identification with being a wheel chair user
- Acceptance of need to use a wheelchair
- Resistance to changing status as a w/c user
- Resistance to making changes to accommodate w/c
- Cognitive ability to confront the change and intellectual capacity to cope with it
- Challenging social attitudes
- Threatening self-identity
- Identifying self with disability
- Chair as part of self
- Emotional well being
- Acknowledging disability/ difference
- Acknowledging change of identity
- Acknowledging new status
- Money giving options- funding decides options
- Chair fitting life

- Car that fits for Wheelchair
- Minimise the effect of the w/c on everyday life
- Substitution of legs
- Avoiding institutionalisation- worse alternative?
- Evolution of equipment to improve life style over time interested in wheel chair?
- Imagination able to assist intergration
- Accessibility of advice and training
- 'right chair'
- Reaction to media representation
- More than legs
- Customisation of chair
- Function rather than looks
- Events dictating life
- Learning curve
- NHS one size fits all
- w/c means self determination
- Loss of w/c frustrating???
- 'my wheelchair'
- W/c Becoming legs
- Can do anything an able bodied person can do
- Evens out advantage in being able bodied
- Born into his wheel char
- Style essential
- Able bodied attitudes towards equipment
- Growth inside the chair
- Disability improves determination
- Environmental Barriers
- disability viewed as passivity
- ability to shape own life
- Sudden loss of walking
- Never walked
- Gradual loss of walking
- Enforced adaption to w/c
- Pragmatic adaption
- Age when becoming full time permanent user
- Understanding of disability through previous interaction
- Expectations of wheelchair use- fulfilment compared to distress
- Development of life map
- Socialising as a wheelchair user compared to before
- Adopting to new viewpoint
- Gaining control
- Planning lifestyle with wheelchair

❖ **Gender**

- Male
- Female

• Education

- Special
- Mainstream
- mixed

• Marital status

- Single
- Partner
- Married
- Divorced

• Dependent on external help

• Independent of external help

❖ **Employment status**

- Retired
- Employed
- Student
- Unemployed

• Choice of wheelchair

• Appropriate accommodation

• Supplier of wheelchair

• Embodiment

• Adornment

• Detachment

• Image

• Tool

• Hobby

• Showing off wheelchair

• Collector of wheelchair

• W/C Technician training

• Aesthetics key

• Ability for easy adaption

• Frustration with inadequate equipment

• Chair suiting personality

• Passive acceptance

• Goodlooking chair shows expense and class

• Poor perception NHS

• Extension of Ego

- Interpersonal relationships are affected by w/c
- No barriers perceived
- Positive wheelchair experience
- Deterioration of body over time
- Academic success
- Work not using chair
- Adapting environment
- Coping with barriers
- Changing behavioural life map
- Ability to modify equipment
- Withdrawal from community
- Isolation from others
- Facilitating movement
- Limiting independence
- Selecting the right chair
- Participating in decision making process going into a wheelchair
- Interacting with others
- Facilitation of life
- Financial well being
- Emotional support
- Formal/informal care
- Embodying / accommodating
- Welcoming
- Resistance
- Detachment
- Partnership
- Substitution
- Metaphor of clothing
- Independence of movement
- Independence of action
- Adornment
- Tool
- Ambivalence
- Disruption
- Decision making process
- Last resort
- Attendant propelled vs. independent
- Lack of knowledge
- W/C means segregation
- Stigmatisation
- w/c as a breaking down of barriers
- carrier/enabler
- life easier

