

**Disability, Access and Design:
A Study of Wheelchair Access**

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Abstract

The aim of this study is to determine wheelchair user's views about access and ascertain whether designers are able to contribute to issues pertaining to inclusion through design solutions. Popular constructions of disability have established a relatively powerless and deviant status for the disabled population when compared to their able bodied peers. Regulatory controls and legislation require that builders and designers are sensitised to the needs of disabled people, but there is no legislative process to endorse disabled peoples request for a fully inclusive and accessible lifestyle.

The enquiry is divided into two phases. The first phase considers access issues from a sample of wheelchair users via the use of focus groups and individual interviews. The data attained and information collated for the literature review leads the author to conclude that designers should consult with end users throughout the design process.

During the second phase of the study the author proposes a model of inclusive design and an associated design resource. The author advocates that this is to be used by designers and development professionals to ensure inclusion within society is attained for all sectors of the community.

The study concludes that, historically, society has responded to the needs of the disabled by providing separate and special services based on each individual's impairment, as opposed to the promotion of an equitable lifestyle for all. Inclusive design focuses on the design of the environment and not individual impairments. It is a process that promotes inclusivity for all sectors of society regardless of age, race, gender, sexuality or disability. Its principles consider diversity, and provides for an inclusive environment that can help break down barriers and exclusion as everyone will benefit from the end result.

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Somewhere deep in the shadowy past, primitive man, desiring water, instinctively dipped his cupped hands into a pool and drank. Some of the water leaked through his fingers.

In time he fashioned a bowl from soft clay, let it harden, and drank from it; attached a handle and made a cup; pinched the rim at one point to make a spout, creating a pitcher. Intuitively, this prehistoric man was following the same principles of utility that guide today's industrial designer who creates for mass production.

(Dreyfuss 2003, p.14)

I wasn't sure where to put this quote but I wanted it to be in the thesis somewhere and at the beginning seemed as good a place as any. To me, it epitomises the process of design, the inquiry of the mind and how humans will always endeavour to find a way to continue their survival. I have had the privilege of combining my love of all things to do with design and my involvement in the field of disability to complete a project that has taken eight and a half years (that's how long it will be by the end of the viva!). There are several people I need to thank for their help and support throughout this time, because without them my journey would not have been possible.

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And to Harry, for always believing Mummy could be a Doctor of Wood.

CHAPTER ONE - MY PhD JOURNEY

This chapter maps my reflective journey around the fields of disability, design and social science research. It begins during my childhood where I grew up around friends who had varying physical disabilities and where my acceptance of disability as part of everyday life began. It then looks at how my days as an undergraduate influenced my political views about disability and how these views integrated with my opinions about design. The discussion then turns to the research proposal for this study and how the final proposition evolved.

My employment and voluntary work during the course of this study offered various opportunities for validation of the issues discussed within the thesis, although for ethical reasons I could not use them in the research documentation. The chapter explores the relevance of my employment in endorsing many of the issues raised throughout the study and the importance of recognising how different cultural groups use verbal communication.

1.1 The Early Years

I have been involved around disability all of my life. I grew up alongside a peer who was six months younger than me, but who's lifestyle was different from mine because she was born with cerebral palsy. I cannot say I consciously spent a lifetime considering disability issues from a non-discriminatory point of view; disability was just part of my life. The situation was comparable to being a parent and remembering to take the pushchair, potty, bottles and nappies with you when taking a small child out for the day. It was something that was accepted as part of everyday life. Disability was never discussed as being a political issue, or anything that could be changed; it was just something that was there. However, it was something that I always recognised other people seemed to know very little about, and the opinions that I did hear were very different from my own. I remember from an early age noticing other people's comments about disability issues and disabled people being edged with pity, disdain, or complete ignorance. Comments ranged from "...oh that poor girl/boy..." to "...they would be better in homes with people of their own kind...", remarks that seemed alien to me. I spent many school holidays as a child in Dorset where I had contact with several children who had varying disabilities. I did not consider them any different from myself and their disabilities were seldom an issue, we were just children who played together,

argued together and grew up together. It was part of an everyday occurrence for me, they were just my friends.

1.2 University

It was not until much later in my life when I was completing a degree in furniture design that disability became an issue I really had to deliberate. We had to define our own final year project and I opted to design and manufacture a computer workstation for a wheelchair user. My dissertation looked at accessible housing and how adaptations to buildings would be easier to complete if more care was taken during the initial design process. I enjoyed researching and writing about disability so much that I decided to continue my studies and complete an MPhil / PhD. I knew I wanted to study the field of disability from a design perspective, but didn't want to manufacture a product. In 1996 I submitted a proposal to Bournemouth University that was to lead to a study that affirmed my belief that disability discrimination is rife.

1.2.1 The Research Proposal

My initial research proposal for an MPhil/PhD was to complete a study of wheelchair users, carers and planners views of access issues within the built environment in Poole, Bournemouth and Dorset. The study was to be divided into two distinct phases. A qualitative phase that would ascertain participants views and lead to an MPhil qualification and a second quantitative phase where the data from phase one would be used to develop a questionnaire. The questionnaire would then be sent to wheelchair users, quantitatively analysed and used to inform designers of access issues raised by wheelchair users. This would provide a contribution to knowledge to gain the PhD qualification I desired.

The project began with two focus groups comprised of wheelchair users who had all been previously able-bodied. The choice of sample came from the belief that the participants would have a dual view of access issues. One as an able-bodied member of society where access is often taken for granted, the other as a disabled person in an inaccessible world. As a designer embarking on a social science based research project for the first time, I opted for a qualitative style of study as its open minded approach and ability to allow a change of direction '*at the drop of a hat*' emulated, to some extent, the design process. I chose to use an ethnographic stance with its definition "... a

description of a people” (Holloway 1997). Within the ethnographic style research strategy I opted to use focus groups as they promised to produce abundant data. The first focus group was organised at a local day centre in Poole where I had a contact through a family friend and where I done part of my teacher training. Most of my fieldwork had been completed there while I was teaching and I had developed relationships with many of the staff and service users. The second focus group was organised at a day centre in Bournemouth that also catered for disabled adults and was known and used by some of the service users from Poole. Surprisingly the amount of data produced from the two focus groups was far more than expected and the whole project had to be reassessed. It was decided during consultation with one of my supervisors to adhere to the social science research principle of collecting rich data from the information gathered in the focus groups with wheelchair users rather than researching a broader field, so a second proposal was developed.

The second proposal still had two phases one qualitative and one quantitative, but the qualitative data was to be obtained in more depth from wheelchair users in Poole and Bournemouth. I was still aiming to develop a questionnaire for the second phase about access issues from the data collected and to distribute it to a sample of wheelchair users in Dorset. The difficulty with this proposal was that there is no generic data base of people with disabilities or those who use wheelchairs. I contacted the Disability Services Manager of a local wheelchair clinic who was unable to supply specific details of the number of patients provided with wheelchairs or their details for data protection reasons (Appendix 1). A further telephone conversation with a manager at one of the focus group venues confirmed that due to ethical issues and data protection, contacting wheelchair users was going to involve an ethics committee intervention which would extend the length of the project. Further consideration of this proposal also made me realise that the project was slipping away from any kind of design influence and becoming a purely social science based research project, so the project had its third evaluation.

The data from the focus groups was conclusive about the oppression encountered by disabled people. The participants were all resolute that although the environment disabled them through physical inaccessibility, people’s attitudes were a huge contributory factor to their disability through societal prejudices. It was at this stage that

I realised that if designers influence society by the products and buildings they create, then society is influenced by a designer's ways of thinking and their personal prejudices. I considered that if designers change the way they approach a project, allow more input from the end user and allow the end users views to be used, the final project would have influences from the end user that are visible to others. It was at this stage of the project I concluded that if designers alter the way in which they approach a design project, they may not only help disabled people with their quest for accessible environments through design, but they may also assist with the change in cultural views that are needed to ensure that oppression towards disability is eradicated.

Designers consider that design is fundamentally about shaping the future "...in the form of a product, service, communication or environment – then designers' responsibility is indeed profound" (Powell 2005, p.5). However, whilst designers acknowledge their responsibilities with regards customer satisfaction / pleasure, economic vitality and sustaining our environment (Powell 2005), they do not recognise the value of engaging with end users thought out the design process. An improvement in design practice to include engagement with end users would lead, ultimately, to improved policy and practice.

During the last decade of the twentieth century, there was a growth in awareness of the need for service user / participant involvement in the shaping of policy and practice (Beresford 2002). The commitment of the New Right to market-led approaches within health and welfare and the endorsement of individual rights and choice led to a renewal of interest in participation by the "...active citizen..." (Beresford 2002, p.96). This rekindled attention in participation led to the emergence of the emancipatory research paradigm within disability research, where empowerment and the development of broader social changes are central tenets (Oliver 1992). However, this concept of inclusion and participation has not been embraced within design culture. I believe, therefore, that this study should contribute to improved policy and practice in design, by endorsing the inclusion of end users within the design process.

During my four years as a mature undergraduate, I was constantly ribbed by other students on the course for my model making, the amount of work I produced, my questions and my grades. I was no great artist, nor was I particularly aesthetic with my

design solutions, but I did always adhere to the brief, complete copious amounts of market research, produce scale models of everything I designed and walked away one of a handful of students to gain a 2:1 BA(Hons) Furniture Design. The first project I ever completed at university got me a D- grade. I nearly walked away before the end of the first term. If it had not been for a lecturer who said:

Don't worry. One day you'll get an A grade and it will mean more to you than all the A grades the other students ever get, because they expect their A grades, you will have to work to get yours. Your sense of achievement will be far greater than theirs will ever be.

(T. Roe, Personal Communication, 1992)

I did become an A grade student during my second and final years, not because of a newly gained exceptional design prowess, but because I followed each design brief to the letter and constantly asked questions of the lecturers who wrote the brief. It was this constant asking of questions and wanting to '*get the product right*' for the end user that made my approach to design completely different to that of the other students on the course. It was personally enlightening when I discovered the first article about inclusive design, not only did it seem to encompass the social model of disability that I unwittingly purported to follow, but I could see a link to the need to engage with disabled people.

1.2.2 The Final Research Proposal

After completing a successful transfer viva in January 2002 and considering the internal examiners comments, I approached my supervisors with the third and final proposal for the successful completion of a PhD. I maintained that the information from the first phase of the project should be used to develop a design resource for designers to use when designing for disabled end users, rather than a questionnaire. My rationale for this was that a questionnaire would provide statistical evidence of access issues, but that a design resource could potentially be useful in convincing designers that communication with disabled end users would not be as difficult as they might perceive it to be.

Using inclusive methodology successfully enables the development of products, services and environments that can be used by any member of society regardless of race, gender, sexuality, age or ability, but communicating with different members of the population is not always found to be easy. This was reiterated through the literature review, focus group data and personally through experiences from both my private and

working life. A prime example of this was an occasion when I was in the company of someone who had motor neurone disease (MND) and someone asked them if they would like a drink. “WOULD – YOU – LIKE – SOME - THING - TO – DRINK” was shouted at the person with MND, each word enunciated in a monotone style with the questioners head bouncing up and down with the rhythm of the words. Those of us who were party to the event were so dumbfounded that we could not respond. This example is extreme, but it illustrates how some members of society perceive people who have a physical disability as having some type of mental impairment, broken body = broken brain.

It was agreed by my supervisory team in the summer of 2002 that I would develop a resource to assist designers with designing for disabled end users which would accompany a model for inclusive design. The resource would advocate the use of a participatory approach, and ensure the endorsement of empowerment and inclusion for disabled people.

1.3 Employment, Teaching Practice and Voluntary Work

While completing my PhD I was a self funding student and had to work to ‘*pay the bills*’. During the first two years I worked in the University library shelving books while completing two teaching certificates. One of my teaching placements was at the day centre where the first focus group was held and where I completed the majority of my fieldwork. During the course of several weeks I developed and taught woodworking techniques to a group of disabled adults. I was also required to assist at lunch time with the distribution of dinners and general tidying duties in the dining room. While I was a volunteer the day centre service users talked to me about many issues surrounding disability. They told me that they enjoyed having someone to talk to who didn’t work for social services, but was interested in what they had to say. Substantial amounts of information acquired at this time could not be used for research purposes due to ethical considerations, but the information helped to validate my reasons for completing the study. The placement also helped me obtain a job as a Day Service Officer working for elderly day services with social services. Experiences from this job further validated my research although, again, I could not use examples of specific incidents that occurred in my work environment for the purpose of the study. However, I was privy to several conversations about accessibility issues within the geographical area in which my study

was located, and countless dialogues concerning discrimination towards elderly and disabled people. In December 2002 I changed jobs again and began working at the Macmillan unit at Christchurch Hospital. Again, I was party to many incidents that validated my study through both discriminatory and accessibility issues which cannot be used for research purposes. However, on a weekly basis we took patients out for short trips and as an activities leader these were left to me to organise. The organisation of these trips enabled me to endorse many issues raised in the study particularly as I had to consider access issues for patients who needed to use wheelchairs.

In January 2004 my encounters with incidents that validated my thesis concluded when I became a voluntary member of a local access group. The group was comprised of local disabled and able-bodied people who are trained to complete access reviews for both environmental access and service provision. The group also promoted the needs, views and requirements of disabled people. During training courses and attending meetings for the access group I was able to reinforce my assertions about how discrimination, societal prejudices, access issues and inclusive design methods affect the equitable lifestyle disabled people desire. At the time I considered it to be the culmination and authentication of eight years research and something I could never have anticipated.

In April 2005 I changed jobs again and became the Consultation / Participation Officer for the local charity that facilitated the access group. Until January 2006, I worked with disabled people, for disabled people, working on a daily basis enabling disabled people to take empowerment and to strive for the equitable lifestyle they desire. The post was funded by a service level agreement with social services and included the need for research with local disabled people and the development of a training course to enable local people to become far more involved in the development, planning and implementation of local services. During the ten months I was in post I was able to utilise many of the principles I had theorised about while completing this thesis. I was able to influence local planning decisions and to promote local disabled peoples' needs, requirements and views. I was also able to make use of some of the sections / information used within the design resource when I developed a presentation that was given at local disability seminars.

CHAPTER TWO – SETTING THE SCENE

This chapter outlines the study and its two distinct phases. The discussion attempts to encapsulate issues of discrimination and oppression encountered by disabled people. It considers how popular constructions of disability have established a relatively powerless and deviant status for the disabled population compared to their able-bodied peers. Throughout this study emphasis has been focused on the social model of disability and its paradigm that purports to the “...structural handicapping effects of a society geared towards able-bodiedness as the norm” (Hughes 1998, p.77).

One area where disabled people are most disadvantaged is within the built environment (Imrie 1996). Physical, social and attitudinal barriers prevent ease of mobility. Pavements are littered with street furniture, commercial and public buildings require adaptations for ease of access and accessible public transport is the exception, not the rule. Regulatory controls and legislation require that builders and designers are sensitised to the needs of disabled people, but even with the advent of the Disability Discrimination Act 1995 (DDA), there is no legislative process to endorse disabled peoples request for a fully inclusive and accessible lifestyle.

The chapter advocates that inclusive design, and its techniques, can help lead to the “...necessary changes in the social relations of development and design processes” (Imrie and Hall 2001, p.18) that disabled people aspire to. The use of services such as public transport, shops, cinemas/theatres, restaurants, banks, libraries and public toilets are something most able bodied members of society use regularly and easily yet “...disabled people cannot take access to such services for granted” (Disability Rights Task Force 1999, p.53). Few practitioners within the property industry are sensitive to the needs of disabled people when designing buildings and as a result examples of fully accessible areas are rarely seen (Imrie 2003). Imrie and Hall (2001) discuss how a lack of engagement between designers / developers and disabled people overshadows knowledgeable and good practice. They assert that designers and developers need to change their understanding that disability is “...impairment-specific and a medical condition that can be cured through cure and rehabilitation” (Imrie and Hall 2001, p.143). The concept that an individual disabled person’s personal difficulties are the reason why areas are inaccessible must be challenged if comprehensive rights of access are to be realised.

2.1 The Research Questions

Design is a disciplined practise. Designers require unambiguous answers to specific questions to ascertain the needs and requirements of the market they are designing for. However, a change in the relationship between the end user and the designer needs to occur if the principles of inclusive design are to be consequential. This study maintains that, when designing for disabled people, designers need to look beyond products and producers, and consider the views of the end users, the ‘experts in the field’, disabled people themselves. This poses the question: how can designers become more inclusive?

Twenty first century design discourse is changing to purport a more inclusive design methodology. Both universal and inclusive design perspectives are challenging mainstream design, and the way disabled and elderly people are excluded from the design process and the considerations of the designer (Keates *et al.* 2001). Oliver, a prominent disability activist and researcher, contends that ‘Disability cannot be abstracted from the social world which produces it’ (Oliver 1992, p.101). If this principle is to be assumed, and this study purports that it should, then designers will require an understanding of disability issues in order to produce designs that take into consideration the requirements, needs and desires of disabled people. This study further contends that the only way designers can truly include disabled peoples needs and requirements within the design of a product or service, is to consult with the end user throughout the design process. This presents the conundrum: how should designers engage with disabled people to ensure their views are incorporated in the final design of products and services?

In the field of design research, social and participatory paradigms are new concepts, and the power balance between researcher / researched relationships is still weighed in the favour of the researcher. It is this relationship that this study addresses and asks the question: if traditional design methodology draws upon approaches which involve end users, would the resulting procedure enable designers to advocate an inclusive design paradigm, where the emphasis is on utilising the knowledge of the ‘experts in the field’, the end users themselves?

The aim of this study, therefore, is to develop an innovative new procedure for designers to utilise when designing for people with disabilities. The debate will examine current design practice and consider how present processes and procedures need to be adapted to enable the integration of end users within the design course. While the dialogue examines how researchers of the social world engage with service users and participants within the research process, similarly it considers past and present design methodology and how intrinsically designers work. The study further deliberates upon the views and requirements of designers and disabled people regarding access within the built environment, and acknowledges the differences of opinions and views. The debate then considers the perspectives of designers and disabled people, and proposes a user-centred design process which incorporates a resource for use when designing for disability.

2.2 The Study

Wheelchair users account for less than 5% of the disabled population, but disability is frequently not considered as being '*real*' unless a person is sitting in a wheelchair. This is compounded by the internationally recognised symbol for disability being a line drawing of a wheelchair. This symbol is a contentious issue for many disability groups, but as there is no alternative at present it remains the world wide emblem of disability.

The study is divided into two phases. The first phase of the project used a qualitative approach to ascertain the views and issues surrounding access problems for wheelchair users in a specific locality. The use of qualitative methods ensured that the information obtained was from the 'experts' in the field, disabled people themselves, and not entirely from literature or able bodied people purporting to be specialists.

The second phase of the project considered issues raised by participants of the first phase and developed a model of inclusive design and a resource for use when designing for disability. The model and the resource emphasise that end users, the experts in the field, should be consulted throughout the design process.

2.3 Disability and Oppression

As we enter the third millennium disabled people are still encountering oppression, discrimination and exclusion from the mainstream of economic and social life.

Individuals with varying disabilities still have difficulty performing many of the everyday activities that their able bodied peers take for granted (Bynoe *et al.* 1991; Barton 1996; Oliver 1996; Barnes 1991; Barnes *et al.* 1999; Shakespeare 1998). Disability writers and academics have done much to promote disability, but disabled people are still the most oppressed minority in both Europe and USA (Hale 1983). While age, race and gender have terms to describe prejudice (ageism, racism and sexism) disablism has not appeared in popular discourse and disability is still not considered to be a civil rights matter (Marks 1999; Thompson 1993). In recent years disability issues have become a major subject for political protest and many countries, including Great Britain, have introduced a legislative framework to reduce discrimination felt by the largest minority sector in society (Hale 1983). Despite several attempts to introduce legislation to help disabled people, none to date have been as successful as those designed to tackle gender (Sex Discrimination Act 1975) or race (The Race Relations Act 1965 and 1968). At the time of writing this thesis, the efficacy of the DDA has yet to be decided. However, no matter how comprehensive and enforceable civil rights legislation may be, it has to be recognised that a great deal of discrimination is rooted within culture, where what we learn as children remains with us for the rest of our lives (Banks 1999; Oliver 1990, 1991; Barnes 1994).

For most of the twentieth century disability was viewed as a personal tragedy (Oliver 1990). It spanned an era where individuals were ‘crippled’ or ‘confined’ to wheelchairs. People were ‘victims’ who ‘suffered’ from ‘mental illness’, ‘mental handicap’, blindness or deafness and other conditions that affected their physical / mental state (Barnes and Mercer 2003). Many were segregated, institutionalised (Morris 1991) and generally considered a ‘burden’ on society (Oliver 1990, 1996; Barnes and Mercer 2003). During the 1960s there was a call for change which was led by disabled people forced to live in institutions (Hunt 1966). Independent living in the community and the support this needed was high on the agenda, as was the condemnation of ‘second-class citizen’ status which many disabled people felt they had (Oliver 1990, 1996). For the first time social and environmental barriers were considered to be a ‘disabling’ factor for people with impairments (McConkey and McCormack 1983; Oliver 1996).

2.3.1 The Social Model of Disability

During the latter part of the twentieth century researchers, academics and disability activists campaigned to educate society to recognise the social model of disability rather than the medical one (Finkelstein 1975; Barnes 1991; Oliver 1990). They contended that although there is a need to appreciate an individual's medical condition, it is equally, if not more important to acknowledge that society itself disables a person (Finkelstein 1975; Barnes 1991; Oliver 1990, 1996). Whereas the medical model had focused on the impairment rather than the person, the social model offered a new paradigm for understanding disability, where the person was disabled by society. However, recent writing by academics who originally endorsed the social model now criticise it as being "...no longer useful at the beginning of the twenty-first century" (Shakespeare and Watson 2001, p.22). Suggesting that now is the time to move on from this model which was developed in the early 1970s and that "...everyone is impaired, not just 'disabled people'" (Shakespeare and Watson 2001, p.25). The notion that we are all in some way impaired, either constantly or periodically during our lives, is a central theme throughout this study. This was highlighted in the choice of sample for the qualitative investigation section during the first phase of the project where participants were chosen who had previously been able-bodied. This meant that participants could view issues '*from both sides of the fence*', both as a non-disabled person and as a person dependent, either wholly or partially, on an inanimate object, their wheelchair, to aid their mobility (Safisios-Rothschild 1981)

Illness, frailty and mortality are issues that Western culture and traditions dictate we avoid or ignore (Kübler Ross 1970; Shakespeare and Watson 2001). Our own mortality and the onset of old age are issues we choose to rebuff. Making provision for future events, such as the onset of disability, is something few of us ever seriously considers (Jolley 1996). Shakespeare and Watsons (2001) paradigm maintains that "everyone is impaired" at some time in their lives. Whether through a broken limb, the commencement of a permanent injury or physical disability, or the onset of old age, at some time in our lives we will all have some kind of impairment, even if it is only for a short period of time (Jolley 1996).

2.4 Disability and the Built Environment

Russel (1999) describes the built environment as being huge, but it is made up of buildings, streets and places which are often inaccessible to disabled people (Imrie and Wells 1993). During the course of a day the majority of us will need to negotiate the built environment. We are totally immersed in its effects and its design as 90% of our day is spent inside artificially constructed surroundings (Russel 1999). The majority of these environs are traditionally designed and constructed for the able bodied sector of the community, with little or no consideration for the less able, visually or hearing impaired, or the elderly (Holmes-Sielde 1996; Barnes *et al.* 1999; Imrie 1996a). However, if Shakespeare and Watsons (2001) paradigm is accurate then at some time in our lives all of us will have difficulty negotiating an entity which surrounds us for the majority of our day (Russel 1999).

2.4.1 Inclusive Design

Inclusive design has much in common with social design (Imrie and Hall 2001), where the fundamental principal of the process is to work with people rather than for them. It develops the principles of universal design and endeavours to "...develop the social relations of the design process" (Imrie and Hall 2001 p.18), whereas traditional design approaches 'add' accessibility to inaccessible situations (Connell and Sanford 1999). Imrie and Hall's (2001) research and evaluation of property professional's attitudes towards people with disabilities appear shocking. They repeatedly highlight the need for designers, developers and architects to consider "...the possibilities for the development of an inclusive design philosophy underpinned by current ideas about civil rights" (Imrie and Hall 2001, p.144). Proponents of inclusive design assert that users will "...have the ability to take control of their environments" (Hatch 1984, p.4), a concept that assimilates with the social model of disability (Shakespeare and Watsons 2001).

"The ability to take control of environments" (Hatch 1984, p.4) is something able bodied members of society accomplish regularly. Moving around the built environment with relative ease is achieved on a daily basis. Researchers view disabled peoples estrangement from the built environment from a variety of standpoints. Societal attitudes (Imrie and Hall 2001), the weakness of disabled people's organisations (Barnes 1991; Drake 1999) and the absence of strong regulatory control (Gleeson 1999; Imrie 1997) are factors that create disabling environments. However, little research to

date has looked at the production of disabling environs by the property development process itself (Imrie and Hall 2001; Imrie 2003).

During the design and development of the built environment, professionals must attend to the needs and views of disabled people, rather than exclude them from the process. This study looks at how designers should incorporate other people's views and needs into the design and development process. These outside influences are fundamental to the design process, and to the final design, if the views of disabled people are to have any credence.

In summary, the issues raised surrounding disability and oppression and ways in which inclusive design can, and should, assist disabled people in their quest for a more inclusive and fully accessible lifestyle, are discussed in the following chapters.

CHAPTER THREE - LITERATURE REVIEW - DISABILITY

This chapter explores issues surrounding the field of disability. In particular it considers historical and cultural aspects of disability, civil rights and the nature of the oppression that disabled people encounter in everyday life. Terminology and imagery of disability are contentious themes that are recurrent throughout the study and they are discussed here in depth to enable the reader to gain further insight into the world of disability and the discrimination with which disabled people live.

The social and medical models of disability are summarised to enable the reader to understand their central philosophies and how they differ. The models and their relevance to this study are discussed throughout the following chapters, however, they are compared here to allow the reader to begin to understand how, and why, the social model is an important theme throughout this study.

The chapter concludes by reflecting on the merits of disability research and how non-disabled researchers can validate their involvement in a subject that has to be experienced to be fully understood (Drake 1997; Branfield 1998; Duckett 1998).

3.1 A History of Disability

To understand and appreciate any form of disability study, it is beneficial to know a little of the history of disability and how modern day attitudes have been moulded by past mis-understandings of disability and 'handicap'. This is particularly relevant for designers if their attitudes towards design for disability are to change and they are to adopt inclusive design methodologies.

Prior to the advent of scientific and medical discourses, disabilities were seen as mythical entities (Woodhill 1994; Braddock and Parish 2001). The ancient Greeks regarded children with visible disabilities as a disturbing message from the gods. These children were returned to the gods as an offering and often left to die in what we might consider in contemporary society, appalling circumstances (Braddock and Parish 2001; Barnes and Mercer 2003). They were offered as a sign of penance and people hoped for forgiveness. Oliver (1996) believes that contemporary attitudes towards people with impairments have their roots in these ancient beliefs. The ancient Hebrews saw disabilities as imperfections and refused to allow disabled people access to the temples

as they were deemed to be 'incompatible' to the sacred (Woodhill 1994). During the Middle Ages disabled people were the subject of superstition and persecution (Barnes 1991) and in Medieval Europe disability was associated with witchcraft and evil. Negative views and understandings about disability do not only occur in European culture, in Hinduism, where there is a strong belief in reincarnation, disability is regarded as a transgression in a previous life. Disabled people are avoided and urged to lead virtuous lives '*this time around*' (Schriner 2001). However, this is not the case in all countries. In parts of Africa people talk about God's will with a more positive emphasis than Europeans. Parents would consider it an honour to give birth to a disabled child and that God had entrusted them to take care of a special person (Schriner 2001).

Bredberg (1999) contends that modern day Christianity has a two handed view of disability. On one hand the disabled are viewed as tragic, sufferers who need all the help they can get with the good Christian who lends a hand gaining favour with God (Fawcett 2000). While on the other hand, the disabled are seen as a punishment for a sin, especially the sins of the parent that have been passed onto the children (Bredberg 1999). The modern day application of this '*old wives tale*' is the belief that '*what goes around comes around*' and that the onset of disability later in life is retribution for sins committed in earlier life (Barnes and Mercer 2003). However, much of modern day theological teaching advocates love and acceptance, and the advent of the DDA also means that "...churches can make sure they do not discriminate by considering their approach towards disabled people" (Dickens 2004, p1; Adams 2006)

The Old Testament describes disabled people as '*impure*' and '*tainted*' and the majority of Leviticus is devoted to physical and mental perfection (Lev.21 16-20; Barnes *et al.* 1999; Braddock and Parish 2001). Catholicism however, encourages the views of disabled people, especially those with learning difficulties who are seen as '*holy innocents*' who are pure and unsullied by temptation, although it has only been in recent years that they have been allowed to take certain sacraments. As the Christian church in the past has had such a profound effect on the beliefs of Western society, the myth of disabled people and 'impurity' has never really been challenged (Oliver and Barnes 1998). Historically, there has in fact "...never been one simple message about disability in Christianity or in other world religions" (Hughes 1998 p.59).

The situation is compounded further by the physical barriers which block access to many Churches. Resulting in disabled people denied the opportunity to participate in religious services or dependent upon able bodied members of the congregation to lift a wheelchair into the church prior to a service taking place.

3.1.1 Philosophical Enlightenment

Revolutionary changes in thinking that came about in Europe in the seventeenth century were to change the lives of the disabled community forever (Braddock & Parish 2001). This '*Age of Reason*' or '*Enlightenment*' drew heavily from the contributions of Francis Bacon, Isaac Newton and John Locke and became the intellectual platform for the rise of contemporary Western civilisation. Changes in attitudes, literary work, interest groups, voluntary charitable societies and new institutions were generated from the Enlightenment's sensationalist school of philosophy (Woodhill 1994; Braddock & Parish 2001). This innovative school was also responsible for a change in the care and treatment of people with disabilities through two principal themes of Enlightenment thinking. The first, a new belief in the value of education spearheaded by John Locke (1623-1704), was that experience and reason were the source of all knowledge (Parmenter 2001). A notion that moved away from the beliefs of divine punishment and innate ideas, and moved towards social and environmental modification to improve both humans and society as a whole (Locke 1690 cited Braddock & Parish 2001, p.24). The second was the concept of the advancement of the species through natural science (Braddock & Parish 2001). The emerging 'sensationalist' philosophies provided new and innovative ways of thinking and the analysis of social problems, including the interconnected dilemmas surrounding disability and poverty

3.1.2 Disability in the Twentieth and Twenty First Centuries

Prior to the twentieth century, disabled people were segregated into institutional settings which continued to some extent until in the 1950's when the conditions of workhouses were questioned by a far more conscientious society (Braddock & Parish 2001). Attitudes towards disabled people changed dramatically during the first half of the twentieth century due to the increase in disabilities because of the Boer and the First and Second World Wars (Barnes *et al.* 1999). Many men who left their loved ones returned a shell of their former selves. There was an employment and rehabilitation programme set up for adults after the second world war, and in 1944 the Disabled Persons Act

(Employment) was developed to improve and secure employment rights for the disabled (Toplis 1975). Unfortunately this Act was more concerned with the attitudes of employers than the rights of disabled people (Oliver and Barnes 1998) and the 1944 Education Act did little to assist the integration of young disabled people as it established segregated special needs education. Since the 1950's successive governments have tried to reduce the number of people in segregated institutions, a trend which took an upward turn in the 1960's when the government of the day announced it intended to reduce the number of beds in mental hospitals by half. By the late 1960's it was apparent that there was a need for drastic reform to counter the effects of discrimination against disabled people and 1970 saw the introduction of The Chronically Sick and Disabled Persons Act (Barnes and Mercer 2003). The Act proved ineffective at meeting the needs or rights of disabled people, and the frustration of the disabled community was enhanced by the 1975 Sex Discrimination Act and the 1976 Race Relations Act. The success of these acts compelled disabled people to demand similar legislation with the principle of equality being enshrined in law. However, it took two decades of campaigning to persuade the government and policy makers that a comparable Act was necessary for the disabled community, and in 1995 the first part of the Disability Discrimination Act was implemented.

Cultural changes in Europe have evolved over the last few decades and, whilst it is true that certain aspects of disability have become less hidden, British society has still got a long way to go before disabled people can say they have the integration they desire and which other European citizens in Sweden and Denmark, for example have already secured (Bynoe *et al.* 1991). Elsewhere, it remains the case that disabled people are "...still the poorest of the poor in all countries" (Swain *et al.* 2003, p.164). Many countries still banish disabled inhabitants to institutions, where the unseen can soon become the forgotten (Frost 1999; Jones 1999; Stone 1997; Stone 1999).

3.2 Disability and Citizenship

3.2.1 Civil Rights of Disabled People

The British campaign for civil rights for disabled people began in earnest in the early 1980's, with the formation of VOADL (Voluntary Organisations for Anti-Discrimination Legislation) which brought together large organisations of disabled people. Both British Council of Disabled People (BCODP) and Royal Association for

Disability and Rehabilitation (RADAR) joined and ensured that the concerns about disabled civil rights were heard through a large organisation rather than several smaller ones. This added considerable weight to disabled people's struggle for equal treatment in the UK (Oliver and Barnes 1998). During the period 1982 to 1995 there were thirteen attempts to get some kind of anti-discrimination legislation through parliament to protect the civil rights of disabled people. Many activists argued that no matter how comprehensive and enforceable any civil rights legislation may be, discrimination against disabled people would not be combated by parliamentary legislation alone (Oliver 1990, 1991). Instead, political action was regarded as necessary to achieve civil rights for disabled people, not pure legislation (Barnes and Oliver 1995). By the mid-1990's all of the major political parties recognised, and agreed to, the need for legislation for disabled people. In 1994 the Conservative Government introduced a bill that was enacted as the Disability Discrimination Act (DDA) 1995 (Barnes and Mercer 2003). The value and potential attainment of this act has yet to be established.

According to Marshall (1950 cited Barnes and Mercer 2003, p.117), social, political and civil rights constitute the basis of modern citizenship. Society in general still has deep rooted inhibitions towards individuals and groups within society that are perceived to be different from '*the norm*'. Disability, especially physical disability requiring the use of a wheelchair, does not automatically mean that a person has a younger mental age or that they are incapable of communicating as well as their able bodied peers. Many disabled people are more than capable of taking part in decisions that not only affect their personal welfare, but to participate in key functions of society such as political debate, religious observance and issues that create or re-create the contours of society (Drake 1999; Powell 1999). Disabled people also have diverse social and cultural identities (Barnes *et al.* 1999; Barton 1996; Marks 1999; Morris 1996) and it is these cultural identities and their positions in society, which shape how an individual's disability is perceived by society. However, although Vasey (1989) notes that

...ultimately, disability culture should be recognised as one of the many strands running through contemporary multi-cultural society
(Vasey 1989, p.5)

Humans fear, stigmatise and shun (Gartner and Joe 1987) and there is a similarity in the experience of disabled people and 'racialised' groups in the sense that they both suffer from people's prejudices and expectations (Goffman 1963). Individuals with physical

impairments are often perceived as also having a learning difficulty, even if they do not, just as an individual with non-white skin may be categorized to be an under achiever in the classroom. Woodward (1997 cited Barnes and Mercer 2003, p.130) believes that an individual should celebrate their difference. Thus, whether gay or lesbian, disabled, a member of an ethnic minority or a 'woman in a mans world', standing up and being proud of ones individuality can be an important part of self (Servian 1996). The BCODP, along with many disability activists advocate this. The term 'disabled people' is encouraged rather than 'people with disabilities' as it is perceived as sounding like an apology than a statement of individuality. However, many disabled people themselves, along with various voluntary sector organisations, prefer the latter terminology.