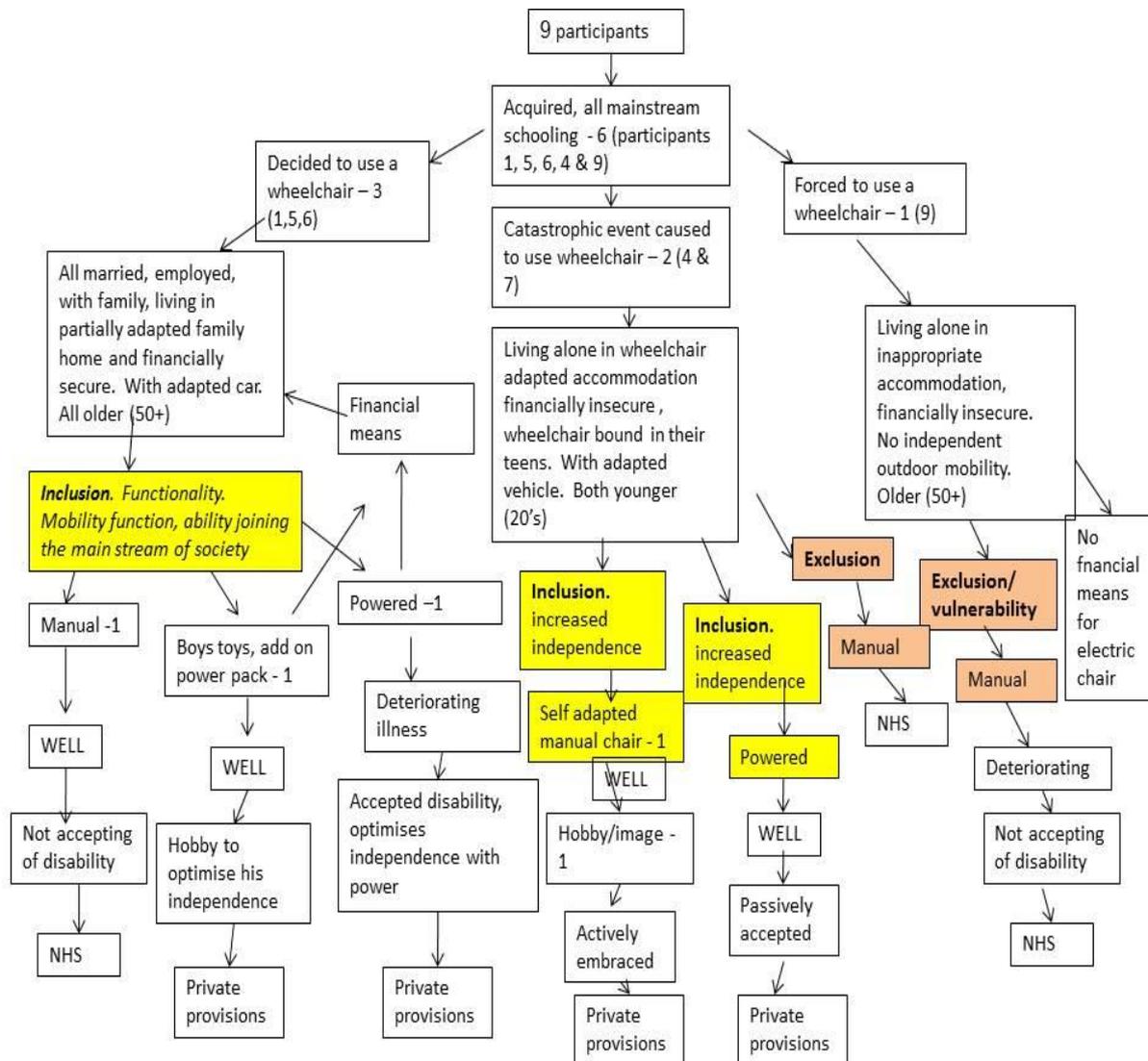
- opening of the world
- manual frustration
- People don't see the w/c
- idea of female users being ignored
- hurtful taunts
- just something to get around in
- uncomfortable on public transport
- expensive taxis
- demanding of rights
- w/c defines them
- moving of public to private
- sense of loss
- Lack of support
- To ill to fight
- W/c means movement
- Religion as a support mechanism
- Assistance with inclusion

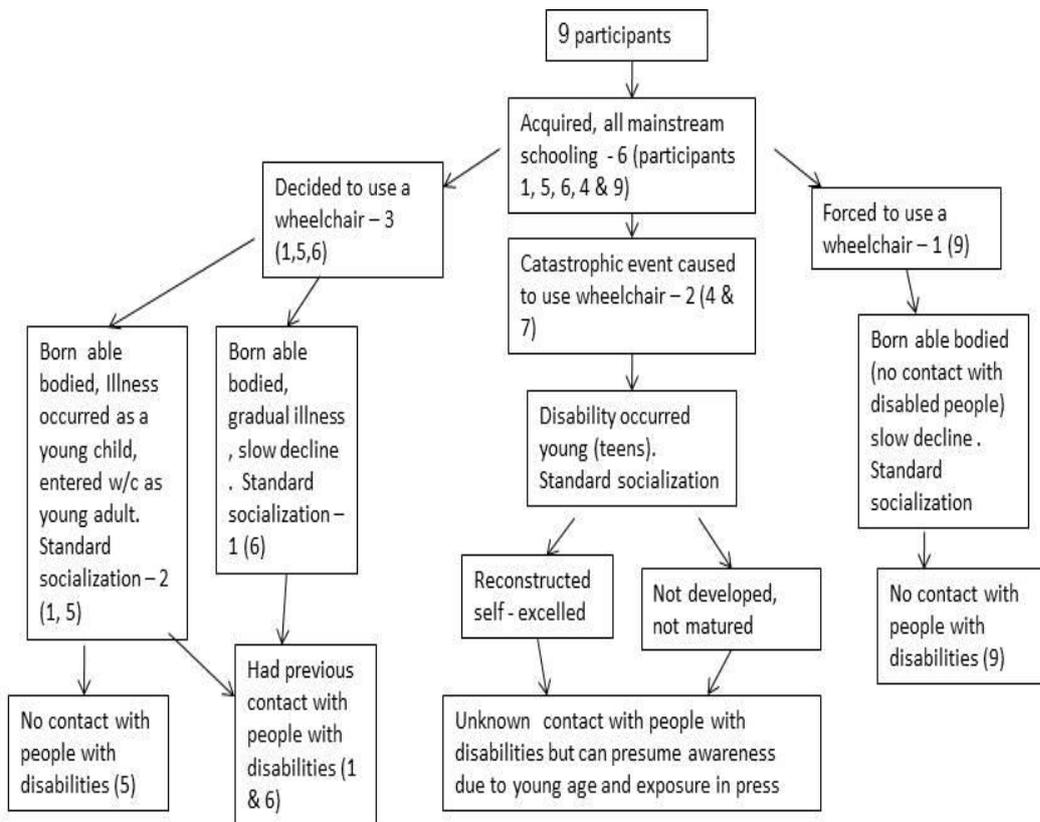
Appendix 3 – Examples of Excel Spreadsheets