Parental influences, peer values, society's views and the media affect the way children perceive the world in which they live. If a child grows up where disability is involved in their life in a non-stigmatised way, their perceptions will be different from those where disabled people are portrayed as being in need of pity. A child's future reactions will be influenced by this early education. Societal attitudes must change if Vasey (1989) is to realise her dream of disability being "...integrated into mainstream culture" (Vasey 1989, p.6), and change must begin within the home.

Local authorities and social service departments increasingly promote an independence driven philosophy since the implementation of the DDA. Independence and empowerment are promoted to the utmost, yet it must be noted that empowerment is something that only people can do for themselves (Oliver and Barnes 1998), and a major challenge for health and social care workers is deciding who is best placed to make the decisions about other people's lives (Braye and Preston-Shoot 1995). In some cases, where a person is unable to answer or think for him or herself due to the nature of their disability, it may be necessary for others to make some decisions on their behalf. However, many disabled people are more than capable of making most, if not all, decisions themselves and request the right to do so. This ability to make their own decisions is important to continue an individuals feeling of self worth, particularly if a person has become disabled following a previously able bodied lifestyle. Empowerment to make decisions can, in some cases, compensate for feelings of frustration and inadequacy felt by many disabled people. However this is not the case for all disabled people, and the insistence by others of empowerment, can be perceived as an act of

disempowerment, as for insisting that an individual be empowered, is to ignore rights to personal empowerment in the first place.

An associated difficulty that disabled people experience (Banks 1999), is that they are often silenced from speaking personally by 'others' who claim to speak on their behalf. These 'others', advocates and researchers, have frequently discounted the skills and knowledge of the disabled, by professing to 'know better'. Although people with disabilities have campaigned for the right to make their views known, society, with its beliefs about disability still firmly rooted in the past, prefers to give the right to voice these opinions to non-disabled advocates (Rioux and Bach 1994). However, Beresford (1999) argues that by developing an emancipatory research paradigm, disabled peoples' movements have demanded changes in social relations in mainstream research. He further argues that this increase in the role of participants in disability research has consequently led to discussions and the development of user-led and user controlled research (Beresford 1999).

Nevertheless, disabled people are still endeavouring to claim their rights as equal members of all communities through their own social movements. Advocacy, through the use of culture, the media, religion and schools, should take all the opportunities available to challenge the image of disability. The inclusion of disabled people (Barton and Oliver 1997; Marks 1999; Priestly 1999) into mainstream economic and social life is a major issue for policy makers and politicians. Since the 1980's disability activists have endeavoured to portray disabled people as an oppressed minority rather than a needy, dependent one. The new 'social movement' among disability activists has rallied support to change the law which in turn can overcome discrimination in welfare rights, employment, housing and social policy. They have sought to dispel the common myth that disability equals dependency to independence for disabled people, where independence is taken to mean disabled people taking control of their own lives (Hughes 1998).

Whilst it should be acknowledged that societal oppression has improved in recent years, there is still a disparity between disabled people, mainstream society and equitable inclusion. In January 2006, Massie observed that

Things have got better for some disabled people; but in important areas the distance between the living standards, opportunities and life chances of disabled people and the rest of the population has widened.

(Massie 2006, p.1)

Massie was scathing in his speech towards a society that he claims

...has chosen to see having an impairment or long-term health condition as the point at which people should be exempted from the ordinary responsibilities of citizenship

(Massie 2006, p.6)

He concluded by stating that for society to move forward, no sector of the community should be forgotten or left behind, and that everyone should play their part in full.

Massie further argued that successive governments are to blame for holding disabled people back, by failing to break the cycle of low expectations that disabled people have. “Despite positive steps in some areas, public policy is in danger of leaving disabled people behind” (Massie 2006, p.1). He also maintained that twenty first century media are still partially responsible for misshapen perceptions of disabled people. With an ever increasing aging population (Bellerby and Davis 2003), people with impairments, and individuals with long term health conditions, the core ambitions for Britain should be equality, inclusivity, empowerment and accessibility for all. This can only be achieved through Massie’s contentions that commitment to equality and social justice must occur through change in public policy and participation of disabled people in civic and political life (Massie 2006).

3.2.2 Age, Gender and Disability

Disability and old age are aspects of identity with which gender is entwined (Morris 1996). There is nothing glamorous about growing old or being physically disabled. Women, although they have the vote, are still treated as second class citizens by some, whilst in ‘a mans world’ a man in a wheelchair is not a ‘man’ at all. Shakespeare (1994) explores the prejudice underlying cultural representations through a variety of theoretical models. One viewpoint he discusses is through the feminist writing of Simone de Beauvoir and her book *The Second Sex*. De Beauvoir argues that the position of women is not natural or biological, but cultural and contingent, that men construct themselves in opposition to women and that women were the ‘generalised

other' within human culture. It is not the description of her feminist writing that is intriguing, rather Shakespeare's suggestion to substitute 'disabled people' for the women in the argument. He does not deny what de Beauvoir says about women, but considers that disabled people could be regarded as 'other' by their visible connection to nature, the physical constraints of their bodies and the constant reminders of the mortality of the human race. It is this reminder of human mortality that 'scares' able bodied peers into many of their misconceptions of disability. This sense of being scared, combined with misunderstandings about disability, are where prejudice begins.

3.2.3 Sex and Disability

Disabled people are often seen as being asexual and disabled young people in particular are not regarded as potential partners by their able bodied peers (Barnes *et al.* 1999; Morris 1991; Shakespeare *et al.* 1996). It is generally assumed (Barton 1996) that disability is a medical tragedy in the realms of love and sex, and individual sexuality is undermined. Professional services do not take sexuality and disabled people seriously and there is an absence of work around sexuality within the disability movement. These factors do nothing to help the image of disability. Just as public displays of same-sex love are met with disapproval, so is a public show of affection by two disabled people. Beauty, independence and potency are central to sexual confidence leaving physically disabled people feeling totally undermined. Men in wheelchairs are often constituted as impotent (Marks 1999) and the imagery of disabled people by the media does nothing to assist the cause for social integration.

3.3 Models and Definitions of Disability

Llewellyn and Hogan (2000) describe models of disability as being

...a particular type of theory, namely structural, which seeks to explain phenomena by reference to an abstract system and mechanism
(Llewellyn and Hogan 2000, p.157)

The models themselves do not constitute an explanation about disability but they do help in generating a narrative.

3.3.1 Medical Model of Disability

By the beginning of the twentieth century, the diagnosis and solution to disability was firmly entrenched in medical knowledge (Barnes *et al.* 1999). The focus of a person's

disability was their body's functional limitations due to their impairments, or their intellectual 'abnormality' (Barnes *et al.* 1999). This conceptual framework allowed disability to be experienced, assessed, understood, planned for and justified (Llewellyn and Hogan 2000; Swain *et al.* 2003). Individual impairments were, and still are, perceived as being culturally undesirable, as their limitations signified disorder, indiscipline and unreliability. Impairments were considered something to be hidden, cured or overcome. They portrayed human bodily weakness and in turn the fallibility of the human race (Swain *et al.* 2003). The imposition of disability, by non-disabled people on disabled people, was reflected in the framework of the medical model which in turn reflected and reinforced concepts about individuals and their roles in society.

3.3.2 Social Model of Disability

In 1976 The Union of the Physically Impaired Against Segregation (UPIAS) pioneered an alternative model of disability to the medical model which became known as the social model of disability. The model was formalised by Finkelstein (1980) and Oliver (1990) and is now codified as the central principal of the disability movement (Shakespeare and Watson 1997).

Within the social model of disability, disabled individuals find they are oppressed by societal views of normality (Llewellyn and Hogan 2000). The model resolutely repositions the problem of disability away from specific individual impairments, and back into society's collective responsibility. Disabled people, their organisations and disability researchers use the social model as a basis for drawing attention to the real problems of disability. These barriers include, patronising attitudes, low expectations that are invested in disabled people, limited options compared to able-bodied peers and the physical environmental barriers which prevent their ease of mobility, movement and access (Imrie and Hall 2001).

The social model epitomises the knowledge that is inextricable from the experiences of disabled people (Beresford 2002). Its employment within policy making processes is fundamental for the inclusion of disabled people within mainstream society. Whilst it has to be acknowledged that the social model and its principles are accountable for many welfare reforms in recent years, the success of the social model within policy improvements, the development of Centres for Independent / Integrated Living (CIL)

and Personal Assistance Support (PAS) has caused controversy within some local authorities (Priestly 1999). The social model has, in fact, indirectly instigated some local authorities to "...see self-managed disability services and direct payments as a further assault on the traditions of public sector accountability and management" (Priestly 1999, p.117). Which has, in turn, instigated local authorities to be more amenable to contracting with voluntary and 'not for profit' organisations (DOH 1994, Para. 4.3). Priestly (1999) has further analysed the fit between the implementation by statutory welfare authorities of community care legislation and the goals of integrated living derived from social model thinking. He concludes that local commissioners need to move towards "...a degree of social model thinking" and "...away from the discourse of 'care'" (Priestly 1999, p.120). Priestly further asserts that user control over community care resources should not be seen as an attack on collective welfare accountability, rather than a way for the disabled community to be accountable for their own lives.

3.3.3 *Choice of Model*

The central point of the social model of disability is that it

...provides a critique from which disabled people can argue that the social exclusion they have experienced has gone on for far too long

(Swain *et al.* 2003, p.24)

The model offers an alternative way of understanding the experiences and reality of disability, and provides a basis for explaining these experiences to others. While it should be acknowledged that the social model provides an invaluable tool for disabled people to use in their quest for the same opportunities as non-disabled people, the medical model cannot be completely ignored. Disabled writers, Swain *et al.* (2003), Crowe (1996), Shakespeare (1996) Thomas (1999) and Watson (Shakespeare and Watson 2001), acknowledge the significance of impairment within people's lives. Thomas suggests that while the social model is invaluable to disabled people, it ignores the "...cultural and experiential dimensions of disablism" (Thomas 1999 p.24). Society needs to be 'mindful' of individual's disabilities and the limitations and characteristics specific impairments can cause. An example of this 'mindfulness', would be the comprehension that the body language of a person who has been sight impaired since birth, will not be the same as a person who has, and has always had, full visual capabilities. Another example would be acceptance of swearing as a form

communicating frustration as opposed to gesticulatory body language, from a person whose physical disability prohibited movement.

It can be seen that the social model, and its philosophies, remains a valuable tool for disabled people to use in their struggle for social inclusion, but there needs to be an open discussion about the nature of impairment and an understanding of an individual's experiences of their body. Society needs to accept the diversity that exists within the population and tender provision for the inclusion of diversity, which in turn would lessen labels for minority sections of society.

3.3.4 *World Health Organisation Definitions*

In 1980 the World Health Organisation (WHO) commissioned Wood to expand on the existing 'International Classification of Disease'. He developed The International Classification of Impairment, Disability and Handicap (ICIDH). This classification has since been used as a basis for government initiatives on disability worldwide. Wood (1980) drew heavily on the work of the British governments' Office of Populations, Census and Surveys (OPCS) (Harris 1971) and developed a three-fold typology of 'impairment', 'disability' and handicap'. The classification states that:

Impairment – the loss or abnormality of psychological, physiological or anatomical structure or function.

Disability – any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being.

Handicap – a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for the individual.

(WHO 1980, p.29)

3.3.5 *UPIAS Definitions*

The first definitions produced by an organisation exclusive to people who experience personal disability was developed in 1976 by the Union of Physically Impaired Against Segregation (UPIAS) which advocated a two-tier classification framework. The difference between the WHO definition and that of UPIAS is that the latter locates the causes of disability with society and social organisation (Davis 1993; Barton 1996; Oliver & Barnes 1998). However, the term impairment, like the OPCS definition, focuses on the physical defection of a limb, organism or mechanism.

UPIAS (1976) defined impairment and disability as being:

Impairment: Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.

Disability: The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.

(UPIAS 1976, p.14)

The UPIAS definition (1976) was later extended by Disabled Peoples' International (DPI) to include intellectual impairments, sensory impairments and mental distress (Barnes 1994).

3.3.6 Disabled Peoples Movement Definitions

The terminology adopted by the disabled people's movement in the UK is that of the BCODP. The same terminology was adopted by Disabled Peoples International (DPI) in 1994 and is based on the UPIAS definitions although some of the original terminology has been changed. 'Mental' has been replaced with 'intellectual' and the term 'normal' is a highly contentious issue (Swain *et al.* 2003). The important factor to note is that social acceptability is an ever changing phenomenon and disability issues, as with any minority sector of society, changes constantly. It is also important to acknowledge that the acceptable framework separates the term 'impairment' which refers to a medically classified condition, from the term 'disability' which is a generic term used to denote social disadvantages.

3.4 Cultural Images of Disability

The human body is a subject of popular and lengthy discussion both in academia and popular culture (Frank 1990). Speech, facial expressions, body language and clothing all portray our own personal character and how we are feeling, the mood of the day can be easily be shared with others through the smallest look, gesture or word. These forms of communication may not always be so obvious if a person has a physical disability. A physical disability can prevent the simplest of communication from being easily understood, even when communication barriers are removed and verbal and non verbal communication is no longer an issue. As noted above, the visual image of the individual can be 'disturbing' even 'off putting' to the human eye.

3.4.1 Visual Images of Disability

Discrimination surrounding the ‘aesthetics’ of disability (Hahn 1988) have long been ignored by disabled people. It is difficult for some, especially if they are not used to being around physically disabled people, to take in the visual images that the eye is greeted with (Evans 1988). Yet it should be remembered that at any time, anyone may experience a disabling ailment. This concept of the onset of a major life change is a scenario that humans choose to ignore. Instead we prefer to believe the premise ‘it will never happen to me’, and naively choose to think disability only happens to other people. It is also too easy to ignore the fact that the physical appearance of the person in front of us probably has no bearing on the person behind the disability (Barnes *et al.* 1999). It is the first contact with a person or an object which dictates how we perceive them. Here first impressions count. Gombrich (1982) in his studies in the psychology of pictorial representation concludes that:

Ours is a visual age..... we are entering a historical epoch in which the image will take over from the written word

(Gombrich 1982, p.137)

The redefinition of disability in a more positive manner is what is needed, perhaps with a scenario similar to the ‘Black is Beautiful’ phenomenon of the 1960’s (Hahn 1988; Zola 1993).

Although individual disabilities cannot be assessed accurately through the written form, there is little doubt that disability has been used through job applications as a device for screening out potential candidates in applications for employment (Hahn 1997). There are few physically disabled people in jobs that are in the public eye (Drake 1996). Individuals with damaged or unreliable bodies are deemed as being unable to be strong leaders.

3.4.2 Media Portrayal of Disability

As the portrayal of disabled people by the media affects the way people think about disability, the subject is of great interest to many disability researchers (Susman 1994). Barnes (1992; 1994), Darke (1994), Norden (1994), Gartner and Joe (1987), Cumberpatch and Negrine (1992), Shakespeare (1994), Shakespeare *et al.* (1996) are just a few of the most quoted studies. Disability in the media is largely taboo except for tales of heroism, tragedy or charity adverts, and the few images depicted are negative

representations that are portrayed in disturbing ways. Through the media, society's negative, powerless, deviant status for people with physical disabilities is portrayed through tragic representations and personal misfortune (Shakespeare 1994). Cashing in on the 'tragedy theory' tugs at heart strings and enables charities to gain much needed finance. People's fear of physicality, mortality and death is projected onto physically disabled people. People who are 'different' present a threat of the fear of the unknown (Barnes and Mercer 2003).

3.4.3 Disability Imagery in Literature

In the hands of literary greats the world of the 'crippled' and 'disabled' is a strange and dark world where stories are easily created, a world which is held up for judgement for those who live in fear of it. The portrayal of disabled men is equally damaging. The best known of these is William Shakespeare's Richard III that is taught to many of the younger generation at school. Shakespeare portrays Richard as an animal like character that bounds across the stage, his crutches emerging as a statement of his presence. The character Richard sees himself as a 'deformed, unfinished man' who is self-destructive (Kriegel 1987). This should not be considered an appropriate image of disability for impressionable young minds.

3.4.4 Disabled Imagery through Films

The film industry and many able bodied actors have made fortunes from others misfortunes with films portraying disabled characters. One has to ask why able bodied actors almost always play disabled characters when a white actor would not 'black-up' to play an afro-Caribbean. It is certainly not because equity has no disabled actors on its books. Marks (1999) questions whether it is the '*its only pretend*' scenario which yet again detracts from the reality of disability which society chooses to ignore. To add empathy to the plight of disabled characters, filmmakers portray them in one of two very different ways. Either as courageous individuals overcoming their impairments at any cost, on the other hand they are portrayed as sad individual self indulgents who are unable to overcome their individual problems therefore existing with a sad and pitiful life (Barnes 1992). Characters with disabilities such as Dr. No and Dr Strangelove are vindictive characters whose disability is portrayed as a sinister 'appendage'. The horror factor associated with their hands and forearms' being encased in black leather

accentuates the fact that they were 'crippled' as a consequence of their evils from previous experiments (Longmore 1987).

3.4.5 *Disabled Imagery through Television*

As 98% of British homes have a television (HMSO 1991) the power of media intrusion into our everyday lives is considerable. Visual images of the perfectibility of the human image (Hahn 1997) are beamed into our homes on a daily basis. In recent years, the Broadcasting Standards Council (BSC) has included in its code of practice a "...fair reflection of the parts played in the everyday life of the nation of disabled people" (BSC 1989 cited Barnes *et al.* 1999, p192). Soaps such as *Emmerdale* and *Coronation Street* have included disability within their story lines as a token gesture, but the characters with disabilities are played by able bodied actors. There are a few specific disability programmes, the most popular of which is *From the Edge*, a programme for the disabled featuring the disabled. Physical disability is not 'sexy' enough to appeal to a majority audience and most advertising portraying disabled people concentrates on disabling stereotypes.

3.4.6 *Disabled Imagery and Photography*

Photographers, whatever kind of work they are doing, (Becker 1979) want to be recognised as artists. With this in mind, we, the observer, purchaser, admirer, have to concede that in order to fit into current fashionable styles that the photographer may have made the photograph fit the purpose. In the case of disability the photograph must look tragic to fit the pre-conceived ideas already formulated about disability, particularly physical disability. There are few photographers who specialise in photographing disabled people. Probably the most prominent photographer of disabled people is Diane Arbus. Arbus became known as the photographer of "...freaks" (her words) (Evans 1988, p.46), through her oppressive construction of disability in her photographs (Becker 1979; Evans 1988). Arbus portrayed her subjects as "...a sign of disorder" (Hevey 1997, p.336), a physical manifestation of her own chaos and horror. Before killing herself Arbus admitted that she viewed her relationships with disabled people as "...encounters with souls from an underworld" (Hevey 1997, p.336), rather than social and equal relationships. Not only were her representations purposefully negative, but she abused her relationship with her subjects to obtain the shots she wanted (Hevey 1997).

By contrast, David Hevey's work is described as being

A landmark in the struggle for alternative imagery and empowering process...he is a pioneer in visually articulating the state of the disability movement and its challenges to oppressive imagery

(Langley 1992 [No page number])

Hevey (1997) has empathy towards disabled people as he himself is an epileptic, who 'came out' as a disabled person in later life. His photographs differ completely from those taken by Arbus.

3.4.7 Charity Advertising

The largest disability charities are big and powerful organisations (Drake 1996; Morris 1991) which really only exist because society fails to address the needs of disabled people, but they further demean disabled people and reinforce prejudice by portraying them as deviants. Since the mid to late 19th century charities have been strongly linked with the medical model of disability. Charitable adverts in the 1980's (Hahn 1997) presented a view of disability being contained within the body and the tragedy of impairment, gaining a sympathetic vote and the guilty feelings of the 'more fortunate' able bodied viewers. The deviant portrayal prompted the emotional side of able bodied society to put their hands in their pockets, parting with the much needed money the charity is after in the first place. Fortunately since the mid to late 1990's charities such as Scope and Mencap have recognised the existence of the social model of disability and the medical model with its negative imagery is being phased out. The question is – is it too late to change the image of disability through charity advertising? Charities for disabled people are also often linked to religious organisations and their construction of disability which is often that disabled people cannot be '*cured*' so they need '*help*' and '*moral management*'.

3.4.8 Language and Disability

The use and understanding of language is a key factor in how we define and explain the world around us (Zola 1993). The use or mis-use of words can change a situation or conversation to mean something completely different. The understanding of this concept and present day socially acceptable terms mean that in today's society there is a need to think before we speak. The growing recognition and awareness of social issues has meant many terms are no longer acceptable to be used when describing a disabled person. 'Cripple', 'spastic' and 'mongol' have lost their original meaning and are now

used as terms of abuse. Other terms are still used by the media and in academic literature even though the disabled population consider them de-personalising and unacceptable. Terms such as ‘the impaired’, ‘the disabled’, ‘the deaf’ or ‘the blind’ (Barnes *et al.* 1999). It is difficult to keep abreast of the changing values of political correctness and social service departments frequently update their staff with the latest versions. There is a growing consensus on the oppressive implications of the use of terminology within the disabled population (French 1989; Swain *et al.* 2003). However, it should be acknowledged that not all disabled people feel this way, but while the majority do, it is important to observe the general consensus. Many disabled people dislike the use of the term ‘handicap’ as from historical perceptions it is deemed to represent mental health problems, the workhouse and optimises the ‘cap in hand’ scenario. The translation from some languages of the word impairment has a negative meaning so it is avoided by disabled organisations. It is also argued that much of the work carried out on classifying the definitions of the terminology surrounding disability has been carried out by non-disabled people who have not had the personal experience of disability on a day to day basis (Oliver & Barnes 1998).

The naming and classifying of objects is part of human nature and society’s way of ensuring everything has, and knows, its place (Swain *et al.* 2003). The use of language and badges influence our understanding of each other and the world around us. Burr (1997) describes how language is more than simply a way of expressing ourselves.

It is when people talk to each other that the world gets constructed. Our use of language can therefore be thought of as a form of social action
(Burr 1997, p.7)

Labels are ‘given’ to individuals at various stages during their lifetime, often by people who have power and authority upon those who do not. (Swain *et al.* 2003). Doctors, social workers, teachers and psychologists make judgements and impose labels on people, and are institutionally endorsed to do so. These labels or tags can oppress, control and exclude (Clarke and Cochrane 1998). People label themselves and each other in positive and negative ways. Individuals may be labelled by the school they attended, ‘he’s an old Etonian’, which in some circles would be seen as positive. But the category they fell into at school ‘...has special needs’, could have a long term negative affect on a persons future. People may be labelled by the country they were born in -

‘she’s a yank’, by a person’s sexual orientation - ‘she’s a dyke’ (Swain *et al.* 2003). Names and labels for people with impairments have a dominant discourse of tragedy and inferiority. ‘Sufferers’, ‘victims’, ‘cripples’, ‘the blind’, ‘the deaf’ are descriptions with tragic overtones and are frequently associated with charities. Other labels applied when describing disabled people are ‘extraordinary’ and ‘brave’, which appear to be positive, but are regarded as being negative by disabled people. French (1989) describes the use of such words as:

...either giving rise to the notion that disabled people are superhuman, or that anything they achieve – however minor – is worthy of congratulation and admiration

(French 1989, p.30)

Labels can, and do, evoke stereotyping and discriminatory assumptions. “Label Jars not People” (Swain *et al.* 2003, p.15) is one of the slogans of People First, an organisation of people labelled as having learning disabilities. It is a slogan that sums up how many disabled people, their organisations and disability researchers and activists feel about the terms used when labelling disabled people.

3.5 Disability and Legislation

Legislative recognition of equal rights will not be enough alone to bring about the changes disabled people campaign for (Banks 1999). Although the law can remove barriers, the formalities and structures required to do so effectively can create other barriers, and no matter how concise the law is, it can not dictate the attitudes and behaviour of individuals or organisations. The DDA is the most recent in a long line of legislative attempts to ensure the rights of disabled people. As with the Americans with Discrimination Act (ADA), the DDA is based on an individual, medical approach (Barnes and Mercer 2003), and is complex with many caveats (Swain *et al.* 2003). The act does not amount to civil rights legislation and is full of “...loopholes and phrases such as ‘if it is reasonable’” (DDA 1995, p.7), and ill defined words such as “substantial” (Swain *et al.* 2003, p.158). Discrimination is defined as “...less favourable treatment” (DDA 1995, p.6) and the Act only provides limited protection from direct discrimination from the provision of goods, services and in employment. Prior to the onset of litigation an individual has to prove they have an impairment and originally the DDA had no enforcement agency to monitor its implementation. The Disability Rights Taskforce was organised by the new Labour Government in 1997 which arranged for the Disability Rights Commission (DRC) to be formed in April

2000. The DRC was set up to facilitate "...the elimination of discrimination against disabled people" (Barnes and Mercer 2003, p.121). The DRC has no less than ten and no more than fifteen commissioners appointed by the secretary of state, a budget of £11million and a staff of approximately 150 (Swain *et al.* 2003).

3.6 Disability Research

Twenty years ago there was no such thing as disability studies (Barton and Oliver 1997). Disabled people were beginning to write about themselves and activists were bringing people together to promote disability issues and to campaign for civil rights but disability was not an area of academic interest. Academics finally began to acknowledge that disability studies could and should form part of the academic curriculum during the late sixties and the first course was developed in the 1970's. Since then disability studies have evolved and developed into an academic discipline which really only took off in the last decade of the twentieth century and is now being compared with racist, gay and lesbian and feminist studies. There are now academic journals that support developments in disability studies - Disability, Handicap and Society and Disability Studies Quarterly are the most popular and there are many textbooks and readers are now available.

A further sign of the growth of disability research in recent years is the Internet discussion group Disability Research. Priestly developed the discussion group, which is based at Leeds University, in 1994. It now has a listing of over five hundred member's world wide who debate emergent issues in the field of disability studies (<http://www.mailbase.ac.uk/lists/disability-research>).

Finkelstein's research has helped introduce over 8000 students to "...a different way of understanding human behaviour" (Finkelstein 1998, p.49). He is concerned that the introduction of community care has allowed more direct intervention into the lives of the disabled community, which then maintains the boundaries between disability and normality. In relocating disability into this new field he is resolute that disability studies are now struggling to be recognised as an academic discipline. Finkelstein contends that disability studies should be one of the subjects used to draw attention to the need for topic-based courses and to ensure that the "...academic elite do not avoid the opportunity of our time" (Finkelstein 1998, p.49). Other academics in the field of

disability studies do not agree with Finkelstein. Swain *et al.* (2003) assert that disability studies are “a burgeoning domain of study... evident in the growth of courses, research and literature” (Swain *et al.* 2003, p.1).

Disability writers and academics have done much to promote disability but disabled people are still the most oppressed minority in both Europe and USA. While age, race and gender have terms, names which describe prejudice (ageism, racism and sexism) disablism has not received the same type of recognition and disability is still not considered to be a civil rights matter (Marks 1999; Thompson 1993). The European research community has been influential in the development of disability studies, but not as effectively as its North American counterparts (Priestley 2002). Academics in North America have taken the initiative in defining the field of disability and its research priorities. In 2000 several European researchers decided to move towards a more formal European Network on Disability Studies (Priestley 2002). The aim of this network is to help further the goals of the European policy community. It will focus on five priority areas:

- Identification of disabling barriers to citizenship and inclusion;
- Understanding of disability rights movement;
- Knowledge about disabling cultural values and attitudes;
- Evaluation of disability policies and institutions of governance;
- Development of innovative environments and practices to further the social inclusion of disabled people.

(Priestly 2002, p.848)

The intention of disability research has been to overcome the perceived shortcomings of mainstream social research (Barnes *et al.* 1999). Rather than being guided by professional agendas and policies to assist disabled people cope with their ‘*personal tragedy*’, early disability research attempted to follow the theoretical and political foundations of the social model of disability. Unfortunately this was not always the case. In a scathing critique in 1992 (Barnes *et al.* 1999) Oliver condemned conventional research on disability as having done little if anything to confront the social oppression and isolation experienced by disabled people. He states:

...Disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life

(Oliver 1992, p.105)

In the same article Oliver (1992) discusses the development of the new emancipatory research paradigm, which stems from the rejection of the positivist view of social research (Oliver 1992). A key criticism of research, by disabled people and their organisations, had been the allocation of funding for research projects, and the control the funding bodies and policy makers had on the projects content (Barnes *et al.* 1999). The new paradigm allowed confrontation of social oppression at what ever level it occurred and the ability to challenge existing power relations, making emancipatory research an openly partisan and politically committed method for disability research (Barnes 1992; French 1992). Emancipatory research should not be confused with participatory research (Zarb 1992) and it should be recognised that increasing levels of participation in research for disabled people does not necessarily alter the social relations or challenge research production (Priestley 1999).

The emancipatory paradigm further seeks to change the established relationship between researcher and researched (Barnes *et al.* 1999). Rather than researchers using disability studies as a means of “...advancing their own status and interests” (Barnes *et al.* 1999, p.217), researchers adhering to the emancipatory paradigm should become detached from the researcher-as-expert approach. Barnes (1992) argues that:

If disability research is about researching oppression, and I would argue that it is, then researchers should not be professing ‘mythical independence’ to disabled people, but joining with them in their struggles to confront and overcome this oppression

(Barnes 1992, p.110)

Whilst emancipatory methods offer control and empowerment to disabled people throughout the research process, and accountability to everyone involved (Beresford 2002), it should be acknowledged that this type of open research within a design setting may not be easily feasible. Issues surrounding cost as well as convincing designers of the appropriateness of including end users within the design course are just two scenarios as to the methods limitations. However, illustrating successful examples of how emancipatory research can benefit all parties is a suitable approach to encourage designers to try this new and inclusive methodology. It is encouraging to note that recent literature (Lynch *et al.* 2005) purports the successful utilisation of emancipatory paradigms within the design profession. Examples of the utilisation of social research methods are now emerging. Which, combined with the realisation that the DDA is ‘here

to stay', and continued pressure by advocates within the disability movement and academia, are forging the way forward for inclusive, emancipatory and / or participatory research in the field of disability.

Disabled writers have argued that the researchers should offer their research skills "...at the disposal of disabled people" (Barnes 1992, p.122), "...from them to use in whatever ways they choose" (Oliver 1992, p.111). This would ensure that researchers are engaged directly in the emancipatory struggles of disabled people (Priestley 1999).

3.7 Non-Disabled Researchers

Disability research is dominated by non-disabled researchers (Kitchin 2000). Many disabled people feel that non-disabled researchers might misrepresent and misinterpret disabled people's experiences and knowledge, as they have never experienced disability for themselves. This predicament elicits a need for 'non-disabled' researchers working in disability research to justify their involvement (Branfield 1998). Branfield (1998), who admits to being disabled, is vehement that no matter how positive 'non-disabled' people are towards the disability movement, they cannot possibly understand the socio-political reality of being disabled. She is impassioned that disabled people should be the "...initiators and designers of their own liberation" (Branfield 1998, p.144). Barnes (1992) argues that cultural differences such as life experience, class and education can present as many barriers to a researcher as a disability. Drake (1997) reinforces this when he writes:

I write as a 'non-disabled person'. I do not use a wheelchair, or other aids and adaptations, nor have I a cognitive or physiological impairment, the possession of which would render me vulnerable to pernicious or damaging experiences of social and environmental oppression and exclusion.

(Drake 1997, p.643)

Drake (1997) however, does go on to say that 'non-disabled' people should seek no position of power within the disability movement or to "...lobby on behalf of disabled people" (Drake 1987, p.644). Duckett (1998) has a different view again, and is concerned that Branfield's discourse may lead disability research to a kind of "...binary opposition, female/male, black/white, child/adult, homosexual/heterosexual etc" (Duckett 1998, p.625). Duckett, unlike Drake and Branfield, does not disclose whether he is disabled or non-disabled, and asks the question "Would it make a difference to

how you read this (his) paper?” (Duckett 1998, p.628). He ends his paper by claiming that:

The voices of non-disabled allies *should* be heard, as voices that add to the vociferous activities surrounding the disability movement. We must avoid the oppressed becoming the oppressor, and the children of the revolutions becoming the parents of the oppressors of the future.

(Duckett 1998, p.628)

Kitchen (2000) concludes that although many disabled people agree that disability research is “...alienating and disempowering...” (Kitchen 2000, p.45), the majority of respondents from his study recognised the role research can have in the emancipation of disabled people. Their ideal model for disability research was one of inclusivity “...an equal-based, democratic, partnership between disabled people and disabled/non-disabled academics” (Kitchen 2000, p.45). Non-disabled researchers would be positively welcomed within the model which would be action-and politically-led. The idea being that there is a conscious effort to change social relationships between researchers and researched. Interviewees felt that this model of research would balance “...the concerns of focus, lack of action, the inaccessibility of disability studies literature and levels of representativeness” (Kitchen 2000, p.45). A premise that the researcher concurs would improve the relations of future disability studies.

3.8 Mobility Rights

It can be seen from the literature that cultural and societal views have an impact on the lives of disabled people. Childhood, adulthood and old age is the notion society has of a ‘*normative*’ life course (Barnes & Mercer 2003). These stages are culturally and institutionally produced by family, education and economic influences which define our roles within society. But the introduction of an impairment into the life cycle means that life takes on a very different pattern for the individual and their family and friends. This is an issue that most of us never consider, until it is too late for speculation and impairment unexpectedly becomes part of every day life. The unexpected onset of a physical disability can occur to anybody and the onset of old age can limit mobility causing a complete life change. But as humans these are factors most people choose not to contemplate. The majority of the population expects to move around with ease of access, completing tasks that enable life to be lived as the individual pleases, giving little or no thought to how different life would be if the rights attached to mobility were to cease. Experience of the onset of old age or a physical disability, either personally or

via a family member, allows some insight into the discriminatory world of disability, but often only for a short time.

Disability is shunned and its globalisation is often more negative than positive. But as Barnes and Mercer (2003) state, raising questions about disability ensures that it is a subject that is firmly on the political and academic agendas. The politics of disability are inseparable from social and cultural changes and will have implications for everyone at some time in their lifetime. This study recommends how designers can, and should, ensure that independence of movement around the built environment is inclusive for all members of society.

The key points and conclusions from the literature reviews about disability and design are deliberated in chapter 5. The subject areas are amalgamated in a discussion that develops and advances the understanding of these two very different disciplines, demonstrates how they can combine to help disabled people gain the equality and inclusivity they desire and provides the milieu for the foundation for the study.

CHAPTER FOUR – LITERATURE REVIEW - DESIGN

This chapter provides an overview of the meaning of design and its multi-faceted disposition. It examines the process of designing and how designers affect the world around them with the products they create. The design process is analysed and a case is made for the use of total and inclusive design methods, where the ‘end user’ is a vital part of the design course.

The chapter considers the physical barriers to inclusion experienced by disabled people and how designers can, and should, work towards a design methodology that assists the disabled community in its quest for accessibility. Universal and inclusive design methods are reviewed and inclusive design is shown to be central to the development of the design resource that accompanies this study.