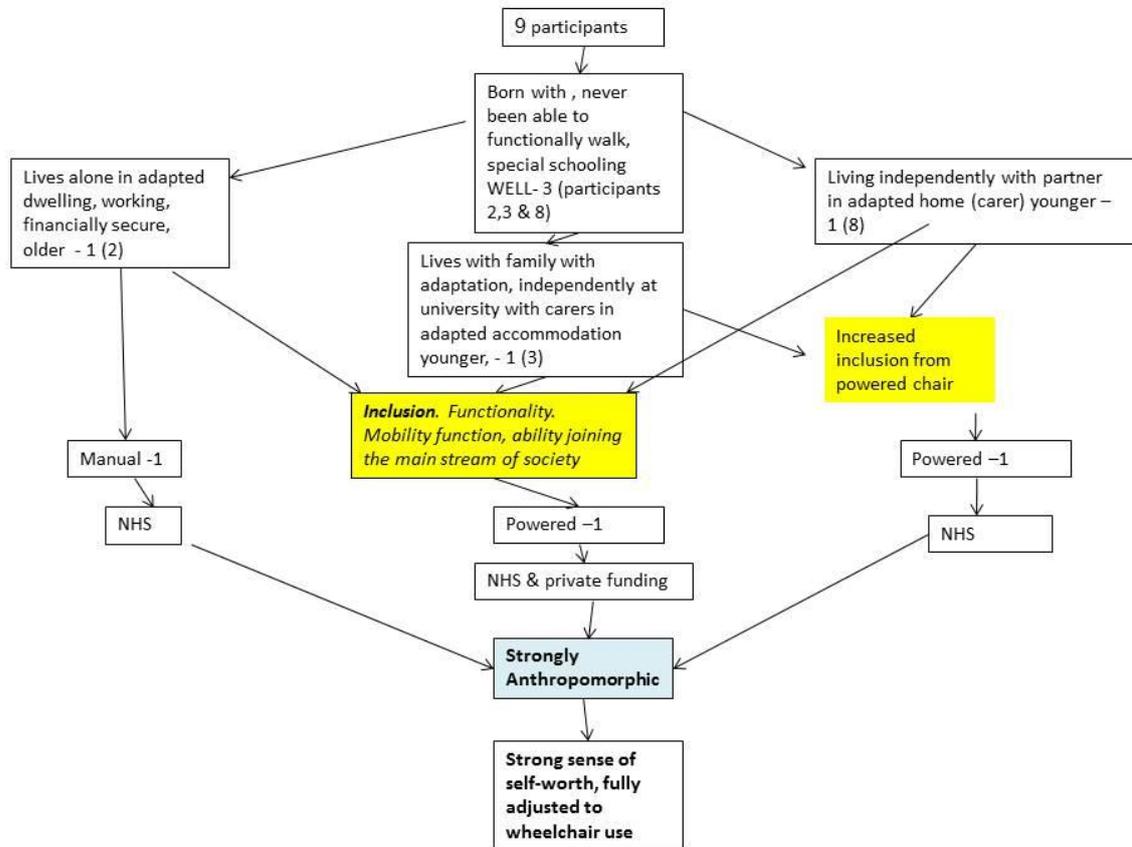
	born with or acquired	special school or mainstream	married/partner or single	Age	Time (years) in Wheelchair	Carer Y/-	Employment	residence	case: Wheelchair as extension or part of self	wheelchair as freedom/ liberator
participant 1	A	Mainstream	Married	60+	50	-	Professional	Family home - suitable	it had this ugly colour I've never noticed the colour since & no one ever notices the colour (58-61) It's not trousers I had on (58) it just does what your legs do you don't spend the whole time thinking about your legs your brain is wired up in such a way that you don't think about walking.....it something which once you've got it organised, you don't think about, till it goes wrong (344-360) it's just a substitute for your feet essentially. No different from your feet at all." (411-413) you know, it just has to be a good substitute for your legs (582-584) "Well it's not worse than having your feet chopped off I'm sure, in some, you know... but um... it's about the same, it's just a... it's just a substitute for your feet essentially. No different from your feet at all." (408 - 413)	it's a whole lifestyle thing. You've got to decide what your /style is& then get the chair for that /style when lifestyle changes then maybe your chair needs will change (250-256) It's just a substitute for your legs it should take no more of your attention than your legs (435-437)
participant 2	Born	Special	Single	40+	40	-	Job	adapted sheltered home - suitable	it's with you all the time. There when you go to bed at night...it's with you when you go to work....so you have to make it part of you in order that there's no difference...the whole person is me....so if you separate my physical body from the w/c perhaps my personality wouldn't change but my ability to interact with people would be severely restricted....not socialising, not using what society provides for disabled people to my advantage (12-37) the whole person was me and the w/chair (216) We really have to get over this idea that you can separate the wheelchair from the person." (339-241) meaning of w/chair is variable depending on the personality of the individual that uses it (380-383) Aw/chair has no meaning until someone sits in it (394-386) to achieve integration with a powered chair is difficult.... you sit in it and are part of the chair a manual chair can physically become part of you (778-788) I've got that wheelchair... got to function.... as invisibly as possible (363) It's there all the time, so you have to make the wheelchair part of you in order that there's no difference between (9-10) We really have to get over this idea that you can separate the wheelchair from the person." (90-91)	so to me the wheelchair is the ability to interact, the ability to use what society provides for disabled people to my advantage. A wheelchair in lots of ways is an advantage (33-38) you adapt to the fact that there are places you can't go (47-50) never know what it's like to be able bodied (86-88) we knew what we could do with the wheelchair, which gives you confidence to do things in the open community in society and it got to the stage where, in the later school and in the college years, we were fairly independent, (190-197) what the wheelchair means to me is ability really. Ability to overcome the hand... some of the handicaps imposed by my disability. (1039-1042) If you're weak in the legs or need to sit down because of medical problems, a heart problem or anything like that, (16-17) . The strength of this is that there is no... there is no wheelchair if you like. There is an ability to move around (134-135)
participant 3	Born	Special	Single	20	15	-		adapted sheltered home	I was born this way (18-19)...major advantage I haven't had an accident....I've been born in a wheelchair...it's second nature (26-33) the w/chair is mine because it is my legs it's not just a chair (519-523) without a w/chair an able bodied person has a myriad of advantages over me but with a chair there are virtually none (571-575) my chair says a lot about me & how I carry myself in the world...the first time I meet someone they make a judgement as to the chair I'm sitting in..I want the impression to be a good one (831-837) want my chair to say something about the confidence I have in myself (841-843) it's not just a functional piece of equipment....it says an awful lot about you & will enhance my confidence (893-897)	with a wheelchair I can do virtually everything else that an able bodied person can do. (568-570) Um... because it was the first opportunity that I had to actually move around. Without it I was on the floor (586 - 589)