The discussion continues by analysing how people are affected by the built environment in which they live and how person-behaviour-environment relationships, the spatial caste system and social construction play a part in inclusion, or non-inclusion within the world. The chapter concludes by appraising how psychology and geography play a part in human beings understanding and acceptance of the world, how they define territory and how, in turn, territorial segregation establishes the spatial and psychological boundary between self and other whether the self is an individual or group (Weisman 1992).

4.1 Design in Context

Lorenz (1990) asserts that “...design means different things to different people” (Lorenz 1990, p.x). It is a term that conjures up many diverse images. It can signify the way something looks, the way it performs, the way it is developed (Hollins and Hollins 1991; Jones 1992; Otto and Wood 2001) Clothing, fabrics, furniture, crafts, interiors and industrial engineering are just some of the images associated with the word design (Lorenz 1990). Prior to the 1950’s the traditional objective of design was the need to draw, and designing took place on a drawing board. It was a process that architects, engineers and industrial designers completed in order to produce drawings needed for manufacturers and clients (Jones 1992). However, designing has outgrown its reliance upon the mystery of being able to draw. Modern day designing incorporates research and development, product planning, marketing, system planning, purchasing and design

for production. Designers must consider changes that manufacturers, distributors and end users will have to make, or adapt to, in order to benefit from the new design (Jones 1992). The addition of these processes to a designer's repertoire means that designing is now described as "...a multidisciplinary activity" (Hollins and Hollins 1991, p.137).

Design theorists descriptions and definitions of designing differ immensely. Jones considers several definitions in his book *Design Methods* (1992) and concludes that they are "...diverse in description" and produce "...little support to the idea that designing is the same under all circumstances" (Jones 1992, p.4). Archer (1965 cited Jones 1992, p.3) describes designing as "...a goal-directed problem-solving activity", while Page (1966 cited Jones 1992, p.4) considers it to be "...the imaginative jump from present facts to future possibilities". Gregory (1966 cited Jones 1992, p.3) defines designing as "...relating product with situation to give satisfaction" and Reswick (1965 cited Jones 1992, p.4) thinks it is "...a creative activity – it involves bringing into being something new and useful that has not existed previously". All of these quotes refer to what Jones describes as design 'ingredients' rather than design outcomes. He maintains that whether the design is successful or not, society will not be the same as it was before the emergence of a new design. Therefore, the effect of designing "...is to initiate change to man-made things" (Jones 1992, p.4). A simple, but universal definition, that defines succinctly a process that has changed dramatically during the second half of the twentieth century.

4.2 The Bauhaus and its Influence

The Bauhaus, led by Gropius, was established in 1919. It was an organisation that developed a set of challenging theories that went beyond mere functionalism and whose impact reverberates today (Lorenz 1990). The Bauhaus ideas, students and designs were considered to be five to ten years ahead of their time (Bayer *et al.* 1938). In 1919 the Weimar Bauhaus proclaimed:

Let us create a new guild of craftsmen, without the class distinctions which raise an arrogant barrier between the craftsman and artist. Together let us conceive and create the new building of the future, which will embrace architecture and sculpture and painting in one unity and which will rise one day toward heaven from the hands of a million workers like the crystal symbol of a new faith

(Bayer *et al.* 1938, p.16)

This first proclamation of the Bauhaus caused division of thought within post-war Germany. Many could not accept that the pre-war world was 'dead', while others struggled to be part of the section of society that was striving to find a new way of life (Bayer *et al.* 1938). Under the leadership of Gropius a collaboration of teachers, Kandinsky, Klee, Itten, Moholy-Nagy, Albers and Breuer (Bayer *et al.* 1938), to name but a few, developed an innovative and radical school of design that developed a set of principles that have had far reaching consequences on the world of design. Its principle, 'form follows function', is central to this project and its findings and recommendations.

4.3 The Role of Designers

The designer's role is basically the same whichever section of industry they work in, to create a product or change (Jones 1992). The process of design is fascinating but difficult as the instability of the design solution is that you can end up back at square one at any time during the design process. Carroll (2000) describes designers as being intelligent people performing complex and open-ended tasks who work backwards. They are given an '*outcome*' (in the design brief) and have to work backwards from an '*assumed event*' (product completion) to the beginning of a chain of events that will bring about the '*final effect*' (Jones 1992). Designers may be constantly back tracking and circling backwards and forwards as designing progresses as each stage in the life history of a product is dependent on the stages before and after it (Jones 1992). Changes at any stage can cause a domino effect sending the designer off at a tangent to sort out other stages before returning to the one they were currently working on. In a speech to the Wynkyn de Worde Society in 1974, Black (1983) described the attributes he considered necessary for a designer

To be a designer is to be conscious of, and accept, some responsibility for the physical form of our world; to be continuously aware of the shape, size, colour, pattern and texture of those parts of our environment which are man-made; to be prepared to distinguish between those objects and relationships which are aesthetically acceptable and those which fall below our personal standards

(Blake 1983, p.13)

Black believed that the Bauhaus was a "Vatican from which all truth emanated" (Blake 1983, p.5) and that good design could transform our environment, and in doing so transform mankind. He confirmed Moholy-Nagy's dictum "...design is an attitude of mind, a search for perfection in an imperfect world" (Blake 1983, p.13) He theorised

that technical skills and experience are essential attributes that a designer should not only have, but be willing to utilise to “...improve the environment and not desecrate it” (Blake 1983, p.13). His philosophy and attitude influenced the world of design from the 1930’s until his death in 1977 and could be considered to be a precursor to later writings about the total design process.

“People have always designed things” (Cross 1989, p.1). Development of the species and the desire for bigger and better artefacts has ensured the wish to design things is inherent in human beings. How individuals have the ability to design is a subject of great debate, but professional design is a disciplined process (Lawson 1990). Designer’s work in the future not the present, what they design is not here and now, but it will be, in the future (Jones 1992). Imagination and intuition are designer’s key skills as they try to create opportunities for their own reflection whether as individuals or as part of a design team.

When designers are asked to discuss their abilities and to explain how they work, three common themes emerge.

1. Intuition
2. The solution and the problem are interwoven (the ‘solution’ is not always a straightforward answer to ‘the problem’)
3. Sketches, drawings or models are used to explore the solution and the problem together

(Cross 1989, p.16)

Whether intuition, imagination or a combination of both is used, designers have to convey their ideas and how they work to others. To enable a formative evaluation of a product, designers will frequently create prototypes. This type of evaluation assists in verification of the product design specification (PDS) and the product’s development, and allows amendments and refinements to take place through direct observation and interaction.

The design process is seen by Schon (1983) as a ‘*conversation*’ with a situation comprised of many interdependent elements. The designer makes moves and then ‘*listens*’ to the design situation to understand the consequences (Carroll 2000).

In the designer’s conversation with the materials of his design, he can never make a move which has only the effects intended for it. His materials are

continually talking back to him, causing him to apprehend unanticipated problems and potentials.

(Schon 1983, p.101)

Designers need a language for managing this conversation and they need techniques for managing the consequences (Carroll 2000). It is easy for designers to interpret situations, products and their development from a personal viewpoint, whereas the real design situation is the situation that will be experienced by the user, and designers need to stay focused on that (Carroll 2000).

The social oppression experienced by disabled people and their quest for inclusion and accessibility within main stream society are issues designers should be attentive to. If designers included end users in the design process then large numbers of the population would not be excluded from using the final product, which in turn would bring greater revenue, which is a major factor within the design process. Users may be unable to be represented during the design process for many different reasons, but their views and needs should be paramount for the successful development of the final product.

4.4 The Design Process

The design process encompasses both the form and function of a manufactured product (Lorenz 1990; Pugh 1991). There have been many attempts to provide models of the design process. Some models describe sequences of activities while others attempt to prescribe a better or more appropriate pattern of activities (Cross 1989). Descriptive models of the design process reflect the '*solution-focused*' nature of design thinking, and emphasise the importance of generating a solution concept early in the design process. This solution is then analysed, evaluated, refined and developed and fundamental flaws at the analytical and evaluation stages initiate new solutions and the cycle begins again. This process is heuristic. Using rules of thumb, previous experience and general guidelines, the designer is assured of no guarantee of success. Cross (1989) developed a simple descriptive model which broke the design process into three stages. Generation, evaluation and communication are the three essential activities performed by a designer (See Fig. 1)

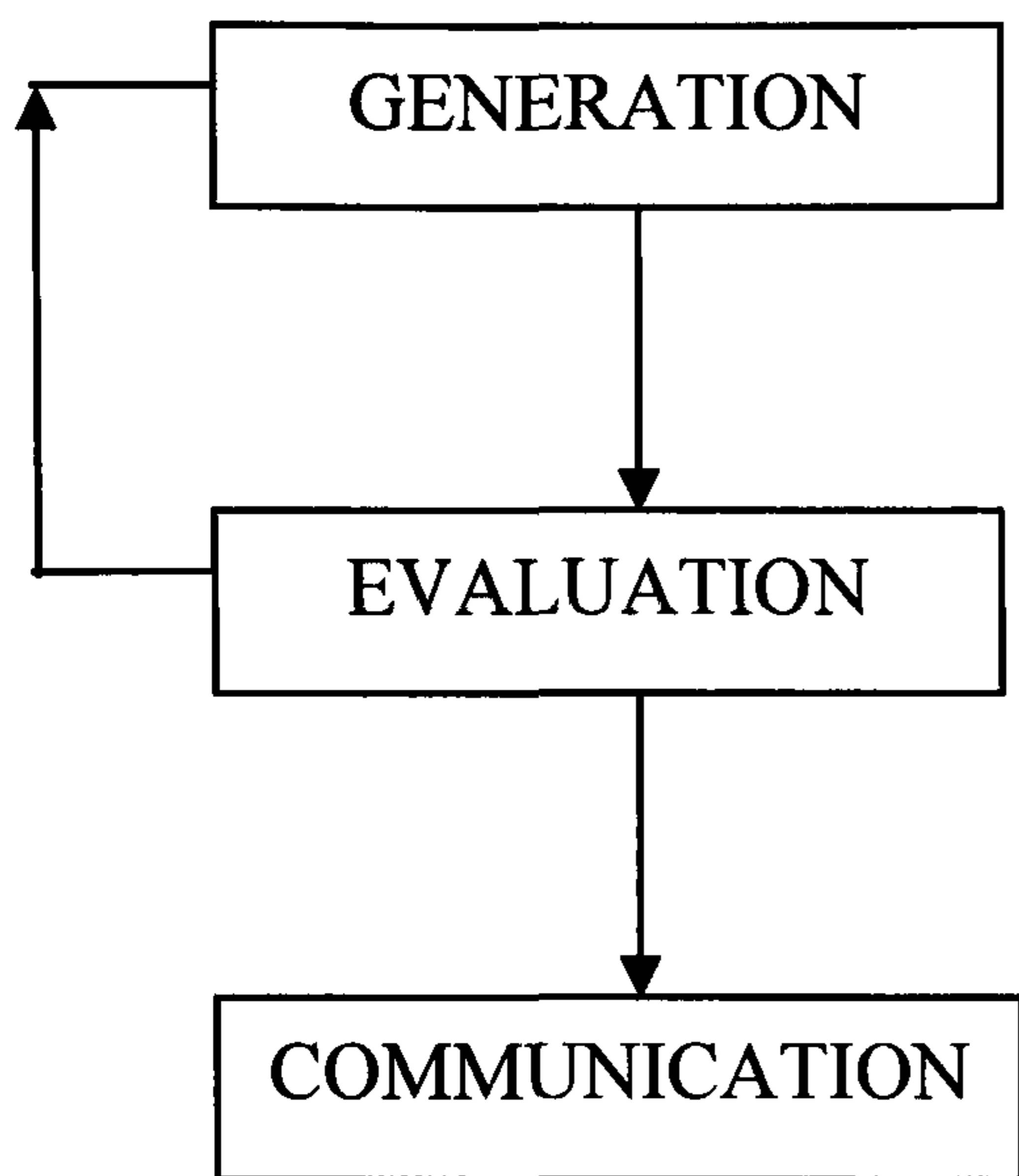


Fig 1 - Simple three-stage model of the design process (Cross 1989, p.20)

Design process models are usually drawn using a flow diagram format. This enables the process to be shown in developmental stages but with feedback loops showing returns which are frequently necessary. French (1985) developed a more detailed model of the design process than the one developed by Cross (See Fig 2). It is based on four activities of design: analysis of the problem, conceptual design, embodiment of schemes and detailing, and gives a better example of how the flow diagram format is useful when drawing models of the design process (Cross 1989, p.21).

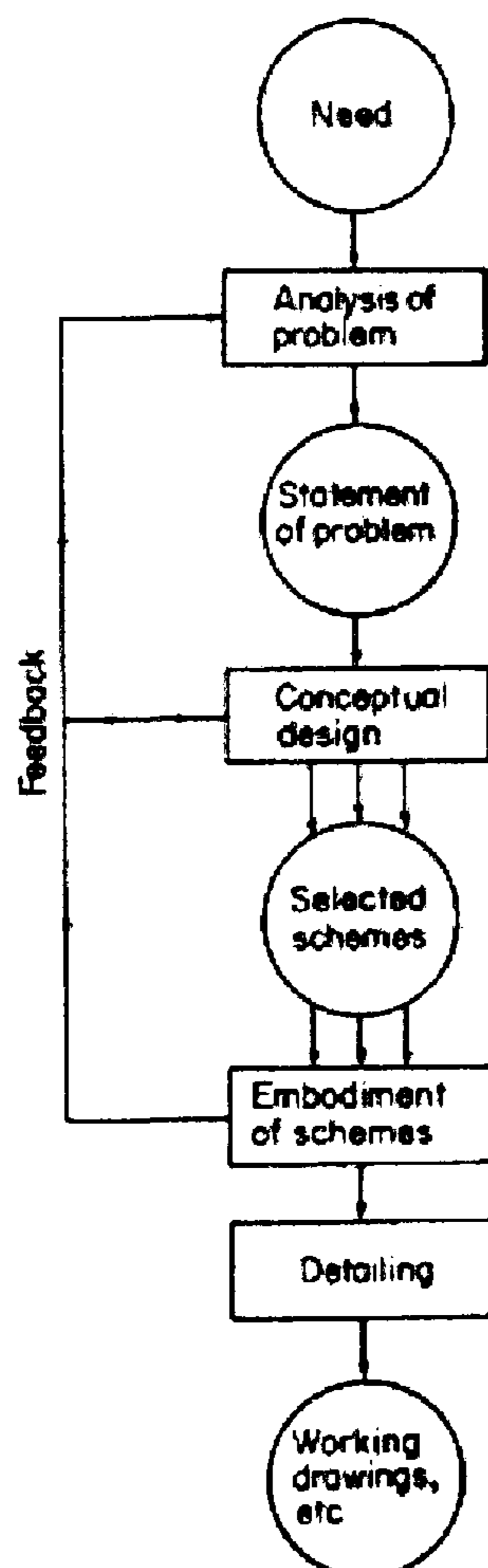


Fig 2 - French's four-stage model of the design process (Cross 1989, p.21)

The prescriptive design process models attempt to encourage or persuade designers to adopt improved ways of working. They are often regarded as offering a particular design methodology in their algorithmic, systematic procedures (Cross 1989). The main difference prescriptive models offer from descriptive ones is that they emphasise the need for more analytical work before the solution concepts. The stages are defined by Jones as: “Analysis, Synthesis and Evaluation” (1984 cited Cross 1989, p.24). The emphases are on logically derived performance specifications derived from the design problem. This type of model encourages the designer to make a rational choice by considering all sub-solutions before committing to a final solution at an early stage (Cross 1989).

4.4.1 Design Methods

Cross (1989) describes design methods as being “...any procedures, techniques, aids or ‘tools’ for designing” (Cross 1989, p.33). “Pugh was one of the great leaders of product development methodology and practice” (Clausing and Andrade 1996, p.xix). He challenged engineering designs underdeveloped concepts and developed a “cohesive, structured approach to engineering” (Pugh cited Clausing and Andrade 1996, p.xxvii) that was based on practice, rather than theory. With a background in the design industry as a design engineer and manager, Pugh embarked on a teaching career at Loughborough University in 1970 thinking he knew all there was to know about design (Clausing and Andrade 1996). However, “...he quickly concluded that he knew very little about design” (Clausing and Andrade 1996, p.xix) and saw a lack of understanding about the essence of design activity. He spent the next twenty years developing a cohesive, structured approach to engineering design based firmly on practice rather than theory. Pugh’s total design concept is an effective systematic activity which embraces all design aspects from user or market need to product completion and sale (Pugh 1991; Hollins and Hollins 1991; Clausing and Andrade 1996). He believed that a designer’s work is multi-faceted and that their contribution is not limited to the creation of form alone (Pugh 1991).

4.4.2 Total Design

Pugh (1991) described total design as “...an activity that encompasses product, process, people and organisation” (Pugh 1991, p.5). It is a systematic activity that starts with the identification of the market / user need and ends with the satisfying of the initial need

and the selling of that product. Pugh developed a design core that consists of market, product, design specification, conceptual design, detail design, manufacture and sales (Appendix 2a). The design process begins with a 'statement of need', often termed 'the brief'. From the brief, or statement of need, a PDS is formulated (The PDS is a detailed specification of the product being designed). Pugh developed a method for ensuring all the factors necessary when writing a PDS are shown in a visual representation. He developed Pugh's plates, which allow designers a systematic and thorough detailed representation of the total design activity (Appendix 2b). Norman *et al.* (1990) illustrate Pugh's plates succinctly.

If you imagine a circus performer trying to keep all the plates spinning on poles and each one representing a factor the designer must take into account, then the designer must give them all the necessary attention to keep them aloft. If one plate crashes then the designer has failed.

(Norman *et al.* 1990, p.14)

The PDS then acts as a mantle or cloak (Pugh 1991) that envelops all the stages of the design core. It places boundaries on subsequent designs and so acts as the control for the design activity. The design flow is constantly iterative, enveloped by the PDS and susceptible to external influences from discipline-independent methods such as analysis, decision making and modelling (Appendix 2c)

The designer must be aware of the priority necessary to any one factor of the total design process at any given moment. It is not an easy process, and designs often fail, often through no fault of the designer. The procedure for the total design process is set down in a concise, user friendly fashion in Pugh's 1991 book 'Total Design'. Design can be a luxury or a necessity, but the designer's role is basically the same whichever section of industry they work in. To create a product or a change (Jones 1992).

If Pugh's total design activity is taken literally, his inclusive methods could be a technique for designers to ensure end users views are encompassed within the design process at all stages. This would ensure the inclusivity that disabled peoples organisations strive for.

4.5 The Built Environment

The built environment is huge and navigating it is an essential component of every day life for the majority of the population who spend up to 90% of their time inside

artificially constructed environments (Russell 1999). It is made up of buildings for living, working, shopping and leisure, activities we all take part in to varying degrees every day (Oliver 1990; Steinfeld and Danford 1999). The infrastructure that links the buildings, roads, footpaths, rail links, transport inter changes and landscaped environments all have an effect on our travel and communications (Russell 1999). As we are totally immersed in the effect of the built environment, the design of it is important to every one of us as individuals and as members of the differing social groups to which we belong (Giddens 1993). Traditionally much of the built environment was designed for the majority of the able bodied sector of society with little consideration for the less able, visually or hearing impaired and the elderly (Russell 1999; Holmes-Siedle 1996; Barnes *et al.* 1999). Architects were traditionally white, middle class, males who made up the professional classes (Russell 1999) and did not see themselves as part of the wider political implications of their profession (McGlynn and Murrain 1994). Imrie (1998) discusses how architects often seemed to prefer to concentrate on technocratic and technological design theories rather than values, design objectives and design intentions. This type of functionality ignores the social psychology of design and the attainment of understanding what people want, as opposed to what they actually require (Davies and Lifchez 1987). Attitudes towards environmental design began to change in the 1960s and were mainly attributed to Goldsmith, an architect, who was instrumental in setting the mould for the practices of designing for disabled people. In 1961 Goldsmith was appointed to undertake a research project by The Royal Institute of British Architects (RIBA) which resulted in the production of his first book published in 1963 'Designing for the Disabled' which set the mould for designing for disabled people (Goldsmith 1997). Goldsmith updated the book in 1967 and 1976, and in his 1976 edition observed that:

...buildings always have been, and always will be, geared to suit two-legged able-bodied people and not people propped on sticks or rolling about in chairs on wheels

(Goldsmith 1997, p.16)

This sentiment has been echoed in the writings of many disability researchers who have documented aspects of disabled people's oppression in the built environment both through design and social construction (Barnes 1991; Imrie 1996a, 1996b, 1997). Despite numerous publications about oppression experienced by disabled people, and the implementation of Part M of the building regulations, which should ensure reasonable access for disabled people, research shows that there is still a shortfall in

knowledge, and a lack of understanding, of the access issues encountered by disabled people (Imrie 2003).

4.5.1 Architects and the Built Environment

During the last twenty years the ideologies and institutional practices of design professionals has been critiqued (Knox 1987) and professional designers and architects have been compelled to consider their practices within the wider context of socio-economic structures (Imrie & Kumar 1998). There is much literature showing that the built form is inattentive to women as well as disabled people and spaces are segregated on a disabilist and racist basis (Imrie & Kumar 1998; Weisman 1992). Many architects are white, male and from the middle class and designs are geared towards white, male, middle class able bodied people (Imrie 1996a; Imrie and Hall 2001). These observations recognise the inappropriate-ness of much building design in relation to the needs of users (Danford and Steinfeld 1999), principles which need to be addressed if architects and designers are to truly facilitate access for all types of persons (Imrie and Hall 2001). There is a need for architects and designers to understand the people who will use their designs in a practical rather than theoretical way, rather than concentrating of the functional aspects of the subject. Davis and Lifchez (1987) consider much building design to be impersonal and alienating and comment:

...how ethical is it to practice architecture to be professionally licensed to design buildings, without having first developed an intellectual and emotional understanding of people.

(Davis and Lifchez 1987, p.87)

Architectural practices are often considered elitist and architects favour creating visions that belongs to them alone (Knesl 1984; Imrie and Hall 2001). Knox (1987) accedes with this concept and ratifies this theory by suggesting that architects such as Le Corbusier considered that people "...would have to be re-educated to appreciate his visions" (Knox 1987, p.364). This premise continued within the architectural profession throughout the modernist and postmodernist periods and was summed up by Knesl (1984) who wrote "...it is an adage that if architects lived in or used the buildings they designed they would not design as they do" (Knesl 1984, p.7).

Architects affiliated to RIBA should take a Continuing Professional Development course of thirty-five hours a year, to keep abreast of ongoing issues within their profession. Unfortunately this process goes unmonitored so it is left of the honesty and

integrity of individuals to enroll on courses (Imrie 1996a). In 1998 Imrie conducted a postal survey to ascertain architects conceptions of designing for disabled people's access. A questionnaire compiled of open and closed-ended questions was sent to 10% of architectural practices in the United Kingdom and the data obtained was divided into four sections.

- Architects definitions and conceptions of disability
- Education and training received by architects in relation to disability and design matters
- User involvement and to the extent architects consider the views of disabled people during the design process
- Statutory regulations and architects perceptions of how they should be integrated into the design process for access in the built environment

(Imrie and Hall 2001, p.95-112)

The results make interesting reading, and can be summed up by one respondent out of the 770 participants who said:

...disability is a function of a disabling environment, not of the individual. By promoting inclusive design the environment can be made more accessible for all
(Imrie and Hall 2001, P.100)

There is little evidence to prove that professionals, architects and designers are listening to the views of the lay community or that the disabilist structures of the design profession have been broken down (Imrie 1996a).

4.5.2 The Influences of Modernism and Postmodernism

Modernism is not exclusively responsible for the construction of disabilist cities, but it has been dominant in their post war reconstructions (Harvey 1990; Giddens 1991, Knox 1987). The Bauhaus, Les Congres Internationaux d'Architecture, Archigram and the Ekistics school (Imrie & Kumar 1998) influenced modern architecture in contemporary Western society and buildings built during the modernist period were designed using abstract, geometric forms and built using mass-produced industrial technology (Weisman 1992). Wolfe (1989) asserts that this non-contextual architecture was built following the Bauhaus tradition of 'form follows function', which expresses function and structure and very little else. This style of design demonstrates little consideration for human behaviour and access requirements, and is based around the conception that man is abelist, gender specific (male) and the embodiment of normality (Imrie & Kumar 1998). Le Corbusier, one of the leading exponents of modernism, commented that

“...all men have the same organism, the same functions.....the same needs” (Le Corbusier 1927, p.27). In 1925 Le Corbusier developed a diagram called the Modular which was a device that utilised the proportions of the (able) body for use by architects when creating built spaces (Imrie 1996a). The Modular presented an image of a perfect human specimen, a strong, upright male showing no sign of disability and all architectural design was based around this image of a human being (Imrie 1996a). Le Corbusier, Gropius and Van der Rohe, the main exponents of modernism, ensured that building of the time was governed by experts rather than democracy, and clients, other professionals and users of the system were systematically excluded and often patronised (Weisman 1992; Knox 1987). The uniformity and sameness of the modernist style and its failure to recognise the need for multi-functional spaces and the diversity of human needs is in part where the estrangement of sectors of society began (Imrie & Kumar 1998). Architects and designers were in effect attempting to persuade people to use predetermined design where bodily differences were denied and bodily interactions with the built environment were engineered. Theoretically post modernism veered away from these concepts by providing the possibility for liberation for individuals. However, Imrie (1996a) argues there is no dominant core value for postmodernism and describes it as being “...fluid, not fixed and open to all who wish to influence it” (Imrie 1996a, p.88). He goes on to describe spaces as seemingly thrown together and increasingly reflecting the affluence of the middle classes (Imrie 1996a). Harvey (1990), Savage and Wade (1993) and Jameson (1991) concur, describing postmodern spaces as ‘*placeless realms*’ where “...links to other parts of the urban fabric seem tangential and haphazard” (Jameson 1991, p.140). Frampton (1992) corroborates Imrie’s (1996a) contention about the affluence of the middle classes by describing the postmodernist use of aesthetics as nothing more than “...a set of seductive images which sell both the building and its product” (Frampton 1992, p.23). Warehouse conversions, out of town retail units and contemporary architecture in general are built for the new rich rather than the new poor (Imrie 1996a). Society has become more affluent in all social classes and consumer needs are fed by professionals who themselves wish to make money. Giddens (1991), Knox (1987), Cooke (1988), Davis (1985), Frampton (1992) and Imrie (1996a) all conclude that postmodernist environments are oppressive and abelist although post-modern architecture, theoretically, attempted to restore human proportions (Knox 1987; Marks 1999). Matrix (1984) maintains there was, and still is, an assumption by many architects that “...all sections of the community want the

environment to do the same things for them” (Matrix 1984, p.3). This viewpoint is debated by many of today’s disability researchers and activists (Barnes 1991) and was argued by the European Commission in 1996 who stated

To ensure equal chances of participation in social and economic activities, everyone of any age, with or without any disability, must be able to enter and use any part of the built environment as independently as possible

(European Commission 1996, p.7)

Walker (1996) takes the argument on a more personal level

...I don’t want respect.... I don’t want to have to ask to get in and out of buildings and buses.....what would it be like if black people, pram pushers or homosexuals couldn’t use public buildings?

(Walker cited in Imrie 1996a, p.87)

The modern built form is still not sympathetic to the needs of the access requirements of people with disabilities, and postmodernism is actually more de-humanising than modernism as its promises can never be delivered (Frampton, 1992).

4.5.3 *Physical Barriers to Inclusion*

Legislation and building regulations compiled to assist the disabled population have to be adhered to, but the recognition that the built environment can, and does, create disabling environments has to be accepted by the individuals who implement them (Steinfeld and Danford 1999). Understanding what disabled people want rather than perceiving what they need, cannot be written into legislation and is an essential principle to providing adequate solutions to accessibility issues (Imrie and Hall 2001). In 1991 Colin Barnes observed that “...the physical environment...has been constructed without reference to the needs of disabled people” (Barnes 1991, p.179). Disability researchers and advocates are still promoting this over a decade later. During the last fifteen years disabled peoples’ access issues to public buildings and environmental access has become an important part of the political agenda with many local authorities implementing strategies for accessible built environments (Imrie and Kumar 1998). Many towns and cities have been designed and built using able bodied values; from steps instead of ramps to the lack of signage suitable for the visually impaired the barriers encountered by the disabled population are extensive (Barnes 1991; Holmes-Siedle 1996; Imrie and Kumar 1998).

Data from research carried out in Weymouth and Gateshead in 1996 (Imrie and Kumar 1998) illustrated the oppression felt by disabled people when using the built

environment. The research was part of a wider project funded by the Economic and Social Research Council (ESRC) and the sample from Weymouth and Gateshead was comprised of thirty people with a range of different physical impairments. The participants took part in focus groups that were carried out in order to gain a greater insight into disabled people's feelings of their experiences within the built environment and two themes were recurrent throughout the research that highlighted the oppression felt by the participants. The first was that the built environment and the inaccessible places within its structure were a key element in disabled people's marginal status within society. The second was that disabled people have little or no influence over key issues of land use or building design (Imrie and Kumar 1998). These themes were reiterated during the focus groups carried out during this study. There were several issues raised by the participants of this present study about discrimination from their able bodied peers, which was exacerbated by inaccessibility for the disabled community within the built environment. A participant from the second focus group explained that some banks and shops have a system where a nominal charge is made to acquire a small hand module you could use to call for assistance.

If you want to buy one you can have these things but you'll get one free if you encourage a particular shop or bank to install one and the person who has encouraged the bank or what ever will get one free

(Focus Group 1999, 2m1)

All of the participants of this present study agreed that local planners had improved their outlook towards accessibility for disabled people but that there was still a long way to go before they could feel fully integrated into the local community. One of the participants of the first focus group had participated in a workshop arranged by the local council and was displeased that suggestions made by the group of disabled attendees had been ignored.

About 2 years ago I went to a workshop at the civic centre and we had councillors opposite us – all the top bods – and we were split up into workshops, some doing access, some doing transport, some doing shops – you know. And this came up so often at the end of the day, it was suggested by blind people that they should walk around with blindfolds on, wheelchairs get in a wheelchair and actually wheel yourself round, not somebody pushing you, you actually do it yourself. Nothing from that side of it had been done.

(Focus Group 1999, 1m1)

The barriers experienced by wheelchair users within the contemporary physical environment are looked at from the point of view that "...design aesthetics reflect

certain idealised assumptions about the inhabitants and users of the built environment” (Marks 1999, p.82). This was reiterated by participants in the study who complained that although some of them had been in discussions with planners, when the project was finalised advise given by disabled participants was disregarded.

4.6 Universal Design

One of the ways modern day architects and designers have attempted to overcome the barriers that prevent more inclusive environmental access, has been through the concept of universal design. The main principle of universal design is to draw away from people’s impairment as a source of difference and to sensitise the environment to the broadest possible range of bodily shapes (Table 1).

Table 1 – Principles of universal design

Principle	Description
Simple and intuitive use	The use of the design is easy to understand regardless of the user’s experience, knowledge, language skills or concentration levels.
Equitable use	The design does not disadvantage or stigmatise any groups or user.
Perceptible information	The design communicates necessary information effectively to the user, regardless of ambient conditions or the users sensory abilities.
Tolerance for error	The design minimises hazards and the adverse consequences of accidental or unintended fatigue.
Flexibility in use	The design accommodates a wide range of individual preferences and abilities.
Low physical effort	The design can be used efficiently and comfortably and with a minimum of fatigue.
Size and space for approach and use	Appropriate size and space is provided for approach, reach, manipulation and use, regardless of the user’s body size, posture or mobility.

(Adapted from: Calkins *et al.* 2001, p.22.21)

Weisman (1992) defines universal design as “...flexible architecture.....based on structures which are demountable, reasonable, multi-functional, and changeable over time” (Weisman 1992, p.32). Effective universal design is only obtainable through teamwork which is necessary to surmount the limitations of any one perspective or professional viewpoint (Preiser & Ostroff 2001). Working together, architects, designers, planners and builders can offer flexibility, adaptability and interchangeability of fixtures and fittings to provide an “...adaptable environment that can be easily adjusted to meet the needs of any person” (Steinfeld 1994, cited Imrie 2001, p.16). Universal design deviates from modernist principles and underpins the values of postmodernism (Imrie & Kumar 1998; Imrie and Hall 2001), where the emphasis is on the importance and vitality of cultures and the need to generate space for people rather than integrating people to fit into available space. It maintains that accessibility is more than purely the logistics of admittance to a building (Imrie & Kumar 1998). As Davis and Lifchez (1987) comment:

...how one feels about a place, how one interprets it, or even whether one can adequately interpret it – these are all less quantifiable, but crucially important, aspects of accessibility. A place that supports people’s activities and desires, permits them to be and do what they want, and causes them a minimum of pain, frustration, and embarrassment is more accessible than a place that confuses, harasses, or intimidates people. Many ostensibly accessible sites differ substantially in the quality of experience they offer.

(Davis and Lifchez 1987, p.40)

These principles are potentially progressive towards restoring disabled peoples’ self esteem, dignity and independence through user friendly design, but universal design does have its critics (Imrie and Hall 2001). Goldsmith (1997) considers that there are too many differing impairments for a single design to accommodate. While many skeptics of the principles of universal design consider it to be too costly, relevant only to a minority of the population and something adhered to only to the extent of the law (Connell and Sanford 1999).

4.7 Inclusive Design

Inclusive design is a development of universal design where the users are placed at the fulcrum of the design process rather than in the margin. The emphasis is working with people rather than for them, allowing the users to “...have the ability to take control of their environments” (Hatch 1984, p.4). It is a concept which challenges the technical,

social and institutional relations of the design and building process, by prioritising users views, rather than being an ‘*add on*’ to existing knowledge or a theoretical response to the needs of disabled people (Imrie and Hall 2001). It encourages designers to re-think their relationships with those who they design for (Sommer 1983) and to challenge and change the hierarchy of their profession while allowing users knowledge to be a key resource in building design (Imrie and Hall 2001). The intention is not for the users to determine the design but for the lay person to input some of the expertise needed; the difficulty here is defining exactly who the user should be (Imrie and Hall 2001). Gathorne-Hardy (1999a, 1999b) criticises designers views of the people they design for and remarks that they ought

...to recognise themselves as users and the fact that they share with all people a corporeality and physical vulnerability that renders the ‘normal’ body grossly misleading.

(Gathorne-Hardy 1999b, p.5)

People who use the environment are “multiple, differentiated and complex” (Imrie and Hall 2001, p.19) and not inherently middle class, masculine and able bodied. Sommer (1983) believes the crux of social design is working with people rather than for them. Gleeson (1999), Towers (1995) and Hatch (1984) agree with this social design philosophy and Towers (1995) states that “...participation can be justified on the grounds that people have a right to greater control over their environment” (Towers 1995, p.172). The complexity and diversity of design relations and processes is difficult to capture but Sommers (1983) has developed a table (Table 2) which shows comparisons between inclusive and non-inclusive design. Unfortunately few design professionals see inclusive design as being beneficial to the design process (Imrie and Hall 2001), naming user involvement as a hindrance which slows down the development process rather than assisting it (Towers 1995). Other professionals have been quoted as resisting utilising user participation saying that there is too much user involvement in modern society as opposed to too little (Ventriss 1987). Disability groups argue that if their advice is sought during the design stage, expensive re-adaptations would not be necessary (Jolley 1996; Imrie and Hall 2001). As Imrie and Hall (2001) concur

...there are few examples of inclusive design or how to re-orientate the social relationships between property professionals and those that use the built environment.

(Imrie and Hall 2001, p. 24)

Development professionals are resistant to the principles of inclusive design and disability activists, researchers and access groups have a long way to go to convince professionals to re-consider their "...narrow and fragmentary pre-occupations" (Towers 1995, p.195) about the design process.

It can be seen that inclusive design enables products to be developed that are usable by as many people as possible. The Research Institute for Consumers Affairs (RICA) describes the aim of inclusive design as "...to design mainstream products and services so as many people as possible can use them" (Ricability 2002 [No page number]). Designers rely on information supplied by marketers to provide a target population for the products to be designed. These market segments all contain disabled people by virtue of socio-demographic criteria such as age, income or attitude. If design decision makers acknowledged that the market segments their products target already includes disabled people, they would realise that inclusive design is not specific to a special needs market segment and that it is beneficial to all.

Table 2 – Inclusive and non-inclusive design: a comparison

Inclusive design	Non-inclusive design
Concern with meaning and context	Concern with style and ornament
Participative	Non-participative
Human oriented	Corporate or institution oriented
Client re-defined to include users	Owner as exclusive client
Low cost	High cost
Grassroots design approaches	Top-down design approach
Democratic	Authoritarian
Seeking to change design attitudes	Acceptance of prevailing design attitudes
Use of appropriate technology	Use of high technology
Use of alternate models of the development process	Development process controlled by corporate interests
Heterogeneity	Homogeneity

(Adapted from Sommer 1983, p.7)

4.8 Psychology and Geography

An understanding of the relationship between the social environment and an individual can be found in Lewin's (1951) psychological concept of 'life-space'. Lewin (1951) perceives individuals are seen as having a private life-space and a public one which is shared with others. He contends that in the private, non-geographical, life-space an individual has a conception of the universe in which movement is unrestricted by thought, memory or imagination. Personal perceptions of the past, present and future make a unique private world with no boundaries. In the public life-space however, Lewin (1951) asserts that restrictions are placed by societal constraints. There is a sharing of geographical space, ideas and values, and individuals have assigned roles where they behave very differently from when they are at home. Although there are no tangible boundaries between private and public life-spaces, private beliefs affect public role-playing and vice versa. The constraints of public life-space and the liberal views of private life-space may lead to a conflict of attitudes and emotions, which can be further complicated by the inclusion in various different social groups. These groups, at home, work or leisure will themselves require different patterns of identification from individuals that will vary from setting to setting (Carver & Rodda 1978).

Peoples behaviour in environments and across space is analysed by both psychologists and geographers. These two very different disciplines have flirted with combined research since the 1960's and the formation of behavioural geography (Kitchen 1995). The development of collaborative links between the two disciplines and the adoption of an integrative approach to research offers complementary, broad, theoretical conceptualisations of environment and behaviour interactions (Kitchen *et al.* 1997). Behavioural geography explored a different way of considering how the human phenomena on the earth's surface could be understood. Rather than the phenomenon itself, geographical behaviour looked at the thoughts, knowledge and decisions that influence the location and distribution of the phenomenon. At the same time psychologists were becoming increasingly interested in the modular environment. Collaboration began in earnest after the Association of American Geographers Conference in 1965. Ten separate disciplines met at the conference and the Environmental Design and Research Association (EDRA) was established. The cross-disciplinary journal, Environment and Behaviour was developed in 1969 as a direct result of the success of EDRA (Kitchen *et al.* 1997). During the last forty years cross-

disciplinary links have been tentative but the integration of ideas, concepts and theories are shared by both psychologists and geographers (Kitchen *et al.* 1997). Spatial behaviour and decision-making can be understood better by a greater understanding of spatial thought. How geographic knowledge is acquired and structured in the mind, whether by images or propositions, and how this information is later accessed and used for guiding behaviour, is of interest to both psychologists and geographers. Researchers in both fields have recently begun to understand, through spatial abilities and behaviours, how people with disabilities find their way around (Matthews and Vujakovic, 1995). A greater understanding by planners of spatial behaviour would assist with the design of environments that can facilitate greater and easier use for people with disabilities.

4.9 Person-Behaviour-Environment Relations

Design influences behaviour (Ferguson 1997). How a person behaves in a particular situation is an interaction between both the person and the environment they are in and can differ from situation to situation (Lewin 1951). This person – behaviour – environment relationship is known as a transactional perspective, where each of the factors influences the other two and, in return, is influenced back by the consequences of its own effects (Steinfeld and Danford 1999). The divergent outcomes of the dynamics of these relationships are known as Dynamic Reciprocal Determinism and are used to explain why the environment has heavy influences on behaviour sometimes and none at other times. Spatial scientists, urban designers, geographers and architects, have been discussing physical accessibility and space since the 1970's, concluding that disability is a profoundly socio-spatial issue and that social processes produce space which shapes social evolution (Gleeson 2001). Gleeson regards the problem of accessibility as being "...embedded within the wider socio-political processes that frame the production of space in Western culture" (Gleeson 2001, p.252). Golledge, whose 1993 paper was the catalyst for the debate concerning disability and socio-spatialisation, does not endorse this notion. He gave a clear implication that disability is

...a set of physiologically given deficiencies rather than socially created limitations, which society seeks to compensate through environmental design concessions.

(Gleeson 1999, p.360)

Fortunately today's professionals prefer the modernist view which is characterised by physical in-accessibility and exclusion from socio-spatial mainstreams (Gleeson 2001).

Hahn describes the situation succinctly

...the built environment is basically designed for the average human being, plus or minus half a standard deviation. From the perspective of a bell-shaped curve, persons with many types of disabilities that place them in the tails of the distribution are effectively isolated by their environments.

(Hahn 1986, p.273)

The ways in which the built environment affects our lives is of particular interest to social scientists and there is documentation of variation across social groups with evidence that social exclusion is more apparent for those with mobility limitations (Giddins 1993; Barnes *et al.*, 1999). Disability activists and researchers argue that the built environment plays a crucial role in determining and even creating the experience of disability. As Napolitano states

...being able to use the environment is about more than being able to 'get about'. At a deeper level it is about a sense of belonging. Until the environment supports mobility impaired people's participation with dignity and pride intact, this sense will continue to evade them.

(Napolitano 1996, p.34-35)

This sustains the theory behind the social model of disability which advocates that attitudes towards inclusion should go hand in hand with the design and construction of the built environment.

As individuals "...we do not understand who we are until we know where we are" (Weisman 1992, p.9). Comprehension of the experiences of daily lives and the culture in which they are immersed can be understood through an awareness of how the built environment shapes relationships between human beings. The place held within society by an individual is symbolised by the buildings they inhabit, the surrounding neighbourhood and the city in which they live. The wealthy live in large opulent buildings while poorer members of society live in housing developments that are often unkempt and squalid. The world and the people in it are slotted into a framework provided by the space each individual inhabits. Every day conversation illustrates that people exist in relationship to time and space. '*High society*', '*climbing the ladder of success*', '*narrow-mindedness*' and '*everything has its place*' are frequently used expressions (Weisman 1982). '*Looking up*' to someone is a symbol of respect while '*looking down*' on someone signifies disrespect or disdain. Language is also constructed

to help us to comprehend time and distance relations, examples are '*stones throw*', within '*shouting distance*', twelve inches in a '*foot*'.

Like language, space is socially constructed, and the spatial arrangements of communities and buildings reinforce the nature of relations within society (Weisman 1992). The use of both space and language influence the power some groups have over others and, in turn, contribute to the inequalities found within society (Weisman 1992). Men and women are born with bi-hemispheric brains making each gender equal at birth. The right hemisphere of the brain controls the left side of the body that functions in an intuitive, holistic, affective and receptive way. The left hemisphere controls the right side, which functions in a logical, assertive, linear and rational manner. Society values the latter set of attributes leading to the right side being called masculine and the left side feminine. The value here is weighed towards males, which is demonstrated from childhood as boys are raised from small children to be dominant, while girls are protected by the homogenous environment of their home and immediate environment (Clarke and Cochrane 1998). This concept is followed through in social space as the guest of honour sits on the right side of the host. It is further echoed in religion where in western society Christianity teaches that Christ sits at the right hand of the Father (Luke). This concept of male domination can be further enhanced through examples linked with height. The idea of height symbolising masculine superiority originates from cosmological space where heaven has a '*sky father*' while earth has an '*earth mother*'. There are many examples throughout history of male domination being represented through height. Obelisks and columns were constructed in honour of military conquests, temples were built on platforms and thrones were elevated. Today, executive offices and penthouses are built on the top floors of buildings commanding the most visual space, assuring social position by giving the impression of the owner / occupier having the world at his feet (Weisman 1992). Few of these executive offices and penthouses are accessible for a person with a disability, which further adds to the exclusion of people from mainstream society just because they are not perceived as being '*normal*'.

This chapter describes how designers affect the world around them by the introduction of their designs. It has argued that the advantages of inclusive design, and its

fundamental principles, could be potentially liberating for designers when designing for disabled people, enabling greater access to products for a larger majority of the market.

4.10 Ethics in Design

In chapter 1, the discussion considered the concept that designers do not recognise the need to engage with end users. Subsequent chapters have considered *why* designers should include end users, and ensuing chapters will look at *how* this should be done. But one factor that must be central to the latter concept of *how* designers engage with end users is that any engagement must be ethically sound.

Ethical issues within social research, health care and social work are discussed in chapters 6 and 7, whilst the discussion in chapter 13 contends that an ethical code or framework for use within design research should be developed. However, it is important to understand the concept of current design ethics in order to realise the need for the development of a code or framework, and the impact that ethical considerations will have on designers when working with participants.

Design is a fundamental activity; and it has an important relationship to ethics (Madsen 2005). Ethics in relation to design can be defined as ‘responsible design’. A definition of responsible design is “...an activity of appropriately relating means to ends within a set of constraints” (Madsen 2005, p.38). If this definition is broken down into three parts, they consist of, what has to be done (Ends), how to do it (Means) and any limitations (Constraints). A failure of any of these three integral facets would result in the failure of a design project. If this tenet is considered then the link between design, design management and ethics can be seen. Ethicists purport that ‘ends’, ‘means’ and ‘constraints’ are central to philosophical questions. “‘What is worth doing?’ (Ends), ‘What is right conduct?’ (Means) ‘How should one act under certain specific circumstances?’” (Constraint) (Madsen 2005, p.38). These are a set of criteria that are comparable to those of responsible design. This similarity of principles shows that there is a fundamental relationship between ethics and design.

However, ethical issues within design have typically been interpreted as relating to business ethics. Where the premise “...responsible design must be responsible business” (Sethia 2005, p42), is the overriding factor. This means that the foremost responsibility

of designers is to their clients or the company they are working for. This inherently necessitates designers being responsible to customers as well. The interest of customers is then related to the interest of the business, which in turn links back to the designers' client, forming a relationship between Client – Business - Designer – Customer, that is intrinsically interlinked. However, in today's ever increasingly socially responsible world, there is a growing expectation for designers to consider their responsibility to society. This manifests itself not only in terms of environmental impact, but through cultural and behavioural connotations within business practices. Designers are also now being encouraged to consider their own business and professional responsibilities (Powell 2005; Sethia 2005).

However, whilst there is abundant literature available concerning a designer's responsibility to the consumer (Cooper 2005; Sethia 2005), there are few accounts available regarding a designer's accountability towards research participants, or their moral and ethical responsibilities concerning end users involved in the design process. Indeed, Gaughran and Billet (2003) maintain that surrogate wheelchair users could be used in research relating to bench design. Concluding that the use of surrogates would "...allow easier access to suitable test subjects" (Gaughran and Billet 2003, p. 90). This study disagrees with such an argument, and instead contends that planners and designers should consult with disabled people themselves, as they are the experts concerning issues relating to disability (Chapters 3; 8; 9)

Goodman *et al.* (2005) consider that ethical issues are important in any design, but even more so when designing for elderly and disabled people. They maintain that control, privacy, independence, choice and trust are important factors to be considered. Yet, whilst they affirm the importance of involving users in an inclusive design process, they concede that further work needs to be carried out to evaluate and implement the efficacy of their contentions. They further contend that "...user-centred research has the potential to harm participants, both physically and psychologically" (Goodman *et al.* 2005, p.5), confining this studies assertion (chapters 6, 7 and 13) that an ethical code or framework needs to be considered for designers to adhere to when including end users in the design course.

Such a code would be created to respond to actual or anticipated ethical conflicts and would need to be contextualised through real life design to take on any meaning. Case studies would need to be compiled to give the guiding principles of the code and to provide it with the context required to comprehend its manufacture. (See chapter 13 – Contribution to Knowledge).

CHAPTER FIVE – SUMMARY OF THE LITERATURE REVIEWS

This chapter considers and summarises the disability and design literature discussed in the previous two chapters. The discourse links disabled peoples' requests for inclusion, the principles of the social model of disability and inclusive design methodologies. It then purports a way forward for designers to assist the disabled community in its quest for an equitable and accessible inclusive lifestyle within mainstream society.

5.1 Disability and Inclusion

It is important for designers and development professionals to have an overview of the history of disability and how disability is perceived within modern society so that they can begin to understand the frustrations of the people they are designing for. While disabled peoples' groups acknowledge that there have been many changes in societal attitudes towards disability, they maintain that the changes are not enough to enable them the equitable and accessible inclusion within modern society that they desire.

The DRC developed a unique website in 2005 (DRC 2005) that provides an insight into key issues surrounding disability. The Disability Debate (2005) was created by the UK government and is used by disabled and non-disabled people, policy makers, parliamentarians and public and voluntary sector workers. This 'first of its kind' website enables discussion on a varied range of subjects including independence, interaction, empowerment, risk and inclusion. Employment, education, attitudes within society, equality, segregation, exclusion, frustration, marginalisation and independence, are all topics being discussed by a diverse list of subscribers. From the debates to date, the DRC have compiled a list of their top 10 priorities for change:

- Increase disabled people's participation
- Close the employment gap
- Ensure no-one is obliged to live in an institution
- Support independent living
- Create safe communities
- Improve housing conditions
- Promote children's life chances
- Enhance vocational and personal skills
- Tackle health inequalities
- Effective equality legislation and institutions

(DRC 2005 [online no page number])

The website gives disabled communities the opportunity to come together as ‘one voice’ and to be heard by planners, policy makers and health care workers through this unique approach. Massie (2005) contends that for too long, society has treated disability as something that does not affect many people, when in fact, “...it affects everyone in Britain” (Massie 2005, [online no page number]). Massie further asserts that when thinking about disability we need to think about all different types of disability, not just wheelchair users, people with visual impairments or leaning disabilities. He argues that we should also consider people who have HIV, arthritis, mental health problems and other hidden disabilities. The DRC further challenges that society needs to stop treating disability as being just about ‘care’ or ‘welfare’ and consider it more in the terms of equality and social justice. If the DRC are successful in attaining these attitudinal changes, then disabled people will begin to enjoy the human rights that they currently fail to receive. Only then will they stop being seen as vulnerable or at risk; be able to talk freely about hidden disabilities; have their voices heard and, in essence, become active citizens in an equitable society

As previously stated Vasey (1989) considers that “...ultimately, disability culture should be recognised as one of the many strands running through contemporary multi-cultural society” (Vasey 1989, p.5). If designers are to design successfully and include all sections of the market they are designing for they need to appreciate, and accept, that disabled people are inherent within existing market segments and therefore their designs should accommodate people with disabilities. Napolitano states that disabled people need “...a sense of belonging” (Napolitano 1996, p.34-35) and this can be achieved to some extent through design. Imagery is an important factor in design and aesthetics are a significant consideration within the design process. As design affects how people feel, and individuals’ personalities are expressed through the products they purchase, designers should realise that they have the potential to improve disability imagery through their work. If this principle of design psychology is to be substantive then it should be appreciated that design will subsequently affect societal attitudes.

5.1.1 The DRC and Inclusive Design

The DRC is an independent body established to eliminate discrimination against disabled people and to promote equality of opportunity. It endorses inclusive design for

its goal to “...create environments that everyone can use equally” (DRC 2006[online no page number])

The DRC was established by Act of Parliament and has set itself the goal of achieving “...a society where all disabled people can participate fully as equal citizens” (Massie 2004, [online no page number]). It has a broad remit and aims to

- provide advice and information services for disabled people and service providers
- support disabled people in securing their rights under the Disability Discrimination Act (DDA)
- campaign to change policy and strengthen the law so that it works better and protects more disabled people

(Massie 2004, [online no page number])

In a speech in April 2004 entitled ‘Developments in Access and the Law’, Massie the chairman of DRC, described inclusive design as being:

...not a fixed set of technical criteria, but a constantly evolving philosophy that guides the way we design our environment

(Massie 2004, [DRC no page number])

As Mayor of London, Livingstone is an advocate of inclusive design and has developed a Supplementary Planning Guidance (SPG) which requires that “...all future development in London meets the highest standards of accessibility and inclusion” and that Unitary Development Plans “...integrate and adopt the principles of inclusive design” (Fleck 2003, p22-23). The plan was published in April 2004 and in the forward the Mayor states:

My vision is to create an environment in London in which all people have equal, easy and dignified access to London’s buildings, places and spaces. I want all new developments in London to meet the highest standards of access and inclusion. I want to combat discrimination and promote equality of opportunity throughout London. I am committed to London becoming accessible and inclusive, as befits a World City.

I am particularly concerned about people who are excluded from our built environment through inaccessible design, poor management and inadequate information. Disabled people in particular continue to be excluded, disadvantaged and discriminated against and are frequently denied the opportunity to participate fully as equal citizens in our society.

(Livingstone 2004, [London SPG forward])

The SPG (2004) Implementation Point 1: The principles of inclusive design states:

The Mayor has adopted “the social model of disability” (see paragraph 1.1.2) and the principles of inclusive design underpin his approach to planning. To achieve an accessible and inclusive environment consistently across London the Mayor recommends that the boroughs adopt this approach.

(London SPG 2004, p.1)

The London SPG (2004) describes inclusive design as being:

1.1.4 Inclusive design is based on the social model of disability, as it focuses on the design of the environment not on an individual’s impairment.

1.1.6 Buildings designed to be inclusive will be safe, predictable, convenient, flexible, adaptable, sustainable and legible and will be useable by all of us. These principles of inclusive design have emerged from an approach to designing buildings that are accessible to disabled people.

(London SPG 2004, p.13 & 14)

The aim of inclusive design is to create environments that can be used equally by everyone. It should not attempt to meet every single need of all people, but should consider people’s diversity and subsequently assist to tackle exclusion and break down barriers. If utilised, inclusive design has the potential to achieve solutions that would benefit everyone within the community and not be aimed specifically at the disabled community. This would mean that access for disabled people would be part of the mainstream rather than an ‘*add on*’ afterwards (Massie 2004).

5.2 Conclusion

Throughout the world different cultures and societies integrate or exclude groups of people in different ways. What may be acceptable for one culture may not be at all suitable for another. Ravaud and Stiker articulate this succinctly

...we must expect the meanings of words and practices not to remain the same over time (in history of societies) or across space (the synchronic diversity of cultural eras)

(Ravaud and Stiker 2001, p.490)

Giddens describes culture as having “...values the members of a given group hold, the norms they follow, and the material goods they create” (Giddens 1989, p31). Following this premise, culture can be considered to be another word for lifestyle. As disabled people are regarded as having a distinctly different lifestyle from their able-bodied peers, then it follows that disabled people must have their own culture. Morris is adamant that “...disabled people are missing from mainstream culture” (Morris 1991, p85), only appearing in specialised forms (the portrayal of tragic individuals to charity

telephones), which depict disabled people through the eyes of the non-disabled (Barnes and Mercer 2001). The participants of this study echoed Morris' sentiments when they commented that designers and planners don't listen to what they have to say, even though as individuals living their lives with a disability, they are actually the experts who understand their own requirements (chapter 8). It is this perceived "...culture of dependence..." (Barnes 1991, p.23), and the notion of disabled people not being an integral part of mainstream culture, that is one of ten issues being contested by the DRC (Massie 2006 – See chapter 3).

However, Brown (2001), Thomas (2002), Ladd (1996) and Riddell and Watson (2003) maintain that disability culture is not the only culture that disabled people belong to. Individuals are also members of different nationalities, religions, colours, professional groups etc, which makes disability culture no different from any other "...cultural tag" (Brown 2001, p2). Therefore, as with all social phenomena, disability should be "...woven through, and out of, cultural ideas..." (Thomas 2002, p.49) to become one of many strands that run through any multi-cultural, contemporary society (Vasey 1989).

The word 'disability' has a variety of connotations within different cultures, as does the word 'culture'. Join the two words together to form the term 'disability culture', and the diversity of meanings is incalculable (Brown 2001). Whilst it can be considered that socially dominant culture has attributed to how disability is viewed, and that it has subsequently contributed to the oppression encountered by disabled people (Riddell and Watson 2003), disability groups have forged their own cultures. Consequently, culture can be seen as both a source of liberation and oppression for disabled people (Riddell and Watson 2003).

As previously mentioned, disability groups have developed their own sub-cultures within disability culture (Barnes and Mercer 2001; Riddell and Watson 2003). Although disability culture supposes a common identity and interests that unite disabled people, these will vary in cultural style between disabilities due to customs, interaction or distinctive language (e.g. Deaf culture) (Barnes and Mercer 2001). An example of the development of a subculture, might be organisations of people with learning difficulties who argue that they are excluded, and at worst, ignored, by other disabled groups. Exemplifying that there are as many disability cultures' as there are disabilities. The

diversity of disability sub-cultures and the probability of belonging to various other cultural groups, means that disabled people are as unique and individual as their able bodied peers. However, it should be argued that disabled people need a culture to enable them to be proud of their differences, exude confidence and to demonstrate that their experience of life is important and valid (Morris 1991). By producing a unique cultural representation of disability, disabled people can challenge the concepts that their non-disabled peers have with regard to disabled peoples' reality and lifestyles.

This cultural diversity and understanding of words and practices is an issue that became a central theme later in the study within the development of the design resource.

A central theme, recurrent throughout the literature review chapters, is the notion that disabled people are, and should be recognised as being, the experts in the field of disability. The social model provides a method for arguing against societal exclusion while inclusive design methods state categorically that the end user should be an essential component within the design process. This aspect of the literature review was to become the principal argument throughout the study.

As discussed, person-behaviour-environment relationships have a profound influence on how individuals react towards both other people and the built environment. As previously stated Gleeson (2001) regards accessibility issues as being "...embedded within the wider socio-political processes that frame the production of space in Western culture" (Gleeson 2001, p.252). As space is socially constructed and if Gleeson's (2001) contention is to be assumed, and this study asserts that it is, then designers need to:

- Understand and accept disabled people's request for inclusion
- Advocate inclusive design methods

Through active promotion and employment of inclusive design principles designers will assist disabled people in their quest for inclusion and accessibility within mainstream society.

Taking into consideration the philosophies of the social model of disability and the principles of inclusive design the next stage of the project was to ascertain the views of disabled people, the experts in the field, about access within the built environment.

CHAPTER SIX - THEORETICAL ASPECTS OF RESEARCH METHODOLOGY

The major theoretical and methodological debates that shaped the research approach and the data collection in this study are considered in this chapter. Several related issues are considered; peoples' perspective of the world around them, how the social groups they belong to have a bearing on their experiences and knowledge, and the differences between design research and research about the social world. Consideration is given to how design research has historically favoured a more quantitative perspective, followed by a discussion concerning the differences between qualitative and quantitative methods.

The focus of the discussion then moves towards triangulation, reliability and validity, with the debate considering the trustworthiness of the data obtained. This leads to an analysis concerning the question 'whose project is it this?' and the appropriateness of non-disabled researchers completing research about disability.

Some of the wider epistemological and ontological positions that have shaped current disability research are examined, and the chapter concludes with an overview of the methods used to obtain the data.

6.1 Ways of Knowing

As individuals belong to a particular social group, or groups, and invest time and energy to remain in that position, then their experiences and knowledge will differ from individual to individual. The act of knowing is a multifaceted enterprise (Oakley 2000). Individuals know different things, via life's experiences and their beliefs and perceptions. An act which Oakley describes as being "...irredeemably fused" (Oakley 2000, p.291) which in itself is problematic.

Humans need to 'know' in order to predict and gain control of an uncertain universe. Alchemists and mystics believed that understanding casual chains of proceedings and linking events and situations, would lead them to understanding divine revelation. They considered that if A gives rise to B, not only does A precede B, but that A is why B happened. If A was why B occurred, then B would have been different if A hadn't happened, or B would have been non-existent. This tenet relates to theories of human

experience. Early social scientists considered that placing ‘mans’ knowledge of society in a similar law-like basis, to those of mystics and alchemists, was necessary. Consequentially this principle was adopted again by researchers and academics who instigated the “...material roots of people’s social relations and the reasons for inequitable lives” (Oakley 2000, p.292). Leading to further assumptions that what individuals know, may be diverse because of their different social positions.

Experimentation to validate these theories (plants will not grow in just any soil or location; children improperly cared for will not thrive), do not lead to anything shared or systematic, but does clearly contribute to common sense knowledge. Oakley (2000) maintains that experimental and ‘qualitative’ ways of knowing are “...fused at ground level in everyday experience from which all knowledge comes” (Oakley 2000, p.293). If this claim is to be believed, then designers have good reason to include end users (particularly disabled end users) within the design process, as end users knowledge, which comes from ‘living’ their experience of disability, is something that can only be gained from real life experiences. It can never be simulated or acted accurately by designers or actors. Therefore, it is imperative that engagement with people, who will use end products or services, is a fundamental element of the design process.

6.2 Social Science Research V’s Design Research

In social science research the researcher is typically located within a network of stakeholders who will all have different ways of knowing about the problem being investigated (D’Cruz and Jones 2004). Given that individuals and groups within these networks are embedded in different ways of knowing, it is important for the researcher to be aware that the differences generated through power and knowledge may create tensions about the research being undertaken. Within social work research these issues, and the pursuit of knowledge, are important with respect to the ethical and political purpose in maintaining a commitment to social justice (D’Cruz and Jones 2004). However, design research has a very different perspective.

Designers’ often begin the design process with some presumptions about the views of potential end users based on their own experiences and expectations (Dong *et al.* 2005). It is acknowledged that designers, on occasion, will consider themselves as users and

act out the usage process as there is typically a lack of user involvement in the design process (Dong *et al.* 2005; Säde 2001). Few designers include end users in the design process, whilst many will use their colleagues or other representatives as models (Dong *et al.* 2005). (It should be acknowledged that this is an avenue that a researcher in the social world would consider unacceptable and unethical). Designers consider appropriate end users difficult to identify and recruit (Kyng 1994; Norris and Wilson 1999; Dong *et al.* 2005) and typically commission market research agencies to run focus groups and gather data on their behalf. This demonstrates that the conflicting research techniques between designers and social world researchers are immeasurable. However, when designers do engage with end users within the design process, and this study purports that they should, it is important that they are aware of not only the needs of their clients and themselves, but also, the needs of the end user.

Unfortunately, few designers acknowledge the need for user involvement, the benefits of focus groups, or the diversity of the wide range of end users who may use their product or service (Dong *et al.* 2005). To compound this, during Dong *et al.*'s (2002) evaluation of the use of Critical User Forums, the interviews revealed that "...designers tend to be critical of focus groups" revealing that designers consider "...focus groups are prone to 'sheep mentality'", "...the results can be biased by dominating participants" and "...they are 'cost and time consuming' and 'complex'" (Dong *et al.* 2005, p.63). Indeed, designers consider that "...identifying users, interviewing them and interpreting the findings all need specialism" (Dong *et al.* 2005, p.50). Dong *et al.* (2005) suggest critical user forums, as a way for designers to engage with end users, yet, their model for these "...smaller focus groups" (Dong *et al.* 2005, p.51), exhibit no comprehension of any of the concepts considered in social research methods (e.g. ethics, consent, user engagement). On the contrary, Critical User Forums do not embrace the concept of true user engagement, but offer an indifferent, mediocre attempt at user engagement that is mainly for the benefit of the designer and an apathetic attempt to engage with the end user. This is exemplified by Dong *et al.*

Sometimes design teams already had a concept when meeting the critical users; consequently users were consulted mainly for testing the concept and helping developing potential solutions.

(Dong *et al.* 2005, p.54)

If their engagements with end users, the experts in the field, are to be credible and to be of benefit to all, designers need to consider the fundamental principles and ethical issues of social science research. To do this successfully, designers need to consider the basics of social research and to understand the fundamental principles of how different ways of knowing, power relationships and the ownership of knowledge may influence research (D’Cruz and Jones 2004).

It is important for any researcher to consider their positioning and how they, as individuals, as well as the people they are working with, connect with the bigger knowledge picture (D’Cruz and Jones 2004). (This is discussed further in chapter 7). In social work research it is acknowledged that social and cultural beliefs, identities, gender, religion and ethnicity are taken into account (D’Cruz & Jones 2004), whereas in design research, (as previously discussed) very few designers recognise their influence on cultural change. However, if, as this study contends, society is influenced by a designer’s ways of thinking and their personal prejudices, then designers should identify the need to realise, and articulate their position, and that of the people they are working with, within the wider knowledge picture.

As with social work researchers (D’Cruz & Jones 2004), it has been shown that designers can bring about social change. A concept for deliberation is that “...instead of treating methodology as a set of neutral techniques to be applied the same way in every context” (D’Cruz & Jones 2004, p.33), should the researcher consider *how* research gets done? When related to this study, and as Redmond (2005) concludes, the researcher agrees that “...detachment and objectivity, as they have been traditionally understood in the research context, are inappropriate and unsustainable for the social scientist” (Redmond 2005, p.85). If this principle is to be believed, then the concept of designers adopting social science research methods, and realising that they should have a duty of care towards their end users, will undoubtedly impede the concept of participation in the design process with end users. The process of involvement with end users needs to be ‘drip fed’ to designers, through explanation, education and example (Wilcox 2005).

6.3 Research Methods and Methodology

6.3.1 *Qualitative V's Quantitative Research*

There is a vast difference between the methods (the actual techniques and procedures used) and methodologies (the analysis of how research should, or does proceed) utilised in design research and social science research. The two subjects are widely divergent. Historically design research has inclined towards quantitative perspectives, and a positivist stance. Whereas, during the latter part of the last century, social research has resulted in extensions of debates around qualitative or interpretive paradigms that consider that data is produced, not collected (D'Cruz & Jones 2004; May 2002). Decisions about theory, methods, methodology, ethics and politics are now open to routine scrutiny, and ways of thinking inform practice. It is maintained that the choice of methods relates to arguments about knowing (D'Cruz & Jones 2004), and notions of neutrality, position the researcher as little but a passive instrument of data collection (May 2002). Concepts that perhaps are contradictory to beliefs within the design profession, since the ethics and responsibilities of designers are embedded within business ethics (Madsen 2005) and socially responsible design (Cooper 2005; Sethia 2005).

Historically the most dominant type of research, in health care, has utilised quantitative methodologies (Robson 1993; Bryman 2001). Adults have traditionally liked to use figures to qualify things (Oakley 1999), and as Wilcox (2005) states, designers, by the nature of the work they do, prefer visual conceptualisations. There has been a hotly contested debate as to which research methodology is more substantive (Bryman 2001), with both methodologies having strengths and weaknesses. For instance, quantitative methods, favoured by natural scientists and designers, can provide vital information relating to side effects and effectiveness of drugs, and materials. The methods provide ways to gather large amounts of information that can be put into 'easy to read' chart formats and there is usually a guarantee that the findings are dependable (Bryman 2001; Robson 1993). Qualitative methods, however, are more orientated to understanding the human realm, and enable the researcher to 'get closer' to the complex issue being researched (Blaikie 2000; May 2002). The qualitative perspective encompasses a range of methodological approaches, which include ethnography (Atkinson 1992), grounded theory (Glaser and Strauss 1967), phenomenology (Giorgi 1985) and case studies

(Holloway 1997), as well as some forms of action research (Reason 1994) and feminist standpoint research (Roberts 1981).

6.3.2 *Qualitative Disability Research*

It is the contention of this study that to understand the development of an inclusive design methodology, designers need to appreciate how the social world affects disabled people. Qualitative research methods have been shunned by the design profession as being too time consuming and expensive to incorporate into the design process (Bennett 2002). But this study asserts that the multifaceted approach and ability to change direction at any time (Strauss and Corbin 1990), makes qualitative research methods a prerequisite to an inclusive design process. Cresswell (1998) describes qualitative research as

...an intricate fabric composed of minute threads, many colours, different textures and various blends of material. This fabric is not explained easily or simply.

(Cresswell 1998, p.13)

Qualitative methodologies allow perspectives, experiences and behaviours of individuals or groups to be thoroughly explored in depth (Gilbert 1993). The techniques used allow the researcher to gather pictures or words, analyse them, focus on the participants' meanings and describe a process that is both expressive and persuasive. By spending time in the field conducting data-analysis, the researcher is able to understand the views of research participants (Lofland and Lofland 1984; Spradley 1980). Barnes (1992) endorses qualitative research methods as being "...fundamental to the emancipatory research paradigm" (Barnes 1992, p.115). However, Barnes (1992) concludes that qualitative methods usefulness depends on "...the integrity of the researcher..." (Barnes 1992, p.123). As qualitative methods are open to personal interpretation the researcher must recognise their own previous knowledge and experiences (Hammersley 1995; Holloway 1997; Fawcett, 2000). An unbiased viewpoint should be observed but a personal understanding of the research subject should be recognised as part of the process and not ignored.

Oakley (1999) describes qualitative research as having more flexibility than quantitative research and to be potentially less exploitative with respect to the hierarchy between the researcher and the researched. Consequently possessing the ability to reduce the risk of

manipulation and betrayal encountered by research participants. Previous discussion has shown that designers consider qualitative methodology unsuitable for obtaining information for use within a design project, as the research process can be time consuming and often result in resources being stretched to the limit (Bennett 2002). But, qualitative methods allow the researcher to understand the world that research participants live in and to become acquainted with the social world they are studying (Barnes 1992; Robson 1993; Cresswell 1998). As a consequence, an understanding of the real needs and requirements of end users and their input throughout the design process would enable designers to develop more sustainable and suitable products and services. (It should be acknowledged by the researcher that living along side a peer who had different life experiences, due to a physical disability, and working with people with varying disabilities, proved invaluable throughout the research process. This was prevalent both in the understanding of issues surrounding disability as well as in the recognition of the necessity to facilitate the voice of disabled people).

6.3.3 Triangulation

Whilst Lincoln and Guba (1985) highlight the differences between positivistic and naturalistic paradigms and contend that criteria defined from one perspective are not appropriate for the other, Bottorff (1997) argues that in fact the two methods can actually complement each other. She further suggests that the most debated type of triangulation - the combination of qualitative and quantitative methods – does, in fact, provide the researcher with findings that are related to each other and can be used to complement each other. However, she does acknowledge that this simultaneous methodological triangulation can cause perplexity if the two sets of data differ substantially. Oakley (2000) concurs with Bottoff (1997) and maintains that taking data from several sources will increase one's chance of being able to establish trustworthy results. She further asserts that verification and validation of analysis can be checked by the consistency of findings generated by different data-collection methods (Oakley 2000). The triangulation used within this study was to contact respondents from two different geographical areas within the same county. (The geographical locations discussed in chapter 8 were very different). One was a working port that has relatively flat accessibility, while the other is a busy seaside resort where the geographical lie of the land can only be described as 'hilly'. The researcher had a pre-conceived notion (Redmond 2005) that, as the towns were neighbouring locations, the participants may

only discuss issues relating to the town where their day centre was located. However, this was not the case, as discussed in chapter 7.