	wheelchair as a hobby or a collection	wheelchair as label	wheel chair as an invisibility/people not caring about the person - only seeing the chair	wheel chair as an inhibitor	wheel chair as a basic facilitator
participant 1	I have 1 w/c in my car (line11-21) I spent a lot of time getting the right chair, home chair, because it's fully mechanical(21-23)2 downstairs and 1 upstairs, a stair lift to connect me to the different w/c and in my car I have my serious w/c with a motorised Yamaha hub kit. Upstairs a Kusshall Champion(41) Complicated w/c downstairs (75) waterproof one for showering(77)design is abysmal(97) iexo (122) standing w/c (134)engineering of w/c important (214)*Of course yes, I go to Naidek every year, to keep an eye on all the equipment, and er... yeah I'm careful that... I'm careful to know all about, all for sale equipment, anything that might help me." (264 - 269)	user blend in with the family, you want something that is aesthetically acceptable(302-305)			... And it's very sad if you make the wheelchair the centre of your life, it's only there to let you live your life, it's not your life (428 - 431)it does... it rolls you about, it just does what your legs do. You don't spend your whole... the whole of your time thinking about your legs. (344 - 347)
participant 2		feel annoyed that you might not be able to obtain access (54-56)make the w/chair as invisible as possible(881)a burden(940)	A wheelchair only comes to life when an individual sits in it."(156-15) "Do you think to um... the people you pass in the street, they would regard you differently if you were using a manual, self-propelled wheelchair?" "Yes, unfortunately, yes (183-186) Yet if the disabled child goes round and the electric chair tips over, everybody's going to panic. You... society's not used to that. (248-249)	but also can provide... can present a disadvantage in some areas of society where there's no ramps or no access to somewhere where you need to go (42-46) can present a disadvantage in some areas of society where there's no ramps or no access to somewhere where you need to go(17-19) And the third thing would be the mere fact that I'm driving a van now, instead of a car, again puts you in a different... makes a difference... it makes you different, it makes... if a van arrives it's something different to a car and therefore the person that gets out of that van is... is different (288-290) "So really, you'd cancel a social engagement if the wheelchair wasn't providing you with what you felt you required?" "Quite possibly."(381-385)	
participant 3	it's a fashion statement(318-319) the w/chair...a certain amount of style that's the main thing (721-724) . Yes it's nice and yes I can customise it to me and yes I can make it look like this all singing, all dancing wonderful piece of equipment, but let it not be forgotten that every piece of equipment on there and every function that that wheelchair has is entirely necessary. Not a piece of Buzz Lightyear equipment." (781 - 790)	but for me, I think the wheelchair is a lot about projecting the right image (133-135) I want a piece of equipment that I can talk positively about that I could be proud of(181-182) that piece of equipment looks cool...frame a conversation around it (188-190) They look at it kind of... a street cred kind of image enhancing accessory as it were, (308-310) It's like ah, look at that piece of equipment (739-740) my chair says a lot about me and how I want to carry myself in the world (835-827) I want, you know, my chair to say something about the confidence I have in myself (841-843) when I get my new piece of equipment, I will be showing off like a new pair of shoes, because that's what it is. It's not just a functional piece of equipment (889-893)	it would be um...naive to a certain extent to think that everyone immediately looked beyond the wheelchair, because let's face it, it's a massive factor (209-213)		