Bryman (1993) maintains that “...triangulation in its various guises..... is an indispensable tool in real world enquiry” (Bryman 1993, p.383). He further contends that triangulation is predominantly beneficial for the analysis of qualitative data as a tool to determine trustworthiness, as it provides a tool for testing one source of information against another. However, there is another feature of the methodological debate which affected the researchers thinking at the time of data analysis.

6.3.4 Reliability and Validity

Reliability and validity are important factors in establishing and assessing the quality of qualitative research (Bryman 2001). However, the measurement of validity carries connotations about measurement, which are associated with quantitative research not qualitative research. Therefore, the salience of measurement of validation within qualitative research has to be questioned.

In March 2000 the researcher attended a seminar given by Sparkes (2000), a Sports Psychologist from Exeter University. Sparkes discussed validity and trustworthiness in qualitative research with the emphasis on research into sports. He maintained that researchers should accept what respondents say and not concern themselves with validation, as validation implies that the information given may not be the truth. Therefore, questioning the information given by participants and its potential to be untrue. Sparkes (1998) further debates how Clavarino, Najman and Silverman (1995) contend that if qualitative research is not legitimised “...findings could be taken less seriously by potential audiences and the approach defined as merely exploratory or descriptive” (Sparkes 1998, p.371). During both his seminar and his article (1998) Sparkes deliberated how “...some argue that qualitative researchers should abandon the concept of validity and seek alternative criteria to judge their work” (Sparkes 1998, p.377). Wolcott also addressed the absurdity of validity “I suggest we look elsewhere in our continuing search for and dialogue about criteria appropriate to qualitative researchers’ approaches and purposes” (Wolcott 1994, p.369). This notion is contradictory to the thinking of Guba and Lincoln (1989) who discussed criteria that developed from constructivism’s basic assumptions and is totally unaligned with the

principles of feminist methodologies. Nevertheless, at the time this concept influenced the researchers thinking towards the hypothesis of "...accepting what our research participants tell us, and not questioning their responses or looking to validate them" (Sparkes 2000).

Conversely, whilst accepting Sparkes (2000) and Wolcott's (1994) contentions about participant validation, the researcher additionally considered that member checking would be a suitable method for substantiating the trustworthiness of the participants' responses. Member checking can be interpreted differently as can be seen in the writings of Eklund (1996) and Striegel (1993). Whereas Striegel's participants were given their initial interview transcripts for review of clarity and to make any alterations necessary, Eklund's (1996) transcripts were returned to the participants but no amendments or alterations made. Silverman (1993) however, contends that member checking is a questionable validation procedure and he questions whether or not the participants would (or should) have any interest in the report and furthermore, that overt respondent validation may only be obtained from results that are complementary to participants self-image. The style of this iterative process, where the researcher and the researched work collaboratively, is a feature of the feminist argument for qualitative research (Oakley 2000). As a consequence, member checking is a method for decreasing and shifting the power differences between the researcher and research participants as both parties are immersed within the research process and the findings. Although member checking may not be suitable for every study, the researcher considers, reflectively, that it would have enhanced the data obtained from the participants. Unfortunately due to the researcher having to take a year's break from her research after the focus groups and individual interviews took place, this was not possible.

It could be argued that the data obtained from the participants in this study was not sufficiently validated to establish its trustworthiness. But, as Sparkes (1998; 2000), Wolcott (1994) and Silverman (1993) assert, should researchers question the information and data research participants convey? Or as Kvale (1989) and LeCompte and Preissle (1993) maintain, should researchers consider reliability and validity as being justifiable in all research?

The trustworthiness and authenticity of the participants' comments could have been internally validated further by a more comprehensive portrayal of the respondents' assertions about access issues (Schofield 1993). This could have been depicted through a more detailed account drawn from the interview transcripts and the field notes. This would have reflected the reality and concepts that the participants portrayed, and given greater value to the trustworthiness of the research (Lincoln and Guba 1985).

Nevertheless, the researcher contends that in qualitative research what is more important than the notions of validity and reliability, is understanding, and the ability to see through the eyes of the research participants. But that the notion of questioning the trustworthiness of participants' responses must instigate an enquiry about power relationships within research.

6.4 'Whose Project is it Anyway?'

For successful inclusive design, designers must be aware of not only the need to engage with end users, but how to engage with them. The power relationship between research participants and the researcher has profound implications on research production (Oakley 1981; Priestly 1999; Stanley and Wise 1993). As does the concept of who owns the knowledge produced (Stanley and Wise 1993). In the twenty first century exclusive social relations and exploitable investigatory research are no longer accepted by disabled people (Oliver 2002). Maintaining that researchers venture further towards exposing the oppression and discrimination that disabled people experience in their everyday lives by working towards an emancipatory paradigm is the way forward for disability studies (Oliver 2002). As discussed later in this chapter, emancipatory and participatory research methods favoured by disability activists redefine the political position of the researcher (Priestly 1999).

Partnership research has a demanding agenda. To enable real dialogue and partnership some, if not all, control has to be handed over (Lloyd *et al.* 1996). Silverman proposes that researchers choose one of two roles in relation to their work:

The partisan is often condemned to ignore features of the world which do not fit his or her preconceived moral or political position. The scholar goes too far in the other direction, wrongly denying that research has any kind of involvement with existing forms of social organisation. Both positions are too extreme and

thus fail to cope with the exigencies of the actual relationship between social researchers and society.

(Silverman 1998, p.93)

However, Oliver (2002) contends that due to the trappings of the material and social relations of research production it is not always easy for researchers to choose a partisan or scholarly position. Whereas Oakley (1999) maintains that in qualitative research, class and ethnicity interpose their own dimensions complicating the notion of an equal social relationship between researcher and researched. Signifying that there is explicitness on the part of the researcher to define what is done to whom and how.

The basis of the feminist argument that traditional, quantitative research methodology cannot be used uncritically to further the political goals of women, can be paralleled to research with disabled people. Feminists assert that the voices of women as an oppressed group are unlikely to be heard (Oakley 1999). The researcher contends that this premise is as pertinent with the voice of the disabled community. Whereas Belenky *et al.* (1999) contend that "...the male experience has been so powerfully articulated that we would hear the patterns in women's voices more clearly if we held at bay the powerful templates men have etched in the literature and in our minds" (Belenky *et al.* 1999, p.162), and Fawcett (2000) asserts that "... feminist perspectives can be used as a critical tool to appraise developments in the field of disability ..." (Fawcett 2000, p.143), so Wendell (1997) maintains, "I look forward to the development of a full feminist theory of disability" (Wendell 1997, p. 275). Where the theory of disability and the "...theory of the oppression of the body by a society and its culture" (Wendell 1997, p. 275) can amalgamate to ensure that research into disability related issues are specific to disabled people and that their voices are heard and not oppressed.

Whether the outcomes of research for disabled people are beneficial or not, can only be identified by those who it finally affects, the end user, the expert in the field. In the field of design research, social and participatory paradigms are new concepts and the power balance between researcher / researched relationships is still weighed in the favour of the researcher. Margolin and Margolin describe a designers "...professional knowledge differentiating their ability to conduct a design project" (Margolin and Margolin 2002, p.26). To suggest that designers have more authority over a design project than end

users involved in the design process, conflicts with the emancipatory research paradigm and the inclusion that the disabled community are endeavouring to attain

Redmond (2005) describes how the researcher is "...a central player in the research exercise" (Redmond 2005, p.75) who "...cannot be left behind... from discussions and written accounts" (Stanley and Wise 1993, p161). He further contends that a researcher, even when adopting a 'professional' approach to their research, cannot exclude other parts of themselves, i.e. their social persona. The mother, father, parent, partner, husband, wife, comedian, actor or any other descriptive category, that makes them who they are (Redmond 2005). This premise is equally important when considering the respondents within the research process. Everyone has their own life history or story as individual's lives are shaped by experiences and encounters that occur throughout daily living. As previously discussed in chapter 2, one of the requirements of the participants included in this study was that they had been previously able bodied. This criterion was included as it was considered that individuals who had been previously able bodied would be able to view access issues from 'both sides of the fence', and would have a broader knowledge base concerning accessibility issues (Safisios-Rothschild 1981). Feminists advocate that ways of knowing are affected by social position, and that women know in a different way from men (Oakley 1999). This premise can be paralleled to disabled people knowing about disability in a different way from non-disabled people, which assimilates with the concept of engaging with previously able bodied participants as part of the research process (Safisios- Rothschild's 1981). The most common form of feminist research is narratives or life histories (Holloway 1997). Utilising life stories or histories would have enabled the researcher to understand the participants' beliefs and behaviours regarding access issues. However, it was determined that this type of methodology would not fit in with the overall requirements of the study, as the research was primarily to inform designers of how to include end users within the design process through inclusive methodology. As has previously been discussed, designers consider engagement with end users an arduous occupation, and it was deemed that to ask them to consider engaging with end users via life histories would be totally unsuitable (Wilcox 2005).

The concept of engagement with end users raises several issues that designers must deliberate (Cassim 2005; Wilcox 2005). The methods for successful engagement with

end users / research participants (an important factor as it is rarely taught / used within the design process), basic knowledge of different disabilities (not to become medical experts, but a little knowledge may help a designer to understand why someone has specific requirements), definitions and correct terminology (to avoid offending someone e.g. someone has cerebral palsy, they are not a spastic), where / how to acquire statistical information and legislation (it is important for a designer to be aware of regulations within the designing and building professions) and an understanding of power relationships and who owns the knowledge produced (to understand more about the world around them, and the influence that they can and will have on society through their designs and products). Except for the last criteria, which has to be learnt through experience and academic reading, the other requirements provided the basis for the design resource that has been produced to accompany the PACE model of inclusive design (see chapter 9).

6.5 Non-Disabled Researchers

The debate amongst disability groups, writers and academics about non-disabled researchers and their ability, or non-ability, to complete successful research into the field of disability is contentious. Drake began the debate in 1997 when he called for there to be no apartheid between disabled and non-disabled people (Drake 1997). He acknowledged that women and ethnic minority communities sought for equal rights with their peers, and contested that if all citizens are to enjoy equal rights and full social and environmental access, disabled and non-disabled people must work together. In a scathing attack on Drake's observations, Branfield pronounced that non-disabled people who try to justify their involvement in disability research are "...doomed to failure.....non-disabled people will always be non-disabled, they [non-disabled people] are not where we are and can never be" (Branfield 1998, p.143). This sentiment is echoed by Morris who asserts that:

They [able bodied researchers] have few tools with which to understand our subjective reality because our own definitions of the experience of disability are missing from the general culture.

(Morris 1991 cited French 1992, p.184)

As noted previously, Branfield's contention that the disability movement should only be influenced by disabled peoples voices and actions for change and re-definition is opposed by Duckett (1998). He argues that by excluding non-disabled researchers from

the disability movement Branfield opposes inclusion and the principles of the social model. Duckett likens this binary split between disabled and non-disabled people to a similar set of binaries: male/female, child/adult, black/white (Duckett 1998). He contends that

...these are binary oppositions sustained by this type of discourse where one binary is preferred to the 'other' and afforded socioeconomic and political privileges in the process

(Duckett 1998, p.625)

Branfield's assertions turn the historical tables of oppression and privileges so that the 'other', that has previously been dealt the lesser hand, is now the advantaged (Branfield 1998). According to Duckett (1998) this repositions the focus of oppression while leaving the practice of oppression intact. Branfield concludes her argument by stating that disabled people must be "...the initiators and designers of our own liberation" (Branfield 1998, p.144). In opposition to this, Drake (1997) asserts that there are three reasons how non-disabled researchers can be of value within the field of disability research. Firstly to expose the disabling policies and practices of society through research, secondly to supply resources to disabled people's groups and thirdly to respond to specific requests from disabled people's groups (Drake 1997). These roles of non-disabled researchers do not pose a threat to distort disabled people's agenda nor do they compromise disabled people's control over their lives. It is important that non-disabled researchers realise the need to *join with* disabled people rather than lobby *on behalf of* them or their groups (Drake 1997). Barnes is "...not convinced" (Barnes 1992, p.121) that having an impairment is necessary to produce good research in the field of disability. He contends that

...the experience of impairment is not a unitary one....having an impairment does not automatically give someone an affinity with disabled people, nor an inclination to do disability research

(Barnes 1992, p.121)

He further argues that "...cultural differences such as class, education and life experience may present as many barriers to the researcher as disability" (Barnes cited Priestly 1999, p.18).

Glaser and Strauss (1967) suggest that there is a mis-match between 'academic' theory and the lives of the research but that qualitative practice can illustrate the experiences of socially disadvantaged groups. While Oakely (1999) maintains that the power

inequalities between researcher and researched are politically unacceptable. The debates about who is 'suitable' to complete research into areas which are not their own personal expertise are extensive. However, as Oliver maintains "...the world of research is far more complex than many researchers recognise" and that "...researchers have to look at the interaction between their research practices and their own politics" (Oliver 2002, p.12). If this concept is to be believed, then it is irrelevant if the researcher is disabled or able-bodied. The significance of disability research should be embodied in the understanding of the social model of disability, the aspiration towards an emancipatory research paradigm and the feminist premise which enables the voices of oppressed groups to be heard (Oakley 1999).

6.6 Disability Research – A Descriptive Analysis

As discussed in the literature review, the study of disability is a relatively recent phenomenon (Gleeson 1997). Early research surrounding the field of disability was completed by scientists and sociologists. There are examples of studies about institutional living (Goffman 1961; Miller and Gwynne 1972), stigma (Goffman 1963), 'doctor patient' relations (Parsons 1951) and large scale studies that recorded the number of disabled people in the population (Harris 1971; Martin *et al.* 1988). These studies provided insights into today's thinking about disability and related issues (Barnes 2001). Although early disability research, and the assumptions underpinning it, was dominated by a positivist research paradigm (Oliver 1992; Rioux & Bach 1994). Positivist methods and the need to warrant hypotheses with statistics and credibility was questioned by early feminist researchers (Oakley 1999). They questioned epistemology (how we know what we know) and ontology (how we understand reality) and decreed that masculine, quantitative methods treat the researched as enumerable. The development of feminine, qualitative research methods can be seen as a precursor to today's disability research paradigms, as the 'hearing of silent voices' is a tenet of both feminist and disability research methodologies.

It was not until the late 1950s that theories and practices about disability began to change and previous concepts became discredited (Rioux & Bach 1994). As such, whilst medical and biological research continued to look for methods to prevent disability, at the same time the field of rehabilitation began to 'open up'. Early investigations concerned how to enable people with disabilities to learn skills and to

take care of themselves (Rioux & Bach 1994). Rioux & Bach (1994) describe how in the 1970s rehabilitation for disabled people expanded as professionals and researchers worked together with people with disabilities in sheltered workshops and large group homes. Despite knowledge of disability expanding, therapies for the treatment of disabilities were still widespread and continued to compound earlier theories that disability resided with the individual (the medical model). The research question had not yet changed, but the domination of the field by so called experts and the positivist perspective of research began to be questioned by disability activists and researchers (Goodley and Moore 2000).

Since the 1960's qualitative research had experienced a steady growth and has seen the advent of grounded theory and ethnography. Health and social care professionals have used these new interpretive methods as relevant and appropriate to their work and feminists accepted interpretive approaches that were concerned with the understanding of human beings. But, in the field of medicine, qualitative methods were slow to be accepted as a respectable way to complete research. It has been argued that as disability was still entrenched in the medical model; qualitative methods within disability research were not easily embraced.

Encouraged by the effects of the civil rights movement in the United States, politicisation of disability by disabled people began. This was encouraged by the 1976 redefinition of disability by UPIAS and the emergence of the social model of disability. Disability groups began to critique positivist research and critically evaluate traditional research methods and practices (Rioux & Bach 1994). Activists advocated that disability studies should move away from the biological classification of disability and take into account the material constraints in the lives of people with disabilities (Oliver 1992). At the same time the 'second-wave' feminism was developing. As with the disability movement, feminism was encouraged by global civil rights and the gender conflicts that arose around that time as well as increased labour force participation (DeVault 1999). This consciousness raising was at the heart of both the women's movement and that of disability activists.

During the 1980's, research into the field of disability reached a turning point as disabled researchers began drawing on personal experiences of disability to illustrate how social and environmental forces affected their lives (Morris 1989; Barnes 1990;

Oliver *et al.* 1988). The changes in disability research that were paralleled by researchers in the other social science fields, particularly feminism, (Oakley 1972; Stanley and Wise 1993) and literature surrounding critical social research began growing (Barnes 2001). Confidence within the field of disability research developed as disabled writers, activists and organisations began to speak openly about personal experiences of disability. Oliver and Zarb encapsulate this change succinctly when they contend that disabled people require:

...the personal and public affirmation of disabled identities and the demands that disabled people be accepted by and integrated into society as they are; that is, as disabled people.

(Oliver and Zarb 1989, p.225)

The transformation of disability research in the 1980's culminated in 1989 when the BCODP commissioned a study into discrimination encountered by disabled people (Barnes 1991). Social exclusion and oppression experienced by disabled people was brought to public attention and the emergence of the emancipatory disability research paradigm began.

In the 1990s disability activists argued for researchers to join disabled people and use their skills and expertise to assist in the struggle against oppression. In 1991 The Joseph Rowntree Foundation funded a series of seminars that provided a forum for development of the new methodology (Barnes 2001). Barnes (1992), Oliver (1992) and Zarb (1992) were instrumental in the instigation of many of the changes that took place in disability research at that time, specifically the advent of the participatory and emancipatory research models. Disability groups, activists and researchers maintained that the new research methodology should promote social well-being and endorse the elimination of the social and physical barriers that they saw as creating handicap. The proposals for the new paradigm were that it encompassed not only the experiences of people with disabilities, but also the phenomenon of disability (Oliver 1992; Rioux & Bach 1994; Zarb 1992). Oliver was one of the prominent disability activists who condemned research on disability (Barnes *et al.* 1999). He remained resolute in his views that positivist and interpretive research approaches merely reinforced one another and that another paradigm for disability research was required. Whereas feminists (Oakley 1999) considered that positivist and interpretive research methods were as diverse as masculinity and femininity. However, in 1992 encouraged by activists, writers and disability organisations, Oliver coined the term emancipatory disability

research (Barnes 2001). Oliver contended that "...the very idea that small groups of 'experts' can get together and set a research agenda for disability is flawed" (Oliver 1992, p.102). He maintained that this type of notion could only be considered by a society with a "...hierarchical social structure which accords experts an elite role" (Oliver 1992, p.102). Barnes argued that qualitative research methods are "...fundamental to an emancipatory research paradigm" and that they would be relevant if "...researchers challenge the institutions which control disability research production" (Barnes 1992, p.115). Barnes, Oliver and Zarb concluded that previous research methods were inadequate for assisting disabled people in their struggle to relinquish oppression and that a new research paradigm was required. Zarb advocated for "...consultation between researchers and disabled people, subjecting research to critical scrutiny, and making researchers accountable to disabled people" (Zarb 1992, p125). His paper 'On the Road to Damascus' (1992) set the precedence for future research in the field of disability.

Zarb argued that too much talking and thinking was delaying changes in disability research methodology. He considered that to change the social relation of research production, researchers must challenge funding institutions and policy makers as they had much control over the "...material relations of research production" (Zarb 1992, p.127). He further maintained that far from being a solution to oppressive practice, research at the time exacerbated the problem. To understand the changing relations of research production, research practice needed to be subjected to further critical evaluation.

It can be seen that research into the field of disability reached a turning point during the latter part of the twentieth century. The research agenda changed, from being biomedical and service delivery lead, to one where disability was recognised as being socially constructed and an oppressive struggle for the individual (Oliver 1992; French 1992; Zarb 1992; Campell Brown 2001). Previous assumptions underlying disability research had to change to assist disabled people in their struggle for empowerment (French 1992; Barnes 1996). This change in the research agenda acknowledged for the first time that there were wider political implications within the field of disability that were being ignored (Rioux & Bach 1994). However, within the wider realms of historical social research development, disability research was not so prevalent. By

contrast the augmentation of feminism was endemic. The reason for the disparities in the growth of the two methodologies may have been attributed to several factors. The commencement of feminism through academia (more feminist academics than disability scholars), feminist traits linking into Civil Rights Movements and consciousness raising (women's status projects in the 1960's) and the hypothesis that 'feminism' is a movement, a set of beliefs that should be envisaged as a "...changing and contested discourse" (De Vault 1999, p.28). Nonetheless, disability research paradigms are evolving (Swain *et al.* 2003) and emancipatory research techniques are promoted by disability research academics and activists. However, participatory and emancipatory research may not be as straightforward to accomplish as researchers anticipate. As Redmond (2005) states

...embedded in my own grand ideas as to what inclusive research is, and might be, I was the one who was dictating the agenda. I was the one who was insisting on a particular engagement..... irrespective of whether that was what they wanted or not

(Redmond 2005, p.77-78)

As Barnes *et al.* (1999) affirm disability research should "...be judged solely in terms of whether it has contributed to the process of enabling disabled people to empower themselves" (Barnes *et al.* 1999, p.219). If this tenet of enabling empowerment is mirrored into the principles of inclusive design and designers are persuaded that engaging with end users is advantageous, then designers can, and will, influence more cultural change than previously attained.

6.7 Choice of Research Methodology

6.7.1 Emancipatory and Participatory Research Paradigms

In 1992, Zarb acknowledged that although an emancipatory research paradigm was required for successful disability research, the best researchers at the time could strive for was a participatory model. He described the difference between the two methodologies succinctly:

...participatory research is a prerequisite to emancipatory research in the sense that researchers can learn from disabled people and vice versaincreasing participation and involvement will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how.

(Zarb 1992, p.128)

Table 3 summaries the difference between participatory and emancipatory research according to "...Zarb and others on six major dimensions" (Walmsley 2001, p196). It

can be seen from table 3 that participation is not tantamount to emancipation (Priestly 1999). The emancipatory model requires that ownership of the research should belong to the participants rather than the researcher (Oliver 2002). Barnes 1992 description of emancipatory research is succinct

...the demystification of the structures and processes which create disability, and the establishment of a workable 'dialogue' between the research community and disabled people in order to facilitate the latter's empowerment

(Barnes 1992, p.122)

Table 3 - Participatory and emancipatory research

	Participatory Research	Emancipatory Research
Methodology	Phenomenological (getting inside the experiences of research subjects)	Research as political action; either qualitative or quantitative method
Ideology	Not prescribed; likely to be either normalisation or social model of disability, and to promote positive images of disable people	Adoption of social model of disability; research only undertaken if it will practically benefit disabled people
Who is in control?	Researcher in partnership with disabled people, particularly at data collection stage	Disabled people in control of all aspects from formulation of questions to dissemination
Role of researcher	Expert, sharing expertise with research subjects; sometimes also and advisor/supporter	Expertise at disposal of disabled people, accountable to disabled people
Subject matter	Issues relevant to the lives of disabled people	Explores and identifies appropriate avenues for change
Accountability	Accountable to funders	Accountable to disabled people and their organisations

(Walmsley 2001, p.196)

Priestly describes emancipatory research as presenting "...a substantial challenge to the established social relations of research production" (Priestly 1999, p.15). He concludes that it is a methodology that is "...commensurate with the emancipatory struggles of the disabled people's movement" (Priestly 1999, p.15) and, with Stone, identified six core principles that characterised the emergent paradigm.

- the adoption of a social model of disability as the basis for research production

- the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation
- the willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and / or the removal of disabling barriers
- the evolution of control over research production to ensure full accountability to disabled people and their organisations
- giving voice to the personal as political whilst endeavouring to collectivise the political commonality of individual experiences
- the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people

(Stone and Priestly 1996, p.706)

These factors combine to produce a research paradigm that ensures disability research is conducted for the people who matter, disabled people themselves. The research should be guided by the experts in the field, not by the researcher-as-expert paradigm previously employed (Barnes *et al.* 1999; Priestly 1999; Oliver 2002). Barnes asserts that emancipatory disability research should be "...judged mainly by its ability to empower disabled people through the research process" (Barnes 2001, p.16). However, for researchers adhering to the emancipatory paradigm, Barnes *et al.* (1999), Barnes and Mercer (1997), Stone and Priestly (1996), Moore *et al.* (1998) have identified several uncertainties that should be considered,

Is the elimination of power differences always feasible or necessary? Is the relationship reversed or equalised? How is accountability to the research subjects guaranteed? Is it presumptuous to assume that the social world is divided neatly between oppressors and oppressed and that each is a cohesive grouping.

(Barnes *et al.* 1999, p.217)

It can be seen that participatory and emancipatory research paradigms are akin to the social model of disability due to their principles of empowerment (French 1992). Participatory strategies attempt to combat the problem of emancipation by sharing, or attempting to share responsibility and blame, with the research participants (Oliver 2002). In his conclusion Barnes (2001) reflects that the emancipatory research paradigm may not be achievable and that it should be seen as a process rather than viewed as single or multiple projects. He maintains that

Each piece of research must build on and develop what has gone before. It must seek to make a further contribution to our understanding and ability to erode the various forces: economic, political and cultural, with continue to create and

sustain disability at both the macro and micro levels. This is not an easy task that all of us involved in doing disability research should be aiming for.

(Barnes 2001, p.16)

Although the discussion advocates an emancipatory research paradigm, a participatory strategy was employed during the study.

6.7.2 *Ethnographic Methods*

The researcher began to engage with qualitative methods through ethnographic literature (Hammersley and Atkinson 1995; Coffey 1999), which suggested that there was the possibility of a more participatory engagement with the sample than the researcher had previously experienced with design research methods. The first phase of the study utilised a methodology that had an ethnographic perspective in order to obtain data relating to access issues experienced by wheelchair users. Ethnography, taken from the Greek, meaning '*a description of people*' (Holloway 1997) seemed a suitable methodological perspective for this phase of the study by definition alone. It offered an 'open minded' approach that compliments the emancipatory research paradigm and allowed research participants an open forum to discuss disability access issues. Spradley (1979) advocates that ethnographers focus on cultural description and are able to consider

...what the world is like to people who have learned to see, hear, speak, think and act in ways that are different

(Spradley 1979, p.3)

This 'open minded' methodology, with its ability to begin with a blank canvas and to be able to change direction as its participants dictate (Fetterman 1989; Hammersley and Atkinson 1995; Coffey 1999), has recently been advocated within the design profession as its methods are comparable to the design process itself (Lorenz 1990; Pugh 1991; Wilcox 2005). Unlike phenomenology and its philosophical approaches for studying human experiences and phenomena (Giorgi 1985), and grounded theory and its development of theory (Glaser and Strauss 1967), ethnography allows the researcher to explore the area being researched from an objective, interpretive naturalistic stance, which allows the exploration of the perspectives, thoughts and feelings of the participants (Atkinson 1992). In short, ethnographic methods offer processes that are proficient for sociological exploration and allow the researcher to understand research participant's culture through self immersion (Coffey 1999; Davis 2000). They allow real involvement in the field under study and the in-depth exploration of the thoughts

and feelings of the participants (Spradley, 1979; Davis, 2000). The researcher considered this type of interactive approach appropriate for determining disabled peoples views about access issues. Furthermore, some ethnographic techniques (respondent involvement) can be paralleled to the principles of inclusive design, where the involvement of the experts in the field is supported by this study. As Oliver (2002) asserts "... ethnographic accounts are dependent on one to one interactions with key informants" (Oliver 2002, p.4). This notion of participant interaction concurs with inclusive design methodologies.

6.7.3 *The Choice of Focus Groups for Data Collection*

Since the early 1980's focus group research has become an accepted tool in social research (Puchta and Potter 2004). The flexibility and ability to create discussion through peer interaction makes the methodology a useful tool for obtaining participants' views on the subject being researched (Vaughn *et al.* 1996). However, they are a methodology that has only been incorporated in design research in recent years (Langford and McDonagh 2003).

Although the topics to be discussed are likely to be predetermined by the researcher, focus groups are regarded as a participatory research method (Shaw and Gould 2001). Whilst this assertion is contradictory, it also raises an issue that is discussed in chapter 8 concerning the validity of research participants' views, in comparison to the rest of a social group. In the case of this study, the fact that the researcher found out that a select few members of the local disabled community participate in the majority of research and consultation exercises. This difficulty in the recruitment of research participants is summed up by Dullea and Mullender, when contemplating the place of focus groups in social work research.

It is not unknown for so-called participation in social work evaluation to consist of a few representatives of the community being assembled in the ubiquitous focus group, which has no roots in the actual community groupings and derives its *modus operandi* from consumerist market research, not from social work practice or values

(Dullea and Mullender 1999, p.94)

However, the discussions that can be instigated from peer interaction about participants shared understanding of their everyday lives can provide valuable information that would not be obtained from individual interviews or surveys (Knodel 1993; Morgan

1998). The main purpose of focus group research is to draw out participants' experiences, feelings, attitudes, beliefs and reactions in a way that is not found in any other research methodology (Krueger 1994). The unique multiplicity of these insights into peoples' everyday lives is revealed through the social gathering and interaction of the group. Whilst the individual interview is easier for the researcher to control, focus groups enable the participants the ability to take the initiative and offers them empowerment to be honest and direct about their experiences, offering the researcher a true insight into their lived experiences (Morgan 1998; Kruger and Casey 2000; Langford and McDonagh 2003). Although focus groups do prove a challenge for the researcher, they do offer a unique insight into the world of the subject being researched (Langford and McDonagh 2003). They also link into participatory research paradigms, by enabling the researched to participate fully in the research process by offering a personal viewpoint (Zarb 1992). This in turn is associated with the social model of disability and inclusive design principles.

6.7.4 Choice of Methodology

As previously discussed, the main principle of emancipatory research is to dissolve the concept of 'researcher as expert' and to enable the research participants to bring to the fore what matters most to them. It should be acknowledged, however, that the fields of design and social science are very different. When completing research for a project, designers explore the market, technical aspects, materials, costs, statistics, manufacturing techniques, timescales, shelf life, patents, legalities, ergonomics, anthropometrics, dimensions, testing, shipping, packaging, life in service, durability, disposal and any other constraints - all items that refer to inanimate processes (See Appendix 2b – Pugh's plates). Social science research has a different emphasis on increased user participation, with the data being obtained and analysed from peoples' perspectives rather than emphasis upon measurement and statistical analysis, as has occurred historically in design research. It can be seen from previous discussions, that inclusive design, qualitative research methods and the participatory research paradigm can all potentially assist disabled people in their pursuit for inclusion. This study has recognised that designers should listen to end users and proposes a design methodology that incorporates qualities from each of these processes.

The methods used to obtain the data that led the researcher to this conclusion, have enabled the participants to 'have their voices heard' in the process and for them to influence the study by sharing their experiences. The use of focus groups enabled group interaction and peer support to facilitate the participants to speak openly about access issues that they had encountered. While the follow up interviews facilitated a more in-depth discussion with each participant about the topics raised. These sessions also allowed the participants the time and privacy to make any comments that they had not wanted to discuss during the focus group.

It should be acknowledged, as previously stated, that the fields of design and social science are different. However, drawing upon both disciplinary perspectives to produce a new and innovative design procedure that incorporates the end user (the expert in the field) would be beneficial to both the designer and the consumer. The following chapter examines the data which emerged from the focus groups and interviews. It considers the ethical issues, ownership of the knowledge produced from research and the importance of adhering to an ethical code or framework.

CHAPTER SEVEN – RESEARCH STRATEGY AND DATA COLLECTION

This chapter describes how data was collected from wheelchair users to ascertain information about access issues within the built environment. It deliberates upon the importance of fieldwork in the data-gathering process and discusses the ethical considerations of carrying out research in a social services facility. The debate then examines the advantages and disadvantages of using gatekeepers in research particularly during sample selection, and continues by reflecting on the focus group process and how the information gathered was used to complete semi-structured follow up interviews with individual participants. The chapter concludes with an overview of how the data obtained was transcribed and then analysed using content analysis.

7.1 The Research Strategy

The first phase of the project utilised focus group methodology to discover topics raised by wheelchair users about access issues within the built environment (Robson 1993; Shakespeare 1996). Qualitative research was utilised as traditionally it begins with defining general concepts which might change in definition as the research progresses (Marshall and Rossman 1995). One of the disadvantages of qualitative research is that the naïve researcher is open to the constant danger of ‘information overload’ (Robson 1993). However, the data obtained presented a personal and factual perspective about disability and design that could not have been gained through literature alone.

At the data collection stage it was decided to obtain any views that wheelchair users had about access issues. The focus groups began with the question “Tell me about access issues – anything that is important to wheelchair users”. The data provided was extensive. As a consequence the original project concept had to be amended to reduce overload of information and to obtain richer data about the issues raised.

7.1.1 Fieldwork

Fieldwork began during a voluntary teaching placement at a day centre in Dorset, the same day centre where one of the focus groups and individual interviews was to take place. The researcher found as Barnes (1992) did that “...in general, voluntary workers are viewed positively by both users and staff” (Barnes 1992, p.119). A volunteer is on neither ‘*one side nor the other*’ and is impartial to the internal and external politics of an organisation that can affect those who work in, or attend on a part time or full time basis

(Barnes 1992). One element of the placement was to assist in the dining room at lunch time. Duties included helping service users order their lunches, carry their trays, tidying the dining room and generally socialising. Socialisation is a fundamental part of day centre attendance for many service users and several lines of enquiry were brought to light during casual conversation (Oliver 1983). One dilemma encountered was whether or not to disclose information divulged by research participants outside of the research context (French 1993). Confidentiality and ethics had to be considered and it was decided that any information disclosed during casual conversation would be noted anonymously in a journal (Emerson *et al.* 1995) and only referred to as a reminder of topics discussed and to assist with the development of questions at focus group sessions (Lofland and Lofland 1984). Many of the service users were involved with local groups who were lobbying various organisations to improve services, or were making sure they and their peers obtained the benefits they were entitled too. Listening to, and being invited to join these discussions placed the researcher in a privileged position as people's true feelings and animosities were communicated openly (Stanley and Wise 1993). During later stages of the research process, information gathered during the fieldwork assisted in understanding why participants responded in the way they did. As noted elsewhere, an example of this was the development an understanding that if a person has limited mobility, their body language cannot physically be the same as that of an able bodied peer. Therefore when discussing a frustrating issue, instead of gesticulating with their arms as an able bodied person would do, someone with restricted upper body mobility would swear profusely during a conversation.

7.2 Ethics

Unlike design research an investigation within the social world demands an ethical framework or the adherence to an ethical code, in order to minimise the impact of the research process on participants and to govern or guide the researcher – participant encounter. Ethics relate to moral standards and are usually considered to be general principles of what we ought to do (Kimmel 1988; Robson 1993). Ethics for social research, are “...usually expressed in agreed codes that are particular to each academic discipline” (Higham 2003, p.1). At the time of undertaking fieldwork ethical consent was not required from a regulatory body (Bryman 2001). However, new regulations now exist and there is a need for health and social care researchers to be aware of the

‘Research Governance Framework for Health and Social Care’ developed by The Department of Health (2003 cited IHCS 2004, p.6).