Appendix 4 – Examples of Decision trees







Notes/thoughts

9 participants



Born with - 3

Attitude: to chair is overwhelmingly	never walked	See me and the chair- seamless	Wheelchair part of me	Wheelchair is my legs
All attended special schools	Taught independence and self-worth	Taught to be a person first then disabled	Academic rigor questioned by one participant	Physically- in this generation
Question about the level of pushing the boundaries	However, one living independently at University, one older employed and living independently one living with partner who is her carer			Essential limited without it
attitude to chair	2 younger possibly not pushed to be adventurous at school -rely on power	Assists socialisation- P.3 at parties	Powered chair used as work horse carries shopping wide mobility options	2 participants have excelled-P.1 and P.4
seamless, see me not chair-wish to maintain self propulsion				
P.5 chose to use chair to facilitate employment	P.6 chose wheelchair to allow her to join in with family Used working as an excuse to avoid outings. NOW uses chair as a tool to breakdown barriers with strangers in her voluntary work	minimal anthropomorphic feelings	Moderate anthropomorphic	
		P.7 w/c as label ; sees herself as able still. Likes to be on the same level as her friends. Prefers powered to manual. Feels limited in the chair and power minimalises this. Unable to affect the environment around her. Live in/24 hour carers. ??does this affect her feelings of self worth and prevented her from maturing as she might have done if the accident had never happened. Timing of accident therefore crucial for her.		
P.9; little social interaction				

Appendix 5 – Interview Guide

Initial interview questions focused on exploring the following areas:

- ❖ Opening question - Tell me about your life as a wheelchair user.
 - ❖ The participants' interaction with the wheelchair inside the home.
 - ❖ The participants' interaction with the wheelchair outside the home and coping with the environment.
-

After initial analysis of first four transcripts

- ❖ Aspects of how the participants' wheelchair use began explored.
 - ❖ Age of participants when permanent full time wheelchair use began / place of residence / continuity or disruption of life map.
-

- ❖ The participants' perspective of using a wheelchair –provides autonomy/independence/dependency.
- ❖ How has the wheelchair changed them.

Appendix 6 - Participant Information Letter

Faculty of Health



University of Brighton



**Clinical Research Centre
for Health Professions**

Professor Ann Moore PhD GradDipPhys

FCSP DipTP CertEd FMACP

Director of Centre

Aldro Building

49 Darley Road

Eastbourne BN20 7UR

Telephone 01273 643647

Fax 01273 643944

www.brighton.ac.uk/sohp/research/index.htm

Participant Information Sheet

My name is Linda Walker, a physiotherapist, with an interest in wheelchairs. I am undertaking a research project as part of my studies at Brighton University working towards a Professional Doctorate in Health and Social Care. I hope that my learning from this project will help me to understand how the experienced wheelchair user thinks about their chair. With this information I would like to improve the way that wheelchairs are supplied. I hope to influence the attitudes of therapists, engineers and doctors who carry out the assessments and supply NHS wheelchairs. The findings of this project will be widely reported through my contacts with the

Department of Health and the commercial sector. Therefore, your experiences are very important. I intend to explore what the wheelchair represents to twenty experienced users. If you volunteer to be a participant in this research project you will be asked to agree to:

1. Be interviewed in your own home or another place that you choose by agreement.
2. This interview will take about an hour of your time.
3. The interview being recorded.
4. A written copy of the contents of the recording will be made. You can request to see a copy of the transcript of your interview if you wish.

I may ask you to agree to my returning for a second visit to discuss my preliminary findings with you.

The interview will be kept on an electronic database and analysed for the purpose of this research. Sections of the interview may be quoted in the final report. This thesis will be on public display at the library of the University of Brighton and could be read by anyone. The contents of the interview may be published in part in future papers. However, your anonymity will be assured by introducing a numbering system when the recording is transcribed.

Data that is collected is for the sole purpose of answering the question:

What does a wheelchair represent to its user?

The interview data will only be read by the researcher, their supervisors, examiners and advisors. All data, both written and recorded, will be destroyed once data

analysis is completed. A copy of the results of the study will be made available to you on request.

It must be stressed that by volunteering to give an interview, for which there is no payment, you are not obliged to answer any question with which you are unhappy. You can withdraw at any time from the research or your permission for the interview to be used if you change your mind.

I would be very grateful for your help with my project. If you would like to discuss volunteering or would just like more information I can be contacted by

email : lw20@brighton.ac.uk or Mobile telephone : 07768 175 105

Alternatively, please contact :

Dr. Virginia Jenkins

Project Supervisor

University of Brighton

School of Healthcare Professions

Robert Dodd Building

49 Darley Road

Eastbourne BN20 7UR

Email : V.S.jenkins@brighton.ac.uk

Should you wish to make a complaint about the conduct of the study or the researcher, please contact:

Dr. Anne Mandy

Clinical Research Centre

Aldro Building

49 Darley Road

Eastbourne BN20 7UR

Thank-you for considering giving your help with this study, I look forward to hearing from you.

Yours sincerely,

Linda A Walker, MCSP

Appendix 7 - Participant Consent Letter

Faculty of Health



University of Brighton



**Clinical Research Centre
for Health Professions**

Professor Ann Moore PhD GradDipPhys

FCSP DipTP CertEd FMACP

Director of Centre

Aldro Building

49 Darley Road

Eastbourne BN20 7UR

Telephone 01273 643647

Fax 01273 643944

www.brighton.ac.uk/sohp/research/index.htm

Participant Consent Form

What does a wheelchair represent to its user?

- ◆ I agree to take part in this research, which is to explore what a wheelchair represents to its user.
- ◆ The researcher has explained to my satisfaction the purpose of the study and the possible risks involved.
- ◆ I have had the principles and the procedure explained to me and I have also read the information sheet. I understand the principles and procedures fully.

- ◆ I am aware that I will be required to answer questions. This will take the form of an interview that will last for one hour and will be carried out at a location that I choose. I have agreed that this interview can be voice –recorded, transcribed into text and segments of this may be used in the final thesis.

- ◆ I understand that any confidential information will be seen only by the researchers and will not be revealed to anyone else.

- ◆ I understand that I am free to withdraw from the investigation at any time.

Name (please print).....

Signed

.....

Date

Appendix 8 – Letter from Hertfordshire Action on Disability

8th June 2007

Linda Walker MSc, BSc [Hons], MCSP
The North West London Hospitals NHS Trust
Disablement Services Centre
RNOHT
Brockley Hill
Stanmore
MIDDLESEX HA7 4LP



THE WOODSIDE CENTRE
THE COMMONS
WELWYN GARDEN CITY
HERTFORDSHIRE AL7 4DD
T 01707 324581
F 01707 371297
E info@hadnet.org.uk
W www.hadnet.org.uk

Ref:AW4279/sp

Dear Linda

It was a pleasure to welcome you to HAD!

I enclose a draft letter of support and would be very pleased if you would make any alterations you think are necessary before I produce it.

I look forward to receiving your article.

Yours sincerely

A handwritten signature in black ink, appearing to read 'A. Waterfield', written over a large, light-colored oval scribble.

P.P Mrs Annabelle Waterfield
Chief Executive
HERTFORDSHIRE ACTION ON DISABILITY

Enc Draft letter

Appendix 9 – Letter from Harrow Association of Disabled people



Linda Walker
Thamesdale
Londoncolney
Herts
AL2 1TL

Dear Linda

Thank you for your phone call checking out the situation regarding us providing information to disabled people who may wish to be involved in your project. We would be happy to support you in this where possible, and I can clarify that we would not need agreement from the Local authority to do this. Although we receive funding from them to provide particular services, we are an independent organisation and make such decisions independently.

Do not hesitate to contact me if you wish to discuss this further,

Your sincerely

Angela Dias

Harrow Association of Disabled people
Ground Floor, Bentley House, 15-21 Headstone Drive, Wealdstone, Harrow HA3 5QX
Tel: 020 8861 9920 Fax: 020 8861 9926 Minicom: 020 8861 4547
Email: general@had.org.uk Web: www.had.org.uk