In 1996 and 1997 when the focus groups and individual interviews took place, there was no requirement from the local authorities that the researcher liaised with, to adhere to a Research Governance Framework or specific ethical guidelines required to be adhered to. (However, as a consequence of the development of the Research Governance Framework for Health and Social Care (DOH 2003), and a greater understanding of how ethical issues should be considered throughout the research process (particularly research involving service users), at least one of the local authorities consulted during the initial stages of this project has now introduced a research framework for investigators wanting to complete research). Given the absence of any specific ethical code or Research Governance Framework required by the Social Services departments, it was considered of paramount importance to adhere to a number of important ethical principles. These included:

- To respect participants’ autonomy
- Be aware of any potential harm to participants
- The justification of benefits of any research
- Research proposals are fair and just
- To appreciate participants rights to privacy and confidentiality
- To keep promises, fulfil agreements and not to deceive participants

These guidelines, developed by the researcher and her supervisory team, were established in order to provide an ethical framework that would safeguard both the researcher and the participants of the study. A decade ago when the research for this study took place, no specific ethical code was available for the researcher to use. However, had Butler’s code (2000) been developed at the time, the researcher would have used it’s principles to develop an ethical code for use by designers (see chapter 13 – section – contribution to knowledge).

As previously stated, health professionals and care workers have to consider ethical issues as a part of their everyday working life. Ethics are at the heart of these disciplines, as the work of the professionals is intrinsically linked with the care of people with a variety of needs. The way in which these professions are to be managed,

organised, planned and practiced requires a monitoring process as a way to protect both the professional and the patient / service user. This process occurs, in part, via ethics.

This is a very different way of working from that of a designer, whose main concerns are typically profit, market, manufacturing constraints, sustainability and kudos. Although ethical concerns come into play within the design process, it is fair to say that they are very different from the ethical concerns within social care or social research. Gaughran and Billett (2003) contend that ethics relating to design have many facets. Material selection, ecological concerns, safety issues and the designer / client trust being the principal concerns, while the fundamental issue of design ergonomics impacts on a more fundamental level. At the design conference Responsible Design Practice (2003), designers were asked “Should designers have values?” The answer from delegates was

Yes, shouldn't everyone? Designers have a responsibility to their client....More education is needed...

(D-Futures7, 2003, p.5)

However, there was no discussion about the designers responsibility to the end user, the discourse focused purely on the designers' responsibility to the client, although it was conceded that “...design is all around us and is underpinned by society's values” (D-Futures 7 2003, p.6). When delegates were asked whose ethics should be employed, ours (designers) or the rest of the worlds? The answers quoted were:

Anyone successful has to decide their ethics and stick to them. That's out of our control. We need more information on the brief.

(D-Futures 7 2003, p.6)

At the Helen Hamlyn 'Include' Conference 2005, Chesters *et al.* (2005) maintained that empowering disabled consumers can actually empower design. However, the concepts of exactly how to offer empowerment and / or the implications of enforced empowerment and how detrimental it can be to disabled people, or the ethics of research with disabled end users was not discussed.

It can be seen that inclusive designers are now acknowledging (Chesters *et al.* 2005) that user-centred design will produce the “...best designed products and services that result from understanding the needs of the people who will use them” (Cassim 2005, p.1). However, whilst ethics and design are now on the agenda, current writing only pertains to the practicalities of the design process and not to the specific requirements of consulting with end users throughout the design course. It is this element that the

researcher contends should be the next step forward for professionals in the field of design (Chapter 13 – Section – contribution to knowledge).

7.2.1 The Need for Ethical Codes in Research

Ethical codes are a method of ensuring that protocols for user engagement and participation are established. They further guarantee that there is a balance between the requirement for effective scientific research and the need to respect the rights of research participants (Higham 2003). It has long been established that in medical related research, the Hippocratic Oath code of ethics is referred to in order to ensure research is ethically sound. The Biomedical code of ethics is based on beneficence (doing good), non-maleficence (doing no harm), respect for autonomy and truth and justice (Eby 2000). Conversely, social work research has “...struggled to achieve its identity as an academic discipline as well as an occupation or profession” and has “...lacked an identity as a research discipline in its own right” (Higham 2003, p.1). As social work’s responsibility is embedded within the field of social care it has long embraced a code of ethics for practise, but, it is only recently that there has been a commissioning strategy to develop a code of ethics for the social work researcher (Butler 2000).

Butler’s code for social work research (2000) draws on the existing code for medical research and reflects the need to recognise different relationships between service users and their informal carers. He contends that researchers should take moral and practical responsibility for their research while maintaining a primary concern for participants, ensuring that consent is obtained, covert research is avoided and that service user’s participation is acknowledged (Butler 2000). For social workers the code would also require promoting welfare, empowerment, non-discrimination and ensuring that service users’ are not compromised in any way. While this premise is seemingly acceptable for social workers and / or health / social care workers, it does not hold the same connotations for design professionals. However, if designers are to successfully engage with end users throughout the design process, then they need acknowledge a form of ‘duty of care’ towards the research participants that they will work with. Particularly, as with this study, research participants are service users with a social service department.

Beresford maintains that service users’ view research as “...part of discrimination and oppression...” and that it is an activity which “...is both intrusive and

disempowering...” (Beresford 1999, p.1). But, he also acknowledges that “...service users' knowledge grows out of their personal and collective experience” (Beresford 1999, p.1). In 1996 / 1997 when data was being gathered for this study, the latter of these statements was the sentiment at the centre of the researcher's choice of location for the participant. However, during the last decade, via experiences from both academic study and professional experiences, the researcher now questions the utilisation of service users in academic research. This change of heart about research techniques can be summed up from dialogue obtained during the first focus group. At the start of the focus group, while chatting generally about their experiences, participants discussed how on one occasion research students from a local college had been allowed to video service users at a day centre, without consent, and had not returned to discuss their findings with staff or service users. This highlights the need for ethical guidelines in research to protect participants (service users), the researcher and the institution. It also demonstrates a need for gatekeepers to adhere to an ethical code and to ensure that research is completed in an appropriate manner.

This study does not suggest that designers take on social work type roles, or become social workers of a form, but showing consideration for participants' views and ensuring their health, safety and protection will lead to the attainment of more substantive data. During the design process “...each stakeholder has intelligence that other stakeholders need and, by the same token, they themselves need intelligence from each of the other stakeholders” (Chesters *et. al* 2005). As Chesters *et. al* (2005) assert and this study affirms, as few designers are themselves disabled and therefore have little or no experience of the barriers, needs and requirements experienced by disabled users, establishing design priorities can only be successfully achieved through consultation and participation with the experts in the field, disabled people themselves. This in turn, should be done in a way which not only results in the acquirement of data, but also in a manner that protects both the researcher and the participants.

Timms (1983) asserts that:

...ethical principles are not fixed directions in the manner of an instruction manual, but are the basis for making choices in situations where a range of actions is possible

(Timms 1983, p.32-33)

While Homan (1991) contends that:

...codes are established on the basis of a considerable measure of self interest

(Homan 1991, p. 30)

If these principles are, in turn, linked with Butler's (2000) contention that "...codes of ethics need to be contextualised and situated" (Butler 2000, p.1), it can be illustrated that there is a need for researchers to observe a code of ethics to enable them to complete research in a morally, justifiable way that is important to the research question while protecting the participants from harm or risk. This tenet may be biased towards health care professionals, but this study contends that designers should consider it a principle factor when engaging with end users throughout the design process. Furthermore, if Timms (1983), Homan (1991) and Butler's (2000) hypotheses that ethics need to be contextualised and that they can never be morally or ethically be neutral as they will always articulate the beliefs and principles of the maker, then there is a need for the development of a code of ethics for designers who intend to engage with end users as part of the design course.

Committees monitor ethical conduct and give or reject ethical approval by considering the research design submitted to them (D'Cruz and Jones 2004). This means that predetermined designs are more likely to be approved than emergent ones, as the committee can determine the ethical context of a project at the onset. Obtaining ethical approval in this way is not 'the norm' within the design process, as, although people use end products / services they are rarely consulted during the design course. Therefore, for designers, ethical approval for research with participants is a rarity as opposed to a standard. Also, as mentioned previously, as design is similar to qualitative research methods, where there is a constant requirement to be able to change direction at any time (Strauss and Corbin 1990), emergent research designs for a design process would be challenging to develop. Whilst designers could develop research design based around the Pugh's Design Core (1991) it has to be recognised that design concepts can, and do, change frequently and for unexpected reasons, consequently causing the designer / design team to digress in unexpected directions. This, in turn, could mean that writing a substantive ethics statement at the onset of any design research could prove to be problematical. However, while "...codes of ethics may seem tiresome, bureaucratic and socially uncritical..." (D'Cruz and Jones 2004), they are established to "... guard against litigation or otherwise protect institutions as much as researchers and participants" (D'Cruz and Jones 2004). They may also induce researchers to consider ethical issues that have been previously overlooked, curb oppressive practices and combat ethical complacency. If ethics are thought about in these terms as opposed to a

procedure to be endured and tolerated, then the perception of ethical approval within the research process can be seen as something to be embraced to enhance research as opposed to an adverse procedure.

7.2.2 Acknowledging Power Relations in Research

Stanley and Wise (1993) assent to a research methodology that would change the power relationship between researcher and researched. It is not a way that the researcher purported to when completing the focus groups and individual interviews for this study, but it is a methodology that she now strives to achieve in her working life. The nature of power relations within the context of the research setting is pertinent within any study. During this study, where there were no specific ethical constraints to be adhered to, the researcher was conscious to take care not to impose her beliefs on the participants, but to ensure that their voices were heard and their views expressed objectively. However, she was also aware that as the interviews took place in day centres where the participants were service users, and that the participants of each focus group knew each other to some degree, that the power balance was not specifically weighed in the direction of the researcher.

It is recognised by Alderson (1995), Oakley (1981; 1993), Roberts (1981) and Stanley and Wise (1993), that the interviewer is located within a position of authority. Oakley (1981) observes that there is a danger that "...interviewers define the role of interviewees as subordinates..." (Oakley 1981, p.40). She further asserts that, in order to counteract this assumption, the researcher must be honest and answer any questions that may arise, irrespective of whether or not they are directly related to the research question. Conversely, Oakley (1981) also notes that interviewees also have power within the interview context, particularly when the interviews are conducted in the home. The researcher was aware of this power relationship between interviewer and interviewee prior to organising the location for the focus groups and individual interviews to take place. Choosing the day centre setting to be used for the interviews was done purposefully to ensure that the participants felt comfortable with their surroundings which, it was hoped, would in turn, initiate frank responses to the research questions. It did however, put the researcher at a disadvantage within the group as the group knew each other, the setting and the subject. The researcher was not an expert in the field being discussed, knew only a little about the setting from previous visits and

voluntary work for the day centre and only knew a couple of the participants by sight via voluntary work in the centre. The power balance between the interviewer and the interviewees was weighed more in the favour of the interviewees. The researcher attempted to offset any inequality in the interviewer/interviewee balance by offering the participants tea and biscuits before, and during, the focus groups in an attempt to ensure that she established a friendly rapport with the group (Duncombe and Jessop 2002). Oakley (1981) noted a similar circumstance during her research with participants in their own home. Some of the sample in her own research offered her a drink, whilst a few offered her a meal whilst others offered nothing. Oakley also commented that some respondents contacted her between or after interviews in order to clarify something that had been said, or to give extra information. By doing this respondents influenced the scope and quality of information gathered. By offering tea, coffee and biscuits and a friendly rapport with the participants, the researcher of this project hoped to gain enough of the participants trust for them to impart their knowledge and their views about access issues. As Duncombe and Jessop (2002) illustrate, the researcher considered that having a good rapport with the participants would ensure that the interviewees would willingly make disclosures. However, whereas Duncombe and Jessop encountered feelings of intruding or inflicting pain, the researcher was simply inundated with data. This immense accumulation of data resulted in the study being re-designed and is discussed in chapter one. The constant flux in the power relations between interviewer and interviewee exists as each party moves to occupy a position of power during the interview. Although the interviewer, at a basic level, may be in power in terms of the design, implementation and reporting of the research and the data collected, the interviewee redresses the power balance by selecting the information they concede to impart (Reynolds 2002).

7.2.3 Who Owns Knowledge?

A more fundamental issue surrounding power in the research process than that of the interview procedure itself is what happens to the knowledge gained (Gilles and Alldred 2002) and who can claim ownership of it. Knowledge and understanding may be taken from the interview setting and the interviewee who imparted the information, and then rationalised or made sense of by the interviewer or researcher. This knowledge may become generalised or skewed by a third person, particularly if it relates to the private world of the interviewee. In this instance research can be accused of being

fundamentally exploitative (Edwards and Ribbens 1998). People (researchers, professionals within the caring profession, decision makers) claim to know how to improve lives (Oakley 2000). According to Oakley (2000), the question of how these decision makers know this receives too little attention. She further contends that descriptions of reality obtained from knowers' are the only way to help humans to make informed decisions and that the definition of ways of knowing is interlaced with those doing the knowing. By comparison, D'Cruz and Jones (2004) believe that the researcher should consider how power is used in the knowledge making process as it is a moral action, and good research practise still needs to be backed by moral responsibility. This differs vastly from tacit knowledge that is passed between experts by personal contact, as opposed to written, given in a diagrammatical format or verbally described (Shaw and Gould 2001). This type of knowledge is significant in social work research as practical knowledge sharing between practitioners should be brought out and "...sources of trust and mistrust made clear..." (Shaw and Gould 2001, p.193). A similar type of sharing of knowledge about designing for disabled end users and including them in the design process would be ideal. However, until there is an ethical code, or indeed the acknowledgment that an ethical framework is required for designers wishing to engage successfully with end users, then tacit knowledge between design professionals would be of little or no benefit to the people who need to profit from this exchange.

There is an old adage that 'knowledge is power', which is fundamental to various sociological theories. If this is to be believed, and the premise that feminists argue, that language, or 'discourse', may constrain women (Gilles and Alldred 2002), then the same can be said of disabled people, exacerbating the power and knowledge debate within research with disabled people even further (Swain *et al.* 2003). As discussed in the previous chapter, disability studies is a relatively new area of academic inquiry (Gleeson 1997) and "...encompasses many sociological perspectives.... including Marxism and feminism" (Swain *et al.* 2003, p.34). Feminist perspectives, which suggest that knowledge is related to divisions of sex and gender and the establishment of a male standpoint on knowledge (to the detriment of women), is echoed in research about disability. Disabled people who have their own experiences and construct their own knowledge are often undermined by the knowledge of their able bodied peers. This knowledge is accepted as mainstream.

Gilles and Alldred assert that “Knowledge produced is knowledge lived...” (Gilles and Alldred 2002, p.33). If this is to be supposed, then the knowledge that disabled end users involved in the design process can pass on to designers about their needs and requirements, can only be of benefit for all involved. By imparting their knowledge end users can better inform designers, who can then strive to design products and services that are more beneficial to the people who will use them. In this way designers are also offering empowerment to the end user as the ‘expert in the field’ has a chance to voice his / her opinion and views about how products / services should be developed. This is not to say that the end user should become the designer, as design is a professional discipline, but, by working together designers and end users can develop products and services that are beneficial for all.

7.2.4 Consent and Confidentiality

Consent was obtained from the managers of the day centres to talk to service users who were to take part in the study before interviewing began. The managers agreed to the interviews taking place in social service establishments with the following stipulations

- Confidentiality was assured for service users participating in the project
- Service users could withdraw from the project at any given time
- Consent was obtained in writing from service users choosing to participate in the project (Appendix 3)
- Social services and the service they supplied was not discussed or used for the benefit of the project
- Audio tapes would be destroyed at the end of the project
- A copy of the final report was to be made available for participants

These stipulations were agreed with, and adhered to for the duration of the project.

Confidentiality was discussed with participants when they were invited by members of staff from the day centre to take part in the study and reiterated at the start of each focus group. It was explained that transcription of the audio tapes would not be done by an external agency and any issues arising would only be discussed with study supervisors if necessary and that tapes would be destroyed at the end of the study. Anonymity was assured and a specific code was developed by using a series of numbers and letters that would conceal participant’s identities (Diener and Crandall 1979). The first number of

each individual code indicates which focus group the participant took part in, the letter indicates whether the participant was male or female, and the final number is each individual's personal code. Individual's personal codes were determined by the sequence each participant spoke in during the focus group, e.g. 1f1 signifies the first female who spoke during the first focus group. Descriptions of disabilities were avoided in a further attempt to ensure anonymity, but as gender was relevant to some issues, it was specified. This coding system worked well for three reasons.

- There were only three participants of each gender per focus group
- Voice recognition was uncomplicated as members had different accents
- Some of the participants of the first focus group were previously known to the researcher

It was recognised during the transcription of the second focus group that the coding system would not have been suitable for a larger group or for a group comprised of individuals of the same gender, as voice recognition could be problematic.

It was important for participants to feel at ease with the study, its content and the researcher, as some of the participants had been involved in earlier adverse research exercises. (As previously discussed, on one occasion research students from a local college had videoed participants, without consent, and had not returned to discuss their findings). Care was taken to assure participants that they could withdraw from the study at any time should they chose to with no reprisal from the researcher (Deiner and Crandall 1978; Homan 1991; Kimmel 1988; Polit and Hungler 1989). Assuring participants about confidentiality and anonymity was made easier by the fact that the researcher was accepted by the day centre as a volunteer and known to several participants through a mutual peer.

A consent form was developed outlining the project content, the formation of interviews, risk factors and assurance of confidentiality (Polit and Hungler 1989; Robson 1993; Sanchez-Jankowski 2002). The form was looked at and approved by day centre managers who gave their agreement for service users to decide for themselves if they wanted to sign them or not (Holloway 1997; Bryman 2001). The managers knew the service users that were being approached with regard the study and considered them capable of making their own informed decisions (Bryman 2001). Although there was

the danger that the gatekeepers may interfere with the research it was deemed that they would be a further assurance to participants about the validity and sincerity of the project (Holloway 1997). Each participant was asked to sign a personalised consent form at the onset of each focus group and these were retained for the duration of the study (See Appendix 3).

After the welcome section at the beginning of each focus group it was stated that social services and the service they provide could not be discussed. It was emphasised that this was at the manager's request and that any discussion about social services would not be of benefit to the study. It was also stated that, at the manager's request, a copy of the thesis would be available for participants to examine when the project was completed.

7.2.5 Ethical Constraints

The main ethical constraint was the fact that there were an unspecified number of wheelchair users who couldn't be invited to join the research group and offer their comments about access issues. Gaining access to the sample was always a dilemma for the researcher as many wheelchair users do not use day centres or specific disability clubs or organisations. There is no database or list of wheelchair users' available and contacting potential participants through Doctors surgeries or via a wheelchair provider would have required ethical approval. This would have put the researcher in a difficult predicament with the time constraints of a part time research project. It does however highlight one of the difficulties in completing research within the field of disability and recruitment of the sample (Langford and McDonagh 2003).

The choice of sample was further constrained because the day centre managers stipulated that a member of staff, who knew the service users, would approach potential participants. This meant that the researcher had no influence on who came to the group. Consequently, she was at the mercy of 'other' people who controlled the sample. At the time, the researcher wondered whether the participants who were chosen by the gatekeepers would have been the only ones who volunteered to join the study had the recruitment process been more open. Similarly, the researcher questions the basis upon which the managers defined service users as being capable of making decisions for themselves, even though the managers commented that they were confident that the service users, who they had suggested, were to take part in the study were 'capable of

making their own decisions'. It returns us to the notion of 'the expert professional' and the 'incompetent service user' and 'who knows best'.

7.3 The Sample

The sample was chosen from two day centres in Dorset where the focus groups and follow up interviews took place. There were three main advantages for using social service's premises and service users.

- Participants were in a building that was equipped for their needs
- Transport to and from groups was not an issue
- Participants were in an environment where they felt comfortable and relaxed

The disadvantage was that the research process was guided at times by day centre staff and their regulations. However, while employees acted as gatekeepers and instigated some constraints on the research, it was considered by the researcher that the service users who had agreed to join the research group would be vociferous about their views on access issues. This point of view came from previous personal contact with the day centre and a knowledge that many of the service users were involved with access and advocacy groups that were lobbying for equitable rights for the disabled community.

The inclusion criteria for the focus group participants were:

- Adults
- An equal ratio of males to females
- Each participant had to be a current wheelchair user
- Each had to be willing and able to give informed consent
- Each participant had to have been able-bodied at some time
- Participants were assured anonymity

The limitations of the sample were:

- Staff had control over who was recommended to join the research group
- The study was not generalised to all wheelchair users
- Focus group numbers were relatively small
- Not all wheelchair users who were recommended for participating in the research attended the centre on the day the focus group was held

- Many adults who fit all the criteria for joining the study choose not to attend a day centre

The project was not generalised to all wheelchair users as there is no comprehensive list available of people who use wheelchairs. Local disability groups and day centres are the main locations where disabled people can be contacted and asked if they would consider taking part in research projects, with some people attending more than one group. Many adults choose not to attend a day centre, as they feel it is '*not for them*'. It is acknowledged that this was a constraint on the choice of sample, as many wheelchair users are not under the 'umbrella' of social services, so only a minority of the true sample figure could be approached to join the study (See Appendix 1).

The control that the gatekeepers had on the choice of the sample was also an issue, but it was something the researcher had to accept as the managers had requested it and access to the sample relied on it. In this instance the 'ethical' approval or the desire to protect service users from potential harm extended into the realm of influencing the nature of the sample. Fortunately the gatekeepers' choice of potential participants was helpful, but the researcher concedes that there were many wheelchair users who were not given the opportunity to join the study. It is an issue experienced by many researchers working in the field of disability.

As previously stated, managers of the day centres allocated a member of staff as a gatekeeper who recommended which service users should be approached and asked if they would consider taking part in the study. The decision for day centre staff to talk to service users in the first instance was made for two reasons. Firstly the gatekeeper in each establishment was a keyworker to several service users, had known the service user group for a considerable length of time, ran groups and attended regular meetings with other members of staff to discuss service users needs, which ensured that they were proficient at potential participant selection. Secondly, although using a gatekeeper allowed an external influence to guide the research, both the researcher and researched were protected by anonymity.

All of the service users at the day centre were adults with varying disabilities. The gatekeeper was asked to select an equal ratio of men to women to ensure there was no

gender bias within the group, to ensure participants were current wheelchair users and to ensure prospective participants had been previously non disabled. Participants were required to have spent some of their life as a non-disabled person as it was considered that they would offer a certain perspective on access issues as they would be able to see things '*from both sides of the fence*'. Safisios-Rothschild (1981) describes a person who has spent part of their life as able-bodied as someone who "...will have been socialised into the majority status of an able-bodied person.... and into the prejudiced attitudes towards the disabled" (Safisios-Rothschild 1981, p.7).

Members of staff were briefed by the researcher about the outline of the project and were asked to provide participants with an overview of the research. They were asked to explain that consent would be needed for the interviews to be taped, anonymity would be assured and participants could withdraw from the study if or when they chose to. (As the researcher had no control over the information given by the gatekeepers, she reiterated these points at the start of the focus groups).

Each of the focus groups was organised to comprise of six adults. Although the focus group numbers were relatively small in comparison to the amount of wheelchair users in the research location (Morgan 1998; Quine & Cameron 1995), the nature of focus group research methodology allows a rich source of data for constructing a descriptive background of life as a wheelchair user and the problems and issues surrounding this unique lifestyle (Bloor *et al.* 2001). Potential participants were given the outline of the project and a shortlist of eight was compiled at each day centre by the gatekeepers. This list was shortened to six as service users changed their days or were unable to attend the day centre when the dates for the focus groups were finalised.

7.4 The Focus Group Process

Focus groups were chosen as the initial method for data collection from participants because of their unique method of dynamic group interaction (Vaughn *et al.* 1996; Morgan 1998). Individuals form and develop their own opinions; however these can be challenged and reformed by the views of others (Kruger 1994). It is this ability to alter opinions, and the unique interaction between participants, that makes focus group data so useful to researchers. Kruger (1994) reflects that focus groups have traditionally been composed of participants who do not know each other, but for this study it was

considered that participants would feel more at ease in the company of people they already knew. The participants had very strong views about the subject of disability and the interaction and support of others in the group proved invaluable. The ability of participants to feel at ease with each other was demonstrated during the first focus group when one participant spent the duration of the interview lying on the floor on several cushions as they were in considerable pain. Lying on the floor was a situation that they may not have felt comfortable with in the company of strangers, but the participant was able to attend and make a valuable contribution to the discussion.

Provisional dates were set for the focus groups, yet these had to be altered several times until rooms were available for the groups to use and all service users of the day centre who wished to participate in the study were available on the same day. This proved to be frustrating as time constraints could not be adhered to and an external source was guiding the research (Langford and McDonagh 2003). Fortunately the data obtained proved invaluable and counteracted any previous tensions about research control. The length of time the room was booked for had to incorporate adequate time for participants, their wheelchairs and other mobility aids to get into the room and be seated comfortably before the group began. The room had to be large enough to accommodate six people, their wheelchairs or mobility aids, a gatekeeper and the moderator. It also had to enable everyone to be in a position where they could see and hear all other members of the group so that each individual could contribute as they felt necessary (Quine & Cameron 1995). Wheelchairs, both electric and manual, come in varying sizes and even small ones require more floor space than most chairs. This is an issue not only while wheelchairs are stationary but also while it is in motion, as the turning circle of the wheelchair has to be considered (Leibrock 1993; Holmes-Siedle 1997; Goldsmith 1997; Steinfeld and Danford 1999). This necessity for adequate space was one of the reasons that the focus groups were limited to six participants.

In April 1999 the dates for the focus groups were finalised and participants were informed by gatekeepers of times and locations. Each session began with everyone being introduced to each other and a cup of tea and biscuits were offered. This ensured that the group began in a relaxed way and allowed time for a brief outline of the study to be given. The emphasis was that the study would be driven from the participant's points of view rather than by the researchers view point and certainly not just to gain a

qualification (French 1994; Morris 1991; Oliver 1992; Zarb 1992; Barnes 1996; Bury 1996; Shakespeare 1996). This concept concurs with the participatory research paradigm and ensured that the participants, the experts in the field, were in partnership with the research. An explanation was given about the researcher having a life time of personal experience of growing up along side some one who had always used a wheelchair. It was hoped that by sharing this personal experience that participants would feel more comfortable about sharing their experiences and views. As previously discussed the managers requested that service users were approached by members of staff from the day centre and asked if they would be interested in taking part in the study. To ensure that the correct information had been given to the participants, the focus groups began with an overview about the project, its aims and objectives, confidentiality issues and how there would be no reprisals should anyone choose to withdraw from the study.

The focus groups lasted between 45 minutes to 1 hour and enabled members to identify access issues and created discussion and debate while offering mutual support and empathy (Morgan 1998). To gain as much new and fresh information as possible the group began with an open-ended statement which allowed the respondents the freedom to answer in any way they wanted to (Kreuger, 1994), tell me about access issues – anything that you feel is important to wheelchair users.

This initial open ended statement allowed for an open and frank debate with many issues being raised, discussed and re-visited (See Appendix 4). The focus group sessions took a natural progression, in full circle, and reached saturation point by the time each group re-visited the first issue raised in the discussion. Although there were participants who were more vociferous than the others in each group, moral and mutual support was evident, and individual views were regarded by the other group members as being as significant as the views of the more dominant speakers and were supported similarly.

The participants in the first group interacted well allowing members to contribute in which ever way they chose, allowing topics to be revisited, discussed further and personal stories to be told and deliberated. There was no conflict between group members as individuals. The only time the group showed any opposition or animosity

was when discussing access issues which affected their ability to interact with society in the same way as their able bodied peers and when discussing other people's views and comments which were directed towards disabled people. However, the group dynamics in the second group were somewhat different. Group members had an aversion to one of the participants which was expressed sporadically, both verbally and non-verbally. The ill feelings towards the participant were shown from the onset of the focus group, although it did not stop the participant from putting their views across. The conversation flowed and moved from subject to subject quickly, and although the researcher was conscious of the need to ensure that everyone had their say, the incidents which occurred between the participants needed no intervention as the group dynamics were well established and all of the participants had a chance to express their views. Generally, the groups were supportive of each other as they discussed and shared common experiences and both groups stated that they enjoyed the chance to air their views.

7.5 Individual Interviews

The data from the focus groups was analysed and the themes and categories identified were used to develop questions for semi-structured individual interviews with members of the focus groups (Schwartzman 1993). Nine of the original participants took part in the individual interview process, as illness and personal circumstances prevented the other two interviews from taking place. Semi-structured interviews were chosen as while a sequence of themes was covered with suggested questions, there was every opportunity to change the sequence of questioning in order to follow up answers given by participants (Kvale 1996). The choice of semi-structured interviews also maintained the theme of listening to the participants as the experts in the field, continuing to allow their thoughts and feelings to be acknowledged while investigating the field further. This ensured adherence to the participatory research paradigm. An interview guide was developed (See Appendix 4) from the data that was obtained from the focus group interviews, but a flexible approach was adopted and maintained when talking to individual participants (Hammersley and Atkinson 1995). Each participant was interviewed in a slightly different way and there was no fixed sequence to the topics discussed. If the response to a question incorporated information that might be relevant to another of the research questions, then that topic would be discussed at length at that

time and not at the position at which it was located in the interview schedule (Robson 1993).

7.6 Transcription

The focus groups and individual interviews were transcribed by the moderator within forty eight hours of the focus groups taking place. This enabled an in-depth personal analysis of the data while the interview was fresh in the memory (Loftland and Loftland 1984). Transcribing an interview tape requires the transcriber to study the interview by listening to the tape carefully and to consider all the information gained from both the tape and notes taken during the interview (Bryman 2001). It took six hours to transcribe each of the focus group interviews by hand and the information was word processed at a later date. This enabled the researcher to examine the data in depth twice in a very short space of time and enabled the researcher to gain a deeper insight into the data (Bryman 2001). Ideas and concepts emerged during the lengthy and in-depth process which helped the researcher build and create a deeper analysis than if the tapes had been transcribed by someone else. The individual interviews took varying amounts of time to transcribe as some participants wanted to ‘chat’ more than others. On several occasions the researcher had to stop the tape while participants discussed issues other than the questions asked.

Bruseberg and McDonagh (2003) discuss how designers who use focus groups in product development find dealing directly with the data themselves “...more likely to make use of ‘trigger’ words and ideas to ‘spark’ creative thinking” (Bruseberg and McDonagh 2003, p.41). As the researcher was at the interview, the memory was jogged by topics in the conversation to the body language that accompanied the verbal communication and notes were made to this effect (Loftland and Loftland 1984; Burnard 1991; Van-Maanen 1995). As the study progressed ongoing analysis of the transcriptions and tapes occurred to ensure the themes and categories were correctly established and to check on the quality of the transcriptions (Bryman 2001).

7.7 Data Analysis Strategy

When the data had been transcribed in full it was analysed using content analysis which assured concurrence with the principles of participatory research. Content analysis allowed the researcher to analyse the data without imposing a pre-conceived framework (Holloway 1997). This diagnostic tool was suitable for analysing open-ended material

and allowed themes and constructs to be derived as analysis progressed (Krippendorff 1980; Brenner *et al.* 1985; Morse 1994). This methodology allowed the researcher total immersion in the research data which was necessary to obtain a full understanding of what the participants were saying. Although content analysis can be a time consuming and expensive operation (Berleson 1952), it is a systematic and quantitative process that enables objective identification of specified characteristics within the text (Stone *et al.* 1966). The analysis of the data was completed using the long table approach (Kreuger and Casey 2000) rather than using a computer programme such as NUDIST or Ethnograph. There are advantages to using computer analysis, the most popular being that text can be moved around quickly with relative ease and moved back again should it be necessary. However, computer programmes used for qualitative data analysis are not technically analysis programmes, they do not use artificial intelligence, they simply facilitate the reorganisation and management of the data (Tesch 1991). The long table method of analysis (Krueger 1998) enabled the researcher to become fully immersed in the data on a more personal level and assisted with the attainment of a deeper and broader knowledge base.

Krueger (1998) describes this type of analysis as being a "...low-technology option" that "...does not look elegant...but it works" (Krueger 1998, p.57). It is an effective approach that can have a number of variations but the fundamental principles are cutting, sorting and arranging. This technique is similar to some of the procedures utilised within the design process, and the researcher found herself paralleling these methods to previous experiences from her background in design.

The analysis began with each participant being given an individual code which allowed effortless identification of which quote belonged to which participant. Each line of the transcripts was then numbered and two copies of each transcript printed. Different colour paper was used for the transcripts from each group, yellow for group one and blue for group two. This enabled easier identification of individual quotes at a later stage of the data analysis. One of each set of transcripts was then coded into themes and categories (Langford and McDonagh 2003) using coloured marker pens (Burnard 1991), which, along with the use of coloured paper, was a useful visual technique that assisted with the data analysis (Strauss 1988). The categories were copied onto the second set of

transcripts that were cut into sections and divided into one of the themes that emerged from the data analysis.

While this chapter has discussed how the data was collected and analysed, the five themes and twenty categories that emerged from data collection are deliberated in detail in the following chapter.

CHAPTER EIGHT – DATA ANALYSIS

This chapter examines the data collected during the focus groups and follow up interviews. The discussion begins with an overview of the location of the study and how the geographical nature of the areas influenced the themes and categories that emerged from the data. Subsequently the discussion considers the limitations of engaging with a small sample from a minority community within the local area. It considers the limitations of allowing day centre staff to select the service users who would be asked to join the study. It then examines, and outlines, some of the information about the research participants obtained outside of the research forums.

The discussion then turns to the five themes that emerged from the data:

- Transport
- Personal Care
- Restricted Access to Buildings
- Urban Accessibility
- Attitudes Towards Disability

Each theme is sub-divided into categories and examples of participants observations are used to demonstrate their concerns. Where applicable the participants' comments about the categories are reinforced by quotes from Goldsmith (1997). Goldsmith (1976; 1997) was instrumental in setting the mould for practices of designing for disabled people, his book *Designing for the Disabled* (1997) is revolutionary as he was an architect and also "...a person with a severe physical disability" (Goldsmith 1997, p.vii). Goldsmith did not become disabled until the age of twenty three and, as with the participants, he is able to view access issues from both sides of the fence.

8.1 The Participants

As previously discussed (chapter 7), the sample was chosen by day centre staff. The main disadvantage with recruiting the participants in this way was that the researcher had no control over who took part in the study (Bryman 2001). Nevertheless, the framework used to select the participants was respected by gatekeepers (Bryman 2001; Holloway and Wheeler 1996; Chapter 7). When the research process began, the local Physically Handicapped and Able Bodied (Phab) Group had recently closed and members of the Dorset Action for the Disabled (DAD) club were not responsive to

researchers attending sessions as they preferred their meetings to be social occasions. The only alternative was to make contact with wheelchair users via social services day centres.

One of the drawbacks of engaging with a group of service users chosen by gatekeepers was that the researcher knew very little about prospective participants' backgrounds or their disabilities. Nor was she in a position to explore the respondents' wider individual experiences (Priestly 1999). On reflection it is clear that the participant's personal experiences may have had a bearing on how they responded to the researcher's questions about access, and these could have been considered as part of the data analysis process (Oliver 1983; Higham 2003). Similarly, the standpoints adopted by the participants during the interview process could have provided useful context setting information. However, at the time of the data gathering process, the researcher's attention was focused on uncovering any specific problems that the respondents had encountered regarding access issues due to physical barriers. For this, the most appropriate method for data collection was considered to be focus groups and individual interviews (Puchta and Potter 2004; Morgan 1997). The focus groups were to be used to generate discussion from peer interaction and the follow up interviews were to be used to collate more in-depth information about the issues raised (Morgan 1997; Langford and McDonagh 2003; Chapter 6).

The researcher subsequently encountered a number of participants through both her employment and voluntary work. None remembered taking part in the focus groups, but identical comments from two of the participants encountered were "...I talk to so many people and take part in so many studies.." (Personal Communication 2005). It was evident that the limited access to a group of participants willing to take part in research can lead all researchers in a particular location speaking to the same participants. This raises questions associated with their representativeness of the wider population of disabled people (Personal Communication 2006; Dullea and Mullender 1999).

It was only during these later meetings that the researcher became aware of further information regarding some of the participant's occupations, disabilities and social situations. However, given that anonymity was guaranteed at the time of conducting the focus groups and interviews, none of this information can be discussed in this thesis.

Anonymity was essential because the researcher had agreed that a copy of the finished thesis would be available should anyone wish to see it. Sánchez-Jankowski observes that

It is important that researchers assume responsibility for honouring the agreement that they established with their subjects when they began the research (Sánchez-Jankowski 2002, p153)

Descriptions of individual's disabilities and / or their occupations would easily identify the participants to those who knew them (Redwood 2006).

The limited information available to the researcher at the time of the focus groups and interviews was that all of the respondents had previously been able bodied (as requested in the inclusion criteria) and that none lived in a residential home. It was not made clear at the time how many participants had lived in the local area all of their lives, who was married or living with a partner or what their employment had been prior to becoming disabled. However, during general conversations before and after the interviews and focus groups the researcher discovered additional information about some about the participants. But for the purpose of confidentiality and anonymity pseudonyms have been used to give examples of some of the information obtained, but they are not gender specific (Holloway and Wheeler 1996; Eby 2000; Babynames 2006).

- Alex had lived in Poole for many years
- Chris, Gerry, George and Sam all lived with partners or spouses
- Cameron used to work in the health profession
- Pat was single
- Sam was happy to discuss issues about disability with local children who asked about using a wheelchair
- Several of the participants did not agree with the changes that had occurred within local day services due to Local Government restructure
- Tyler wanted to 'get back to work'
- Jan commented how disability was a subject they had never considered until they became disabled

Providing further information on the respondents would jeopardise their anonymity (Holloway and Wheeler 1996; Eby 2000; Grinyer 2001), and whilst many discussed

their disabilities and the circumstances in which they became disabled, any description within this thesis could identify the participants.

8.2 Location of the Study

The study took place in the south of England and the participants discussed access issues within the two Boroughs of Poole and Bournemouth. The two towns are 5.5 miles apart on the Dorset coast and are very different, both geographically and as resorts. To appreciate the participants views a brief synopsis of the towns, their origins and their geographical nature follows.

8.2.1 Poole

Sutton (1988) contends that Poole Harbour is “...a master piece of nature” (Sutton 1988, p.0). It is the second largest natural harbour in the world and is essentially a drowned river valley formed at the end of the last Ice Age about 7000 years ago. Since then salt marshes and mudflats have developed creating a unique natural harbour. The area is a vast sheltered lagoon that has an 84 kilometre shoreline which is home to an abundance of wildlife as well as being a water sports paradise (Sutton 1988).

In the 15th century Poole was one of the largest towns on the south coast (Beamish *et al.* 1974). When Newfoundland was recognised as a British territory the area prospered through the development of the cod fisheries and the associated Newfoundland trade. This past prosperity can be seen in the Georgian houses and public buildings still standing in the town.

Poole has always been a working port and at the beginning of the 19th century 90% of the working population of the town was involved in employment around the harbour. In 1834 the first bridge was built between Poole and Hamworthy which helped with trade from one side of the harbour to the other (Beamish *et al.* 1975). In 1847, in attempt to boost the economy further, the first railway station was built on the Hamworthy side of the harbour (Joyce 2004). The effect of the railway ‘killed-off’ (Joyce 2004) the shipping trade which declined further when a railway line was opened from Broadstone Junction into the centre of Poole in 1872 (Beamish *et al.* 1975). Over the next twenty years the railway continued to expand. The line was extended to Bournemouth West in 1874, a double track laid in 1885 and the Poole to London line finally opened in 1893

(Beamish *et al.* 1975). These improved routes for the economy east of Poole enabled pottery and timber sales to escalate (Beamish *et al.* 1975). While businesses grew due to the extended trade links, the coastal shipping trade continued to decline and employment dwindled. The railway also caused discontent in the town from residents who were displeased with the railway crossing the High Street and Towngate Street. The frustrations experienced by the locals in the 19th century were at having to wait for trains to cross the busy thoroughfares in Poole and it was several years before a footbridge was finally built over the tracks (Beamish *et al.* 1975).

Poole continued to become a thriving town with good industrial and commercial links supported by the railway system (Joyce 2004). However, the frustrations of the 19th century locals are echoed by today's residents and visitors as can be seen in appendix 5 which shows how the whole shopping area comes to a stand still when a train is crossing. The railway lines crossing Poole High Street were discussed at length by the participants who commented on the inability to be able to cross the railway lines safely in their wheelchairs (See Appendix 5).

8.2.2 Bournemouth

Bournemouth evolved in the early nineteenth century and in 1841 was proclaimed to be '...the first invalid sea-watering place in England' (Young 1957, p.53). The Bournemouth of this period was regarded as a health spa rather than a pleasure resort and in 1855 The National Consumption, Chest and Diseases of the Chest Sanatorium was built where the town hall stands today (Phillmore and Co 1981). People with "...a delicate constitution" (Young 1957, p.53) visited the town during the winter months as it was warm and sheltered unlike other coastal areas. It also offered picturesque and leisurely walks through the many fir tree woods (Mabey [No date]). The area became popular as a Victorian spa (Young 1957; Edwards 1998; Phillmore & Co 1981; Boudreau & Dodds 1988) and a walk known as 'the invalid walk' (Young 1957, p.53) was developed through and around the pleasure gardens to accommodate the bath chairs of the day. The walk was so popular that it was extended to include the new pier when it was completed in 1856 (Edwards 1998). This walk still exists today but has now been more appropriately named Pine Walk. During its popularity as a spa resort, Bournemouth was developing architecturally and buildings were being built by wealthy local land owners to accommodate the rising influx of ailing and, often, wealthy

visitors. The two major difficulties builders of the day encountered were the sandy composition of the ground and the hilly geographical layout (Mabey [No date]). Victorians may have enthused about Bournemouth's climate and natural beauty, but then, as today, the geographical layout was limiting where access was concerned due to the composition, natural curvature and undulation of the land. During the next century Bournemouth continued to develop as a seaside resort and by the middle of the twentieth century it was one of the major towns in England.

To put this into context with this study, all of the participants agreed that nothing could be done to rectify the fact that Bournemouth's town centre and shopping area was inaccessible as altering the geographical layout of the town is not possible. All stated that they never visit Bournemouth and would never consider doing so unless absolutely necessary. Their attitude was that there is nothing that can be done and they were accepting that although it was a shame, there were other local towns and shopping centres which were accessible. The problems they described were seen first hand by the researcher and confirmed by covert observation (Lofland and Lofland 1984, Hammersley and Atkinson 1995) when a coach load of wheelchair users from outside the county arrived on a day trip. Observation included:

- Wheelchairs deviating from the path they were being pushed on due to the camber on a badly sloping curb in one high street
- An inability by the pusher to negotiate turning into shop doorways due the incline of the street outside the shop
- Pushers having to turn themselves and the wheelchair 180° and guide the wheelchair down the high street while walking backwards

These three incidents demonstrate that Bournemouth town centre is not geographically suitable for wheelchair access and that the layout makes wheelchair access hazardous for the user and a health and safety issue for the pusher.

8.3 Themes and Categories

The development of the themes and categories was discussed in the previous chapter and the focus groups and individual interviews identified five themes and twenty categories from the data obtained from the participants. These are shown in figure 3. This section continues by examining each of the themes, their categories and includes

some of the participants' comments. To reiterate the coding system for the participants described in Chapter 7 - The first number of each individual code indicates which focus group the participant took part in, the letter indicates whether the participant was male or female, and the final number is each individual's personal code. Individual's personal codes were determined by the sequence each participant spoke in during the focus group, e.g. 1f1 signifies the first female who spoke during the first focus group.

Themes	Categories
Transport	Poor accessibility on buses, Limited availability of accessible taxis, Lack of disabled parking spaces, Financial constraints when relying on benefits
Personal Care	Toilets, Radar Keys, Personal Image
Restricted Access to Buildings	Banks, Shops, Cinemas, Theatres, Restaurants, Civic Amenities , Sports Facilities
Urban Accessibility	Kerbs, Tactile Surfaces, Physical Obstructions (Railway lines)
Attitudes Towards Disability	Information required at the onset of disability, Stigma (Terminology), Negative perceptions (Planners)

Fig 3 – Themes and Categories

8.4 Transport

Wheelchair users have many things to consider before venturing out of their homes. Able bodied people may consult bus or train timetables, phone for a taxi or consider the availability of car parking at the venue they intend to visit on the day of their visit. But for wheelchair users transportation is not so varied or easy to organise. The participants of both focus groups were vociferous about transport and had to be steered away from issues surrounding transport laid on by social service establishments.

8.4.1 Buses

In the late 1990's bus companies introduced buses that have a step which can be lowered to a raised kerb for wheelchair access. Drivers are not in a position to assist wheelchair users in gaining access to buses and pushchairs and shopping are often stored in the area designated for the wheelchair. The buses have space for only one small wheelchair and there are no restraints for securing the wheelchair in position. During the focus group participants commented:

- 2f2 “My wheelchair is too big to get on. It’s alright if you’re a small person in a small wheelchair but if you’re in a larger wheelchair it’s hopeless plus the fact there are regulations that all wheelchairs must be clamped down with straps”
- 2f1 “Sod that they’ve got no clamps or anything”
- 2m1 “Ah but they’ve set the floor in such a way that the wheelchair apparently slides back towards the wall. I don’t know this is what I’ve been told but we’ve only got one space”

Another participant 1f1 explained during her focus group that:

“To come to the day centre you are clamped in if they are that safety conscious here public transport should be more safety conscious and in that aspect I don’t think they are”

A further respondent 1m1 confirmed he had used the buses twice and

“....the wheelchair not secured down and they drive round like lunatics just like they normally do course you get thrown about in your wheelchair going sideways you know”

The onset of disability is not easy to come to terms with and feelings of insecurity are rife as fear of dependency on others for many day to day activities is prevalent (Morris 1991). Paralysis, or the inability to be in control of limbs, means feeling secure in a situation is important. This is especially significant when travelling in a vehicle as one of the participants, a quadriplegic, explains:

- 2m2 “some are alright to travel in and some are not. Centre of gravity is a problem for me cos I swing about”

When a group of able bodied people go out they take for granted being able to travel together, the situation is not the same for the less able. When another participant (2m1) challenged a local bus company representative over the fact that there is only one space per bus which means a group of people cannot go out together, he was told.

“.... that’s alright if we find three or four people want to go out together we can make the buses every 10 minutes instead of every 15 minutes. That’s not an answer cos you end up by waiting an hour for the last one to turn up.....what they’re doing is covering the act (Disability Discrimination Act) that’s all they’re doing”

Goldsmith (1997) considers that should he ever be presented with the opportunity to use a bus he would ‘doubt that I would be encouraged to use it. It could not compete with my private car in terms of convenience’ (Goldsmith 1997, p.212).

8.4.2 Taxis

Goldsmith's (1997) sentiments about feeling insecure during taxi travel echo the concerns of the participants about buses. He describes his use of taxis as 'welcome, although I always feel insecure...' (Goldsmith 1997, p.212). Participants did not mention feelings of insecurity when using taxis. Their comments concerned three other areas.

(1) There are limited number of wheelchair taxis available and if bookings are not made well in advance vehicles are not available.

1f1 "...need more taxis cos taxis do the day centre runs which takes them off the road"

(2) Several participants complained about the height of the taxis and how individuals have to bend their head and shoulders to gain access.

1f1 "The taxis aren't high enough"

1m1 "That's right – the black taxis are no good for anyone over four foot in a wheelchair"

1f1 "You saying that I'm four foot eleven and I have to duck my head – if I sit up my head touches...."

1m1 "Once they get in there if it's going to cause you pain to move your head once you get in there you're going to be in agony by the time you get there"

1m2 "London style cabs are not too good for myself whether I'm a large size I have to check my head ..."

1m1 "...need vehicles where you can go up the ramp and get in without unscrewing your head"

2f1 "but they've got to comply they've got to be able to sit in the taxi as a normal person would"

Participants described how some of the taxis have side door access which is not always suitable for users as they have to travel side-ways on to the driver. This means passengers can't see where they are going and it is not always possible for individuals to twist to see the view.

1m2 "...and I am seated sideways on to the driver so I can't see where I am going"

1f1 ".....taxis are supposed to take two wheelchairs I don't see how unless they are vary small"

A design solution to the problem of passengers facing sideways and being strapped into a taxi for security has been addressed. Participant 1f1 described a style of taxi used locally and in some respite establishments.

- 1f1 “There is only one disabled taxi that I’ve been comfortable in - its that grey one. Don’t know if anyone else has been in it, where they put the straps on and you go up into the middle”
- 1f3 “The one where it winds you up?”
- 1f1 “yeah that’s it yeah”
- 1f3 “Some of the respite places have them”
- 1f1 “I thought it was lovely”
- 1F3 “Some of those respite places have those cars that have been redone – the height is right”
- 1m1 “Oh yeah hmhhh” (AGREEING)
- 1f1 “Yeah”
- 1f3 “They can take two wheelchairs plus people sitting at the front they’re like a great big car”
- 1f1 “Yeah”
- 1m1 “Hmm” (EMPHASIS)
- 1F3 “Now they’re terrific”

(3) It was not always the design of the vehicle itself that participants encountered problems with, but the attitude of the drivers as well. Participant 2f1 had an ordeal with a taxi driver that left her in a precarious predicament.

- 2f1 “I had a bit of a do with them about a couple of weeks ago my chair broke down and I was with a friend who owns a manual chair and I managed to get her into the taxi and I asked the taxi driver to call me a wheelchair taxi and I caught it at the time of a change over one had gone home and the other one was taking his last people out and she said there isn’t one so I said there’s got to be one at some stage in the game and she said I’ve only just come on blah blah blah, so I said well will you please ring again and tell them I’m stuck here I cannot move and I can’t get home without and she climbed in the taxi, as I thought to phone them, and drove away and left me sitting there. It was absolutely bloody terrifying and I got a guy, it was getting dark, and this guy came past and I just had to take a chance and he pushed me home. And he let me in there and I was alone, disable and with a complete stranger anyway I did ring up and complain and he went mental and assured me that this would never happen again”

- 1f2 “Drivers are inconsiderate”

Service provision is an integral part of part III of the DDA which came into force in October 2004. However, at the time of writing this thesis the DDA’s worth has not been tested.

8.4.3 Parking

Disabled car parking is costly as more space is required and it is also limited. Participants who have access to cars all stated that there are not enough designated disabled parking spaces and that the few specific spaces that are allocated are often used by able bodied people who prefer to park as close to the amenities as possible.

2m1 “the worst thing about car parking is the fact that they do not put enough space..... disabled parking – it’s not sectioned out, it’s just one strip. If you get someone that’s paraplegic and they take their chair from the side when they get back to the car they can’t get down the side to get their chair in they have to get someone to drive their car out so they can load up in the middle of the road. They need space, that’s something else the planners need to look at. They say ‘yeah we can get 7 cars in there you only might get 4 disabled ones’”

2F3 “In car parks people that aren’t disabled use the disabled spaces because its nearer the door”

2m1 “car parking for the disabled you’ll get 2000 car parking spaces for able bodied people but you’ll get 2 spaces for the disabled”

Participant 2m1 related a story about a local disability group in Poole who actually monitored a local car park where there were several accessible parking spaces that were frequently used by non-disabled people.

2m1 “DIAL UK they had to sit out there and actually stop people using the disabled spaces”

8.4.4 Finance re: Travel

Disability is expensive. Specially adapted vehicles cost thousands of pounds and taxi fares are an expensive item when organising an outing if an individual is on benefits. Local authorities offer incentive schemes for cheaper public transport for elderly residents and residents with disabilities but the allocation of tokens or cheaper fares is rationed per year. Once an annual allowance has been used there is no more funding available until the following year. This means trips at a reduced and affordable rate are limited. Taxis also charge more for disabled fares. As there are a limited number of accessible taxis, wheelchair users are likely to encounter the same driver regularly. Although this is advantageous as drivers get to know passengers needs and requirements, it can also be problematical as participant 2f2 describes. Participant 2f2 comments that she was “...black listed...” by one taxi firm for complaining about an overpriced fare.

- 2f2 “...if you happen to be blacked by that particular firm you’re stuck you can’t go anywhere. I complained because I had been over charged they’d charged me dead mileage three times which means they over charged me from where they were, to where I lived and on top on that they charged me...”
- 2f1 “they do it in our...”
- 2m1 “they over charged because you are disabled I don’t use taxis because I can’t afford them”

8.5 Personal Care

One basic human function is the necessity to urinate. Individuals produce approximately 180 litres of primary urine per day, 1.5 litres of which leaves the body as urine (Dietchs et. al. 1992). Unless an individual is catheterised it can be assumed that at some time during the course of a day one will need to visit a toilet. At some time in our lives we have all experienced the need to find a toilet quickly and on occasion may have been let down by the results of our search either through lack of cleanliness or not having the required coinage to gain access.

8.5.1 Toilets

Toilets built for use by disabled people have to conform to the guidelines set out in building regulations which are concerned with access and facilities for disabled people. Approved Document M (ADA) of the building Regulations deals with the accessibility of buildings and is enforced when plans are submitted to the building control department of a Local Authority or to an Approved Inspector. The 1999 ADM was in force until 1st May 2004 and only required a building owner or designer to provide a cubicle of a specified standard if they chose to install one in a new building or extension. The regulations were not specific about the requirements and the term ‘*reasonable provision*’ was used.

If Part M applies reasonable provision should be made in:

- i) Buildings other than dwellings
 - e. for sanitary accommodation for disabled people

(ADM 1999 - Section M, guidance paragraph 0.8)

Section M3(3) section 4 states:

4.1 In principle, sanitary conveniences should be no less available for disabled people than for able-bodied people

(ADM 1999 - Section M3(3) section 4)

The wording of ADM (1999) was not prescriptive enough and unless the developer or building owner was aware of their duties under the DDA then the requirements were often ignored.

On 1st May 2004 ADM 2004, entitled Access to and use of Buildings, came into force. The new ADM applies to works undertaken by designers and building owners to any building as opposed to only new builds or extensions and is more regulatory. The new standards for a unisex accessible w.c. are far in excess of those in the 1999 edition and section M1/M3 paragraph 4.7 states:

- The provision of toilet accommodation will satisfy requirements M1 or M3 if:
- a. where there is space for only one toilet in a building, it is of a wheelchair accessible unisex type, but of greater width to accommodate a standing height wash basin
 - b. at least one wheelchair accessible unisex toilet is provided at each location in a building where sanitary facilities are provided for use by customers and visitors to a building or by people working in a building
 - c. at least one wc cubicle is provided in separate sex toilet accommodation for user by ambulant disabled people (this means an increased size and containing grab rails)

The standard in ADM 2004 is similar to that suggested in BS 8300 and it will require that architects, designers, building control officers and approved inspectors to be trained to ensure the requirements of ADM 2004 are met. In the case of toilet design, as with other areas, the detail is often missed and this can make an accessible toilet disabled

Participants 1f1, 1f3, 1m1 and 2m1 have definite opinions about what they consider constitutes an accessible toilet and how many toilets are not actually user-friendly for the people they are designed for. (It should be acknowledged that the focus groups and subsequent comments were made before the advent of ADM 2004).

1f1 “...they’ve got grab rails and a high rise toilet. They think that’s it, they forget that once you are in there you need to manipulate, you need room. They often forget that they think well that’s it we’re giving a nice high toilet seat, got grab rails everything is at low level and that’s it but its no good if you go in there and you can’t shut the door behind you and you can’t get out of your wheelchair onto the toilet”

1f3 “...a big enough disabled loo...they say disabled loo and you can get halfway in and you can’t turn the chair round”

- 1m1 “some places have a stall with a seat that’s wider and that classes as a disabled loo”
- 2m1 “planners create units for disabled loos so they’re big enough to swing the chair round and they stick the pan right in the corner”

As all toilets are built slightly differently and not all individuals require the grab bars to be in the same position or the toilet itself to be in the position it has been situated, individual users often experience different difficulties.

- 1m1 “On the inside of the toilet doors so when you’re in there they have bars that go across like that (GESTICULATES HORIZONTAL)
Instead of ones going like that as well (GESTICULATES VERTICAL)
If they had one like that or had the two it would make it easier for grabbing the door again”

Wheelchair users cannot transfer efficiently in a cubicle where the toilet pan is located in the corner of the room. When asked about hygiene in accessible toilets the majority of comments confirmed that on the whole cleanliness was not an issue.

- 1f2 “I have to say in the main that most of them are pretty clean in comparison with some of the normal public toilets”

However there was one exception.

- 1m2 “There’s one in Poole Park that’s a bit of a dodgy one, it’s too unhygienic really”
- 1m1 “Yeah Yeah”
- 1f2 “Most of them are alright actually”
- 1m1 “I think with the one in the park its because its in the middle of nowhere sort of thing”

Toilets in pubs and restaurants pose a different problem for wheelchair users.

- 1f2 “A lot of them you can’t go in because their toilets are upstairs, up flights of stairs. Normally I have to find out if they’ve got a toilet that’s accessible and on the right floor before I can say yes I can go.... In one place I was told their toilets were ok for disabled but they were up a flight of stairs ‘the toilets are up there, they’re ok for disabled’ I said so how do I get there, she had no answer, she ran off....”

8.5.2 RADAR Keys

Toilets specifically designated for use by disabled people are often under the RADAR scheme (The Royal Association for Disability and Rehabilitation). This entails purchasing a special key which fits all RADAR toilets throughout the country.

Participant's views varied about having to pay for these keys and there was some confusion about the cost or where they could be obtained from.

- 2m1 "You'll find they're different prices in every area from £2.80 - £10....they're in the information centres you know travel information centres are the best places to get them from but they are supposed to ask for some form of ID obviously if you're using a wheelchair you've got it but some people can just walk up and buy them"
- 1f1 "You know the thing that annoys me with these toilets for the disabled – you need a radar key, why should we be penalised to pay for it"
- 1m1 "I agree with that"
- 1f2 ".....pay 10p or 20p or whatever it is"
- Me "How much do you have to pay for a key?"
- 1f1 "I've had mine about 5 years and I paid about £5 for it"
- 1m1 "Yeah I think it costs about £10 for it now"
- 1f3 "I was given mine"
- (DISCUSSION AND CONFUSION ABOUT THE COST)
- 1f3 "Ladies have to pay to use the loo, so I suppose if you're paying that as a one off....."
- 1m1 "I don't have to pay to go to the toilet do I as a man.....No for women, I'm sorry if they're supplying that facility for the disabled erm I don't see why... just say £7 a time 300 people with a key there's a lot more than that"

None of the participants were able to confirm what the cost of the RADAR key was for.

RADAR's web link regarding The National Key Scheme states:

"The National Key Scheme offers independent access to disabled people to around 4,000 locked public toilets around the country. RADAR would like all providers of accessible toilets to keep their toilets unlocked if at all possible. The National Key Scheme (NKS) is suggested only if the provider concerned has to keep the toilets locked to stop vandalism and misuse.

RADAR makes no profit in supplying keys, but has to charge VAT for keys. In order to apply zero rate for keys supplied to disabled people, orders must state the name and address of the disabled person with a declaration of disability (eg "I am a disabled person and I wish to buy a National Key Scheme Key"). Organisations applying for bulk orders must supply a Zero Rate Certificate.

Please note that the toilets are the property of the providers concerned, and as such, any queries or problems concerning a toilet should be directed to that provider, rather than RADAR".

(<http://there.is/cgi-bin/radar/e-shop.cgi> 2004)

Participant 2m1 had an experience that gives credence to why accessible toilets are usually locked:

- 2m1 “I’ll tell you a story me and my wife went up to London and we go up early so we’ve got the whole day and we went into Winchester and I went to go into the loo there in Winchester and I found someone camping in the disabled loo and they must have been able to buy a key just like that ... they’re supposed to issue them on identification only that they are actually for your use”

8.5.3 *Personal Image*

The image of an individual in a wheelchair can often be misinterpreted by others. A physical disability can prevent the simplest of communication from being easily understood, even when communication barriers are removed and verbal and non verbal communication is no longer an issue. The visual image of the individual can be ‘disturbing’ even ‘off putting’ to the human eye (Hahn 1997). The discrimination surrounding the ‘aesthetics’ of disability (Hahn 1997) was commented on by participant 1m1

“Take sandwiches, you can’t see what’s in them then you pick ‘em up and people go ‘ere look he’s holding all that food...”

As previously discussed, all of the participants had been previously able bodied which meant they had dual perspectives regarding access issues (Safisios-Rothschild 1981). During the follow up interviews participants were asked if their opinions towards disability and disabled people had changed since they had become less able-bodied.

- 2m3 “to be honest with you when I was fit and well I never thought about disabled people. If you had told me 12 years ago I’d have ended up like this I’d have laughed at you in your face I was fit, strong and part time pro wrestler, I’ve spent the last 20 years working on the building doing all the ground work, I had a severe stroke at age 54”
- 1f1 “my opinions have changed a lot, not just a problem to get from one place to another it is also people’s attitudes towards them”
- 1f2 “absolutely, definitely, because I had nothing to do, like most people do, with anybody in anyway disabled in fact in my life, not that I chose it that way I just didn’t therefore erm... becoming disabled myself, meeting people, coming her, hospital and the like was such and eye opener that’s why I try to make sure my grandchildren meet varying disabilities from a young age so to them now it doesn’t mean anything they just accept it where as I didn’t I didn’t accept being disabled and I didn’t like seeing disabled people”

8.5.4 Vehicle Design and Personal Imagery

One of the questions asked during the individual interviews was to determine how wheelchair users felt design effected disability imagery.

Participants were asked if they felt the design and image of the vehicle they were travelling in was important. On the whole their attitudes concurred that providing they could travel in comfort and be pain free, that vehicle imagery was not important. The majority of the participants shook their heads, answered no and had no further comments to make, and three participants expressed their views about how they didn't mind what the vehicle looked like as long as they were comfortable.

1f1 “.....wouldn't care if it was a dust cart as long as I was comfortable. I don't think anybody would”

1f3 “no, some people feel really conscious about being disabled but I'm not”

1m1 “As long as I'm in comfort and not in agony I'm happy”

While the majority of participants were concerned more with comfort than aesthetics participant one participant commented that:

“... want it to be as obscure as possible wouldn't want to arrive at the theatre or some party in a bloody great people carrier thing I don't think I would like that”

As with their able bodied peers opinions vary from individual to individual and are guided by their upbringing, life experiences and cultural background (Hayes 1984). For a participant whose life had revolved around the stage and theatre aesthetics were an important part of life.

8.6 Restricted Access to Buildings

The social model of disability states that it is society that disables people (Barnes and Mercer 2003) and disabled people argue that they are disabled by the built environment and not specifically by their own personal disability (Imrie 1996; Barnes and Mercer 2003). The later of these two theories was verified with comments from all of the participants during the focus groups and follow up interviews.

8.6.1 Banks

Accessing banks can have its difficulties for wheelchair users, although modern technology does enable account holders to access the information through telephone banking and online systems. However if a wheelchair user prefers to access the building housing the banking institutions itself access can be arduous especially as several banks have been situated in the same building for many years. These are often listed buildings where there are several steps to gain access or the doors are too heavy to open easily. In some cases it is possible to build a ramp for wheelchair access, but as the participants described, this is not always the case. Participants explained that where access is limited there is a bell to ring for assistance and an employee of the bank will come outside and assist with the transaction. This means that no matter what the weather is like, or how large or small the transaction is, business has to be conducted outside on the pavement.

2f1 “The one I found worse was the Midland in town – I could not believe it. I was in town and wanted to use the hole in the wall... and it had about 6 really steep steps and their attitude was..... or to apologise we did the transaction on the pavement”

2f2 “I know the one’s like that in Parkstone. I hate doing my business on the pavement”.

During the follow up interviews this was clarified by asking if transactions taking place on the pavement was common practice.

2f1 “Well I don’t know, but it certainly happened to me in Bournemouth, all the cash machines are inside, I can understand why they do it, people don’t have to stand in the pouring rain but its no good if you’re in a wheelchair and there are bloody great steps up to it”

Some banks and building societies appeared to have tried to overcome accessibility problems by installing a bell system

2f1 “well what annoys me about them when I go to town I’ve found that in my bank is that out side the door they’ve got a little wheelchair sign – so I thought oh great – I spoke to someone about this – is the reason the doors are so heavy is for obvious reasons.... and erm’ I went and saw the girl who sits up the front there ‘oh yes’ she said giving me all these things I took it home and there was a charge and what you do is you get a bell to ring”

2m1 “Yeah you have a little hand module you press the hand module towards the sign and it alerts the staff or whoever that there’s some body outside who needs assistance..... you can get one free if you encourage a particular shop or bank to install one and the person who has encouraged the bank or whatever will get one free - this is what they were advertising 4/5 years ago”

Although there is little transcription evidence of comments about heavy doors being difficult to use by wheelchair users, all of the participants agreed through nods and comments of ‘yes hmmm’ during the focus groups that they were a contentious issue.

- 2f1 “you need heavy doors for obvious reasons automatic doors would mean people could get in and out so easily”
- 2f2 “banks and building societies they’ve got those flaming great doors that you hold back and get in”
- 2f3 “...heavy doors, have to hang on for someone to open it”

8.6.2 *Shops*

Visiting retail outlets for food, clothes or pleasure is something many of us take for granted. This is not always the case for many of the participants. The main complaint about Poole town centre is that it is dissected by a railway crossing (See Appendix 5). There is a route that can be used to avoid crossing the railway lines but it is lengthy which means that to access all of the shops the railway crossing has to be negotiated. This was discussed during fieldwork with one of the participants who resides in Poole town centre whose shopping is completed in two stages. Half of Poole one day and the other half another day because crossing the railway lines was considered too dangerous.

Accessing the shops themselves can be difficult if there is a step, but it is the obstacles inside the shop that most of the participants had difficulty negotiating.

- 1m1 “Then once you’ve crossed the road and you want to go in a shop and you can’t because of steps and that sort of thing, this is very common throughout Poole. And quite often, even supermarkets are doing it now, in the isles they put the baskets in the middle with all them knock down goods in. When they’re there you can’t get past them, so once you’ve got into the shop you know I know they’ve got to try and sell their goods but if you think of the amount of disabled people that are no going in shop cos they know they can’t get round, they struggle to get in but once they’re in there they would do their shopping”
- 1m1 “50/50 shops in Poole are inaccessible”
- Me “Would you say that’s a fair percentage??”
- 1m1 “Yeah Yeah”
(ALL AGREE)
- 1M1 “Even the ones that you can actually get into you can’t go round because they’ve got these baskets which display stuff you can understand their side of it to get more goods on view”

- 1f3 "It doesn't matter what store it is either"
- 1m1 "But you can't get round 'em"
- 1f3 "Especially those little stores that have got lots of little goodies in them you think I'd like to go in there and you can't get in them"
(ALL AGREE)
- 1f1 "You can imagine what problems we have cos we need extra room"
(REF LEG)
- 1m1 "Safeway, Gateway or whoever they are they're started doing that now, they put big round baskets with the out of date stuff in at the end of an aisle to go back down..."
- 1f1 "You're terrified you're going to hit something"
- 1m1 "They see me coming and they start moving stuff cos I just sail through it I got so fed up with it. Security man gets under foot so I ran over his toes he doesn't stand there anymore its such stupid things like that that make all the difference"
- 1f1 "It's very frustrating, like going over the railway crossing..."
- 1m2 "The ones that are accessible are the established ones"
- 1f3 "...so choc a bloc full of merchandise even if you're alright if you're walking you bump into things"

As discussed in section 8.1.2 all of the participants agreed that Bournemouth town centre is geographically unsuitable for wheelchairs, but that the shopping centre at nearby Boscombe was reasonably accessible, not only in the way it was planned, but also the attitudes of the shop keepers.

- 2f1 "Boscombe itself isn't too bad now they've made it flat, you know a walkway"
- 2m1 "That is a purpose built building where people can actually walk in rather than have to climb in"
- 2f1 "People like Marks and Spencer have put in automatic doors now Sainsbury's they're redoing now so hopefully that'll be good There's disabled toilets at both ends of the sovereign centre".
- 2f1 "Just as Peacocks was being refurbished and I happened to go in just as they were putting the stock out and she said 'oh I'm really glad you've come this morning, will you do me a favour will you do a tour round the stands' and they had two fitting rooms built as well 'will you see if you can get in and out of them because the stipulation was that they had to be able to take a wheelchair to and a double buggy' so I do think people are starting to take notice"

8.6.3 Cinemas

Access to cinemas and theatres for wheelchair users is problematic due to health and safety regulations. Wheelchairs have to be positioned in an area which is suitable for an easy exit should there be a fire or other hazard. In most cases this means that wheelchair users are unable to sit with the other people they have gone out with and frequently establishments are unable to accommodate more than one wheelchair at a time.

Me "What about cinemas"

1m1 "I don't know but at UCI you can get two wheelchairs at a push"

Me "That's not many"

1m2 "I was in the aisle at UCI"

1m1 "You were a fire hazard"

1m2 "Trouble is you're on an incline so it feels like you're falling forward"

1f1 "At Tower Park I was right at the back and my family were further down"

1m1 "...the only place you can sit as a disabled person is at the back behind all the seats and your family are a long way away. There isn't a gap where they can take a seat out where you can wriggle in so you can sit next to somebody"

2m2 "I'm sat on the back row cos I'm a fire hazard"

2m1 "I've actually had said to me in the BIC and in Poole Arts Centre they've got 3000 seats and 7 places for wheelchairs we area actually fire hazards if you think about it pushchairs are a fir hazard, elderly people are a fire hazard even you are a fire hazard"

2f1 "But we're the ones who get picked on"

2m2 "We could probably get out quicker we probably wouldn't panic so much we've got over our panic sessions if there was a real panic we'd probably step to one side and let it fall down you - you'd scream and shout – so we're not a fire hazard"

8.6.4 Theatres

1f3 "I go to the Tivoli in Wimborne sometimes and they say they have to have you down the front near the exit in case of a fire"

1f2 "It could be at the back near the exit. At Tower Park to be near the exit you're near the back"

(ALL AGREE)

1f3 "I suppose it's where ever so they can get you out quick"

1m1 "When we went to the pier theatre they said they couldn't take more than 8 wheelchairs because of the fire hazard"

(JOKES ABOUT THE FACT THAT THE PIER TEATRE IS OVER WATER!!!)

"They haven't really got an area for wheelchairs"

Me "Do you think that would be better to have an area for wheelchairs?"

(ALL CONFIRM YES)

1m1 “Well if they took a row of seats out they could do it”

1f2 “Yes but its moneyyyyyy” (SARCASM)

1f1 “Bournemouth Pier took seats out and we sat both sides
If you give them warning they will arrange things for you”

1f3 (Talking about the Tivoli – Wimborne) “...there’s a side entrance and ramp into building they open the doors for you and there’s a little stair lift then a couple of steps and then a lift to a landing”.

Goldsmith (1997) concurs with the participants and concludes that he is ‘much concerned that certain central London cinemas are effectively out of bounds’ for wheelchair users (Goldsmith 1997, p.234).

8.6.5 Restaurants / Cafes

Restaurants also have limited space for wheelchairs and some limit times of wheelchair access saying that one wheelchair takes up the same space of two able bodied customers therefore the restaurant or pub is losing revenue by allowing a wheelchair user access at busy times. Individuals are not specifically refused access but as 1m1 explained

1m1 “.....sometimes they’re very reluctant (to allow access) or they might say we don’t have room at the moment.....I honestly feel that although they are improving I feel there is a long way to go”

Fixed seating is a problem for many wheelchair users

1m1 “The other thing is if you go into a super market for a cup of tea, normally these days they have fixed seats so you’ll have to sit out like a sore thumb cos you’re stuck out in the aisle. You struggle to get your legs under the table to get near the table and if they’re fixed seats then people like 1f1 and myself the fixed seats are there (GESTICULATES HEIGHT) now my leg is stuck out straight same as 1f1s so you can’t have anybody sitting near you. I go shopping with my wife and mother in law or my daughter. They sit that side and I sit this side”

“You can end up in the corridor in the aisle so if people want to walk past you with the tea you can get a hot cup of tea down your neck”

2m1 “...some places you’ve got fixed seats on the floor there’s no way to get round the table – they’re a pain in the arse”

2f1 “wheelchairs have-to sit on the end”

1f3 “In the dolphin centre you get half and half so there are seats which are moveable, people can sit in the middle I was lucky when I went in.....”

Goldsmith (1997) describes experiences of arriving and leaving restaurants as “...an upheaval of other customers and their chairs. This is invariably done with great good humour” (Goldsmith 1997, p.232).

8.6.6 Civic Amenities

Some participants, who used Poole civic centre for meeting with disability groups they belonged to and for housing and benefit enquiries, felt that the council building was not accessible.

- 1f2 “you can’t get in the lift if your in the wheelchair on your own cos it’s impossible to reach things you can’t get in and turn round cos its so small there is room for 1 wheelchair if its pushed in and possibly 2 smallish people and that’s it”
- 1m1 “I can only go in on my own no-one would know if I got stuck there but if you have a shoulder mobility problem you wouldn’t manage”
- 1m1 “when they (ramps) get wet you wheel spin in manual wheelchairs there’s its tight to turn at the top. Coming down the slope when its wet is a bit hairy”

But 1m2 and 1f1 had different opinions.

- 1m2 “its got a double ramp, one up and one down, the lift is quite ok. I think there’s a good toilet but I’ve never used it. I found it alright”
- 1f1 “...don’t see where the problem is at the civic centre you have ramps its on the ground floor and if you go upstairs they send someone and they come down and get you”

8.6.7 Sports Facilities

Local sports facilities cater for wheelchair users but, as insurance is high, they are often limited to the facilities they can offer. Only two participants were really involved in sport and one other had used the facilities when going on a swimming trip from the day centre.

- 2m3 “You have the Littledown centre which is excellent”
- 2m1 “They’ve done a lot of alterations but some have not been specifically what they said they would do but generally they’re very good”
- 2m3 “I think they’re excellent”
- 2m3 “The slope to get in is too much I need some one to push me”

8.7 Urban Accessibility

In the last twenty years strategies for accessible built environments that promote accessibility for disabled people to public buildings and facilities has been central to political agendas (Imrie 1996). This section compounds the environmental access issues previously discussed by giving examples of participants' views about the areas outside, and the approaches to, the buildings.

8.7.1 Kerbs

The size of the drop from the pavement to the road causes problems for ease of wheelchair access, so does the camber of pavement where dropped kerbs are positioned.

- 1f1 "Yeah and also though some of the dropped kerbs aren't dropped enough"
- 1m1 "yeah not dropped enough"
- 1m3 "If you're in a bad area, I'm from Wimborne and Colehill there aren't dropped kerbs where there should be and some of the dropped kerbs are on a bad corner some are very steep and no gradual, you can go like...."
- 1m1 "Will you stop before a car comes. They put them on corners and the actual gap on the curve, you might if you're lucky get a pushchair down there"
- Me "In the actual dip?"
- 1m1 "Yeah on corners they narrow the gap for some unknown reason so as you go down you're like this (GESTICULATES) You have one wheel higher than the other and you're going down and out into the flow of traffic"
- 1f1 "some shops you cant get into cos they have a kerb"
- 1f3 "...find out what limitations its not so much what you can't do as obstructions, steps into shops and buildings you want to get into and you can't get down off kerbs without help there's not always drop kerbs"
- 1f3 "some are ridiculous if you are on your own it must be worrying because you don't know if you are going to trip over or something....you'd think they'd do a decent gradual kerb they need someone to push them round in a wheelchair to show them just how bad they are"
- 1m2 "...my chair will cope with kerbs of up to an inch"
- 1f3 "sometimes they have a token sort of lowering but its not enough sometimes it makes it in lots of ways worse"

Goldsmith's (1997) conclusions about kerbs reflect the comments of the participants when he deliberates the differences between English kerb ramps and those in America.

While acknowledging that English kerb ramps have improved in recent years they are still steeply graded, have wheel-chair-skewing cambers, are jaggedly finished and have a "...castor wheel-stopping and occupant-lurching upstand at the point where it meets the road surface" (Goldsmith 1997, p.214). The Americans, by comparison, have introduced standardised moulded channel ramps which are set into the sidewalks. Although they too can be too steep for wheel chair users but they do meet flush with the road and are wide enough for a wheelchair or pushchair to negotiate easily.

8.7.2 *Tactile Surfaces*

Tactile crossings that have been specially designed to assist those with a visual impairment can cause discomfort for a wheelchair user. Goldsmith (1997) acknowledges that there is no research that confirms that benefits of 'knobbly bubble pavings' (Goldsmith 1997, p.205) but concurs that as 'everyone is doing it, it must be a good thing to do' (Goldsmith 1997, p.205). Research during the 1980's and 1990's concluded that prominent domes used for tactile paving could be shaved from a height of 6mm to 5mm. This amendment ensured they were still 'easily detectable to blind people without causing discomfort to others' (Goldsmith 1997, p.394). Comments from one group were resolutely opposed to this theory:

- 1m1 "..... where they have the tactile crossings oh, I believe they're really for blind people, a lot of people are in agony going across them"
- Me "In what way?"
- 1m1 "The bumps"
- 1f3 "The bumps oh they're awful"
- 1m1 "Sometime ago it was suggested that they had tactile either side and a pavement in the middle"
- Me "Yes"
- 1m1 "So that the blind people could still find the crossing cos the tactile was there either side and you've got the plain piece in the middle for the wheelchairs"
- 1m1&1f3 "The shake you to hell you're bumped along"
- 1m2 "They may be very good for one lot of disabled but they're not very good for the other"
- (ALL AGREE)
- 1f3 "tactile kerbs are difficult to be pushed over"
- 1m1 "people with bad arthritis or back problems, going across those lumps is murder"

8.7.3 *Physical Obstructions (Railway Lines – Poole Town Centre)*

Poole is a beautiful place to live, work and play that we take pride in passing on to future generations.

(Poole Community Care Plan 1999 / 2000)

That is how the unitary authority of Poole describes the Borough in its promotional information. The Borough provides many facilities for its disabled residents and its geographical layout allows far greater accessibility than that of its neighbouring Bournemouth. However, Poole high street is dissected by railway lines (Appendix 5). They have been there since the 1800's and there is no way to avoid them should you wish to go from one end of the high street to the other where the main shopping centre is situated. Able-bodied shoppers are able to use a bridge to cross the railway lines should there be a train due in or out of Poole station and the barrier is down preventing pedestrian access. Wheelchair users, individuals using rotators and shoppers with children in prams or pushchairs have to wait for the train, or trains, to pass. This can take valuable time out of a trip into town which is often curtailed by the unavailability of transport in the first place. Actually crossing the railway lines is a hazardous experience summed up by participant 1m2

1m2 “Well me and ***** went Christmas shopping a couple of years ago and I wanted to see something down the High Street so over we go so I gets halfway across and the wheel jams in the bloody railway thing
Then all of a sudden I heard this noise and the barrier started coming down and I thought bloody hell I'm going to get stuck here....
But we managed well ***** cos he's quite a big lad pulled me out and we managed to get to the other side but its quite scary”

It was stated that the best way to cross the railway lines is backwards, larger wheels first in some cases. However this requires a carer to assist and not every trip into town is taken with a carer.

1f1 “...so ludicrous all they have to do is build it up between the lines and surely it wouldn't cost much money cos all they have – to do is fill in where there are gaps. All it is, is where the ash felt or whatever it is has dropped so you've got a raised rail and a little dip there so if you've got little wheels as you come up to the rail it just needs to be flat between the rails”.

1f3 “...small wheels.. make sure train not coming, need a proper crossing where its level with the rails”

1m2 “build an underpass or something”

1m1 “get hold of someone from BR (British Rail) stuff ‘em in a manual wheelchair and say ‘get yourself across it’”

8.8 Attitudes Towards Disability

Attitudes towards disabled people were discussed in chapter 3. This section summarises the comments made by participants about the stigma they have encountered since becoming disabled.

8.8.1 Information Required at the Onset of Disability

Subsequent to the conversations about RADAR keys and the confusion about where they could be purchased it became evident that at the onset of disability information about services and service providers was limited. The following dialogue established what information was available.

Me “When you become disabled how did you find out about things?”

1f2 “Through other people – word of mouth is the only way you find out about anything”

(AGREEMENT FROM ALL)

1f3 “Lots of people don’t know things so you talk to them and say how can I get this and they’ve been disabled twice as long as you and don’t know as much”

(GROUP DISCUSSION ON WORD OF MOUTH)

“It’s like people who are your carers they don’t know they can get carer’s money”

1m1 “That’s right”

(ALL AGREE – SOLOM MOOD)

Me “Isn’t there a disability officer or somebody who can help?”

(ALL AGREE THERE ISN’T)

Me “Would something like that be helpful?”

(ALL AGREE IT WOULD)

1m1 “Even if they had on person or two people on the end of a phone.....”

Me “Like a help line”

1m1 “yeah – all the benefits, all the entitlement – if they could put you onto the right track”

As stated previously the focus groups took place in 1999. Since then a local organisation has been formed whose consultation services use the expertise of disabled people. Disability Wessex offers free, accurate, impartial and confidential advice about benefits, housing and adaptations, transport and travel, sources of equipment, leisure and interests and access issues.

8.8.2 *Stigma (Terminology)*

To establish participants views about the WHO and UPIAS definitions, one of the questions asked during the individual interviews was “Do you prefer the term handicapped or disabled?” The responses were varied but the general consensus was that the term disabled was favoured.

- 1m2 “need a word in between”
- 2f1 “I am disabled by my legs that don’t work, not handicapped by it”
- 2f3 “A person with a disability”
- 2f2 “Disabled, far better handicapped has a stigma”
- 1f1 “The word disabled is better than handicapped as to my mind handicapped means mental as well disabled covers it all”
- 1f3 “Don’t think about disabled or handicapped”
- 1f2 “Neither but if I have to use one disabled as opposed to handicapped”

It can be seen that the participants concur with the UPIAS definitions. Participant 1m1 took the answer to the question further than the other participants by asserting that society needs to reassess the way it sees disability.

- 1m1 “Disabled. I’m not handicapped am I? How am I handicapped? I think it’s up to us to prove to society that we are not disabled because all I’ve got in my case is a bad leg, my shoulder is starting to croak but I’ve got a good brain etc etc. So until society realises that the wheelchair is just a way of me walking its my transport”

Several participants divulged tales of how they have been discriminated against by other people who seem unable to communicate with someone who has a disability.

- 2f3 “If someone is pushing you then people speak down to you as if you are not there. They talk to the person who is with you, it’s off putting, you have only lost the use of your legs, not you head or your tongue. Does she take sugar? She has got a brain and is capable of talking to you. It’s as if when you are in a chair you don’t exist. Well you do exist its just as if your not an equal to the sales assistant it makes me so cross, I have got a brain, I had a responsible job. I was a ward sister in nursing”
- 2f2 “You are treated as if you are stupid cos your legs don’t work, if you have a companion with you they talk to them rather than you. My legs are bad, not my brain”
- 1f3 “If you are disabled they think you have no brain”

- 1f1 “you have enough problems without having someone looking down on you whether or not you are capable of carrying on a conversation or not you are still a person and you still want to be treated as a person whether you are aware of it or not”
- 1m1 “Instead of throwing a door open and saying “ere’ then ask if you want it open or say ‘can you manage’. Sometimes I appreciate a push but I prefer to do it myself.....If I go round the shops and people bump into me I don’t excuse it I’m normally quite rude to them”
- 2f1 “...we got a taxi my daughter and some friends and that and we went up cos there’s big steps ‘can we have a hand with mum’ and this big bouncer was standing there and he said ‘you coming in here? Is she coming in here?’ that was to me, ‘what you talking about? Who’s she? That lady there’ I said ‘I have got a voice!’ which surprised him (LAUGHTER)”

The comments made by the participants confirm the information debated during the literature review on disability. Their comments also affirm the theory that society disables less able people and how in the twenty first century oppression, discrimination and exclusion are a societal construct. All of the participants felt that re-education is the only way to change societies view about disability.

- 1f1 “Educate from an early age like a child they accept things from when they’re young. They grow up with it and its not a shock it doesn’t mean anything to them cos they’ve grown up with it I mean you go into a family that’s got a disabled parson or someone in a wheelchair and they have a child well that child has grown up with it. They accept it they don’t see anything different in it. It is the fear of the unknown that puts people off”
- 2f3 “Children with disabled parents are forward about it children are honest don’t know how to cover over they ask to know more”
- 1f2 “Yes I think it should be educated in the first place I mean your going to have to re-educate people who are older because they’ve already been educated but it should start at grass roots right at the beginning. I think they are trying to do a lot to not stick handicapped people away so that they’re educated differently. ‘Normal’ quote people don’t know how to react to them; the children are scared because they can’t answer in the same way. Once you’ve explained to them the reasons why they take it in their stride kids, they don’t worry about it at all once they understand.... Much more integrated as children then there wouldn’t be this bigotry and you know”
- 1m2 “We’ve got kiddies in our neighbourhood and they’re lovely. They come up and say ‘what you got there? What’s that then?’ and that’s fine then

cos they know who I am and who *** is and we're just part of the community"

8.8.3 *Negative Perceptions (Planners)*

Without exception, all the participants felt that planners could do more to create accessible environments. Their views endorsed those of Imrie (2003) when he stated 'Builders and officers do not understand the concept of 'inclusive design'' (Imrie 2003, p.43).

- 1m2 "It's a big wide issue cos there's a lot they can't do with a listed areas. It's a case of individualising certain aspects and bringing it to their attention"
- 2f3 "Not really, because even though they say everywhere has got to be geared up for the disabled it still doesn't happen a lot of the time...."
- 1f3 "I think they could do an awful lot more"
- 1m1 "They seem to make an effort and then it fizzles"
- 1f2 "No I don't think they're doing enough I know the problem is because we're a small minority and they've got only so much money that they're going to spend on the majority rather than the minority because they say well if we spend it that way we could do good for, I don't know, thousands of people but if we spend it that way we'll only achieve half as much for that small amount of people"

When asked if planners should consult with disabled people they said:

- 1f1 "I think planning officers need to have a registered OT with them wherever they go if they're talking of doing improvements or anything like that because they might say we'll do this or we'll do that but it's not what a disabled person wants or needs where as a physio or OT knows the needs of the disabled...it would save an awful lot of money"
- 2f1 "I think they ought to take somebody in a wheelchair with them when they are planning these things"
- 2f3 "...you get someone planning these things the last person they ask is the person who is going to use the facility like us because the doors aren't wide enough, toilets are so low you can get on but not off"
- 2m3 "if they were in a wheelchair they might have a different light on how they plan things out"

Two of the participants had had conversations with planning officers while attending workshops.

2m1 “But with the discrimination act or the change of building act all places that have public access have got to be made available in the next 15 years and as a councillor said to me in Poole – I won’t name him – right all we have to do is just submit plans we don’t have to do anything else for 15 years”

1m1 “About 2 years ago I went to a workshop at the civic centre and we had councillors opposite us – all the top bods – and we were split up into workshops, some doing access, some doing transport, some doing shops – you know. And this came up so often at the end of the day, it was suggested by blind people that they should walk around with blindfolds on, wheelchairs get in a wheelchair and actually wheel yourself round, not somebody pushing you, you actually do it yourself. Nothing from that side of it had been done”

8.9 Conclusion

The participant’s observations demonstrate that a lack of environmental accessibility is disabling. Their conclusions concur with the principles of the social model of disability and the literature discussed in Chapter 3. The five themes that came from the data illustrate examples of how design affects inaccessibility. The first four themes contain instances of bad design, while the fifth presents a solution to design issues.

- Observations about transport include poor bus and taxi design and accessible parking spaces being too small (Section 8.3).
- Comments about personal care include lengthy discussions about how to design a practical accessible toilet (Section 8.4).
- Issues raised about access to buildings include entrances with steps and heavy doors, clutter inside retail establishments, having to sit apart from family members and health and safety issues (Section 8.5).
- Concerns about urban accessibility include small kerbs that are not a problem for the mobile community but that are inaccessible for wheelchairs (Section 8.6).

All of these issues could be resolved by consulting with end users at the time of planning and construction.

It is in data from the fifth theme (Section 8.6) that the participants themselves recommend planners consult the people for whom they are designing / making improvements. Several participants expressed their views concurrently during each of

the focus groups about planners conferring with wheelchair users regarding design issues. Their comments were too distorted to transcribe, but the general consensus of the participants was that if the end users were consulted, the design solution would be successful.

The other factor that emerged from each of the themes was how societal attitudes also affected accessibility. The fifth theme (attitudes towards disability) discussed in depth how participants considered that the attitudes of others can only be changed over a period of time and through re-education. However, the other four themes also contained references towards attitudinal issues.

- During the theme about transport several participants remarked on the attitudes of public transport drivers. An example of this was given by participant 2f1 who was left alone, at night, in a street with a broken wheelchair by a taxi driver (Section 8.3.2).
- Participant's views about personal care were fervent. For most people personal care is a private and sensitive matter. Although most human beings need to use a toilet several times every day, toileting issues are viewed by the majority of people an issue not to be discussed with others. Participants asserted that they encounter an inequitable service due to deficient design as accessible toilets are rarely accessible for the people who need to use them. This was compounded by attitudinal views of other people who did not consider that the need to use a toilet was as prevalent for a wheelchair user as for their able-bodied peers. (Section 8.4.1).
- When discussing access to buildings many of the participants were blasé about being considered a 'health and safety' issue when visiting a public venue (Section 8.5). Some deemed that it was acceptable to give venues prior notice that more than one wheelchair would be attending an event so room could be made for them. This inequitable service was all that was available for most of the participants and the maxim 'anything's better than nothing' placated the desire for equality.
- Section 8.6 examined participant's observations about urban accessibility and there was insufficient transcribed evidence to endorse specific attitudinal aspects towards urban design. However, various comments made about access to

buildings in section 8.5 include incidents that happened outside of the built environment which constitutes urban accessibility.

A further example of people's attitude towards wheelchair users and the urban environment was discussed in section 8.7.2. Participant 1m1 explained how people would bump into him while he was out shopping and think nothing of their actions. His response was to be rude to them.

The attitudinal issues discussed in this chapter disclosed those of wheelchair users themselves, as well as those of societies. The wheelchair users that took part in this study had been previously able bodied and had been effected by societies views of discrimination (Safilios-Rothschild 1981). Individual's views were diverse due to their upbringing and cultural background and, just as their able bodied peers, opinions about issues that affected their lives varied from person to person. All of the participants stated that their views about disability had changed since becoming disabled themselves, and that they had never previously considered that one day they may need to use a wheelchair and be reliant on other people.

The data examined in this chapter is conclusive about the oppression experienced by disabled people through both environmental accessibility and societal attitudes. It can be seen that the participants were all resolute that, although the environment disabled them through physical inaccessibility, people's attitudes were a contributory factor to their disability through societal prejudices. This study maintains that designers can assist with changes in environmental accessibility and societal attitudes by adhering to an inclusive design methodology, where the end user is consulted throughout the design process. This is examined in chapter 9 where the debate considers how designers affect society through the products and buildings they create, and how attitudes are affected by design. Chapter 9 also shows how if inclusive design methods had been utilised and development professionals had consulted with the end user (disabled people themselves) during the design process many of the issues raised by the participants would have been negated.

CHAPTER NINE – INCLUSIVE DESIGN

The contents of the previous chapters substantiate that the oppression encountered by disabled people originates from peoples attitudes. The requirement for attitudinal modification within society can occur in time through advocacy and legislative procedures. This has been proved through attitudinal transformations towards issues of race relations and sexual orientation (Lewis 1998; Saraga 1998). If this tenet about change is to be assumed, then designers should involve end user during all stages of the design process in an attempt to substantiate the requests of minority communities for equality within society. Inclusion in a process that has a direct effect on end users lives would support any quest for equitability and portray designers as advocates of disability.

This chapter begins by examining the effects design has on the end user and how an individual's choice of product and design reflects their personality. This is particularly relevant to an able bodied person who becomes disabled, as their personality does not change as their bodies functionality alters.

The discussion continues by analysing the impact of social design and design exclusion. Inclusive, user centred and participatory methods are a relatively new concept in the field of design and there is little substantive literature to support their merits. However, the limited studies that have been completed using inclusive methodology demonstrate that it is a creditable technique and its value is deliberated as a method to prevent exclusion.

The debate then re-iterates the effect that designers have on society through their work and how their attitudes show through their designs. The manifestation of individual, and in turn, societal perspectives of discrimination towards disability through design is examined and the chapter concludes with the development of PACE, an inclusive design methodology. This type of inclusive methodology is a technique for portraying designers as potential advocates of disability by including end users within the design process.

9.1 Design and its Role in Society

Margolin (1997) discusses Nelson's comments at a 1986 lecture, when Nelson acknowledged that scientists and technologists have the potential to contribute to products, and that design occurs in different places under different names and has a profound influence on the world.

All I am saying is that the world seems to be moving in a direction where more and more things have to be designed by somebody, and my guess is that these somebodies, very few of whom think of themselves as designers, are the people who are really changing the world.

(Margolin 1997, p.233)

The products and designs individuals choose are based on emotions and identification with self-image. The way people dress, the way they organise their homes, their choice of car and their attitudes are related to who they think they are and where they consider they fit in society (Berger and Luckman 1967; Barber 1996; Kristensen 1999). Designers are trained to create products for people that subsequently have an effect on the end users quality of life. Psychological wellbeing and material capabilities may be enhanced, inhibited or supported by design and its moral and ideological attitudes (Kristensen 1999). A piece of furniture may support a person's body when at rest, but it may also enhance an individual's psychological wellbeing through their pride in possessing it or through reminders of past events (Kristensen 1999). Conversely, an individual's work may be inhibited or their health damaged by a badly designed working space (Kristensen 1999). Whitely (1993) concludes that design provides a 'snapshot' of society through its direct expression of cultural, political, social and economic complexities. In doing so, design reveals societies values and priorities. Buchanan (2001) considers that:

Design is not merely an adornment of cultural life but one of the practical disciplines of responsible action for bringing the high values of a country or culture into concrete reality...

(Buchanan 2001, p.38)

Whitely (1993) contends that designers are "...not coy about aligning themselves" and that most are "...white, middle-class males" (Whitely 1993, p.42). He also asserts that:

Many designers are deeply suspicious when they hear talk about such notions as 'the designer's social responsibility'.....as it may harm their own financial prospects and they find such notions anathema, politically and ideologically.

(Whitely 1993, p.43)

Some designers consider that the interests of their clients and their client's customers are the same, they argue that a customer buys a product if they are satisfied with it and this, in turn, satisfies the client as the company remains profitable (Whitely 1993). An amoral designer caters for desires and asks no further questions about how those desires are formed, but the ability of design to provide people with "...new tools for engaging in their cultural and natural environment" (Buchanan 2001, p.38) demonstrates how influential design can be.

This study asserts, as Whitely (1993) does, that a designer's perspective can be instrumental in changing society's attitudes through design. As design has the potential to effect people's wellbeing and quality of life, the designer must abstain from being the expert and either think like the user (Kristensen 1999), or consult the real experts in the field, the end users themselves. If designers alter the way they approach the design process and adopt an inclusive methodology, the methods and attitudes utilised will prevail in the final design.

9.1.1 Social Design

Margolin and Margolin (2002) describe the primary purpose of design for the market as "...creating products for sale" (Margolin and Margolin 2002, p.25). Barber (1996) agrees with this theory, but also states that products designed for people with disabilities frequently

...increase, at a psychological level, a person's sense of being disabled, especially those who develop a physical impairment later in life
(Barber 1996, p.561)

This concurs with the data obtained from the participants as discussed in chapter 8. Margolin and Margolin continue by acknowledging that the "...intent of social design is for the satisfaction of human need" (Margolin and Margolin 2002, p.25). They draw on literature from social work to develop a social model of design that requires designers learn more about the social needs of the people they are designing for. They recommend a multifaceted approach which incorporates qualitative research methods used by social scientists to explore people's needs. The methods they describe include survey research, interviews, content analysis and participant observation which enable designers to "...enter a social setting to observe and document social needs" (Margolin and Margolin 2002, p.28). In conclusion Margolin and Margolin (2002) suggest a research

agenda that purports a social model of design practice that relates to all classes of consumers, including those that do not constitute a class in the market sense e.g. those with disabilities.

When a person develops a physical impairment they lose control over the environment that surrounds them (Barber 1996; Morris 1991). Their new identity as a person with a disability may be perceived as being "...moulded by others" (Barber 1996, p.562) which may lead to a depletion of their sense of self. During one of Barber's discussion groups, participants stated that they considered products designed for people who had developed physical impairments should "...say something about the character and the personality of the individual before he or she became disabled" (Barber 1996, p.562). One of their suggestions was that people who had been previously sporty or physically active would prefer products "...whose message was 'speedy, active, go-getting'" (Barber 1996, p.562). The group considered that this positive type of image would assist with people coming to terms with their new situation (Barber 1996).

The majority of people who become disabled in later life have no previous experience of physical disability (Barber 1996). But as discussed in chapter 3, individuals have a view of disability and what it means to be disabled, that is based on their upbringing, cultural surroundings and media representation. As the majority of these views are negative, and often discriminatory, people who unexpectedly need to use disability products find them in conflict with their own self-image (Barber 1996). This requires newly disabled people having to overcome their negative perceptions of disability as well as their new physical situation (Barber 1996). Barber (1996) contests that the majority of products designed for people with disabilities are designed by able-bodied designers and reflect the designer's own images and expectations of disability. These views will have been developed in the same way as anyone else's through negative and discriminatory imagery. Barber contests that:

...the final product is more likely to reflect the preconceptions and corresponding fears of the non-disabled designer than the individuality and the uniqueness of the user.

(Barber 1996, p.562)

User participation within the design process would alleviate some of the designers' influence and incorporate the requirements of the end user, disabled people themselves.

9.2 User Centred and Participatory Design

Margolin (1997) describes how traditionally designers focused on a products form and appearance and how, as the social perception of the designer has changed, so the emphasis has moved to product use. As he explores the theme of designer / user relationships Margolin (1997) argues for "...an expansion of design knowledge from a knowledge of technique, which has been the traditional emphasis of design training, to a knowledge of user experience" (Margolin 1997, p.231).

User centred and participatory design processes are procedures where the boundary between the designer and the end user "...becomes blurred" (Luck 2003, p.524). Black (2004) asserts that the central premise of user-centred design is

..that the best-designed products and services result from understanding the needs of the people who will use them.

(Black 2004, p.1)

Luck (2003) describes participatory design as

..more than a collection of design methods to influence the built form, it also has a human dimension and can engage the people who form the community in the process.

(Luck 2003, p.523)

User centred and participatory design are methods that reflect design as a social process that extends beyond the designer (Luck 2003). In contrast to other design methodologies user-centred designers work directly with end users as opposed to findings from market research or from their own experiences (Black 2004). It is the active engagement of the designer and the end users when gathering insights into the requirements for the final product, that make user centred and participatory design different from other design processes. Established practices and assumptions are questioned as the designer gains greater awareness of the experiences of the end users. This leads to a form of inquiry that can initiate innovation which yields benefits to the end user (Black 2004).

User-centred designers engage with end users during the design course from the early stages of the project (Luck 2003; Black 2004). The process is based on ethnographic methods as the designer immerses him or herself in the users' context (Black 2004). It is this immersion that enables the designer to observe and appreciate the interaction of the end user with other group members, individually and within the milieu that they are designing for. As the design progresses designers continue to gather input from end

users and the analysis from their feedback is used within the iterative design and evaluation process (Black 2004). This direct involvement by end users in the design and decision making process has proved to be successful, not only in the design of products, but also with the development of individual buildings and communities (Luck 2003). Participatory design is a process that is advocated by Sanoff (2000) who grounds its methodological basis in the action research methods of Lewin (Luck 2003). Luck (2003) asserts that Sanoff's work (Luck 2003) articulates that "...participatory design methods form part of a broad democratic philosophy for participation of people in decision-making processes" (Luck 2003, p.524). This parallels the participation principles advocated by disability theorists (Oliver 1993) that people with disabilities should have an "...empowered consultative position" (Luck 2003, p.524). Siu (2003) concurs with this theory concluding that

...a designer's job no longer is to produce finished and unchangeable solutions, but to develop solutions from continuous two-way communication with those who will use his or her work.

(Siu 2003, p.73)

User participation can only be successful within the context of the design process when designers cease considering themselves as the only experts. This is not intended to devalue design or designers, it is simply to encourage designers to "...respect the value of users' input to the design process" (Siu 2003, p.73).

9.3 Design Exclusion

Cooper (1999) contends that designers instinctively focus on providing design solutions that match their own physical and skill capabilities. He considers this is due to their lack of knowledge about the different capabilities of users or uncertainty about how to accommodate their needs into the design cycle (Clarkson and Keates 2003). Clarkson and Keates (2003) maintain that "...design choices can exclude large numbers of the population" (Clarkson and Keates 2003, p.10:390) by decisions made at all stages of the design process. The participant's views deliberated in chapter 8 concur with this premise and substantiate the need for an inclusive design methodology. However, it should be acknowledged that encouraging designers and managers to employ inclusive design methods will only be successful when the impact of the new methodology is seen through the usability of products and designs (Clarkson and Keates 2003).

Design involves the identification of need, creation of solutions to meet that need and a review to ensure the need is met (Fig 4).

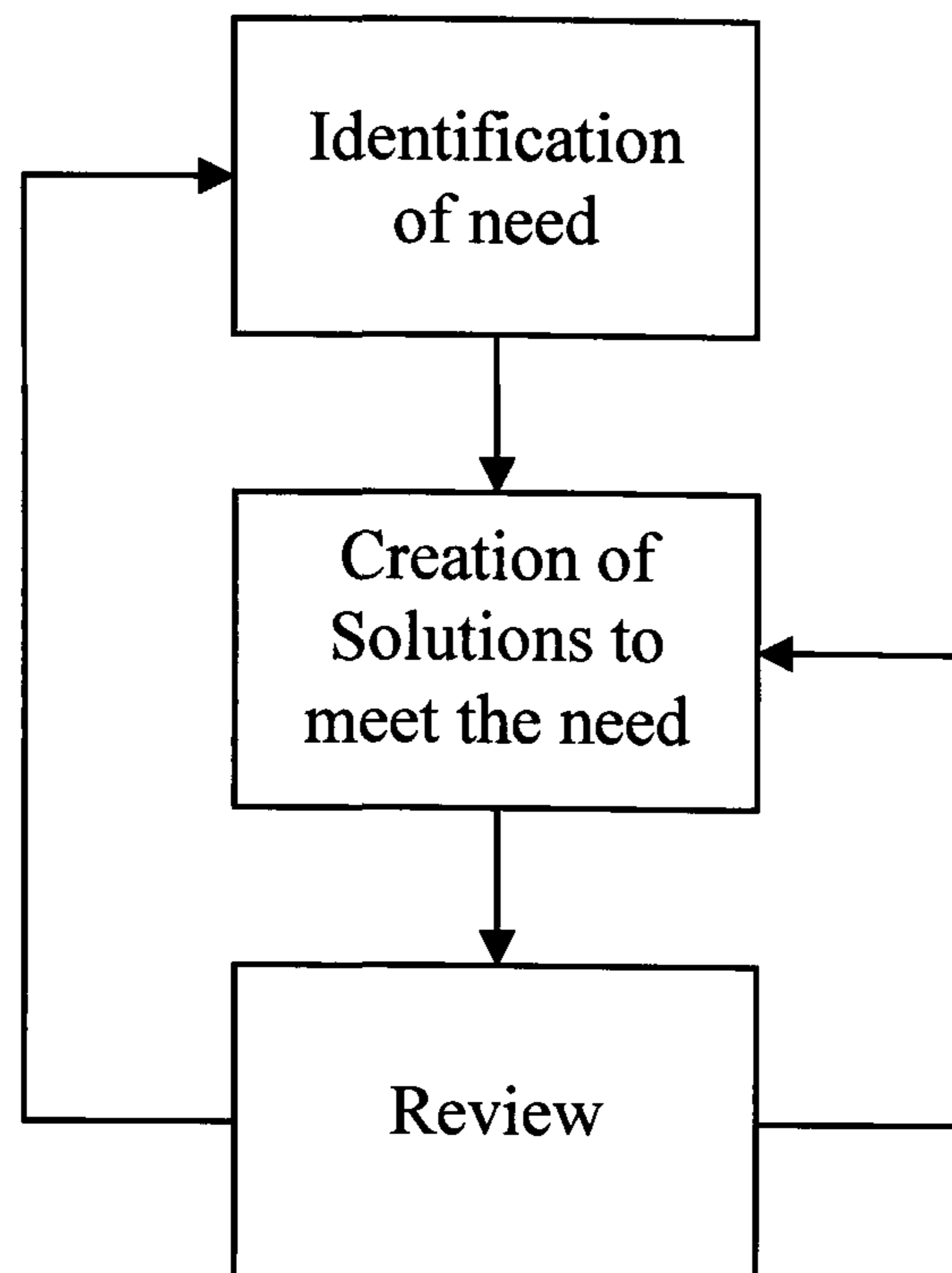


Fig 4 - The Design Process Simplified

Evaluation, quantification and reviewing techniques are necessary to highlight areas of concern in an emerging product or design (Clarkson and Keates 2003). These procedures evaluate and authenticate a product or designs functionality, usability, accessibility, aesthetics, sociability, marketability, cost and any other stipulated requirements. Perception, understanding and performance of functional capabilities are necessary for end users when interacting with design (Cardoso *et al.* 2003), but quantification for designers from a commercial viewpoint may have to be obtained. An example of stipulated requirements that may exclude sections of the population is described by Clarkson and Keates (2003). They consider the scenario of "...a kettle that must boil a minimum volume of water also has a minimum associated weight with the water inside it" (Clarkson and Keates 2003, p.10:391). Users will require a minimum amount of strength to move the kettle and if this is lacking the product will be unusable by some people irrespective of other product requirements or design decisions. Clarkson and Keates (2003) conclude that 'good' design practice would be to ensure only the exclusion of people excluded by the products stipulated requirements. This study contends that good design can be achieved through inclusive design methodology where the end user is involved throughout the design process. However, it also concedes, as

Clarkson and Keates (2003) acknowledge, that exclusion will occur, but by utilising inclusive design it will be kept to a minimum.

Jordan (2003) asserts that designers fail to design inclusively as they do not consider that the product may be used by someone with a disability. He also contends, as Clarkson and Keates affirm (2003), that by adhering to the design brief the product may exclude people by default (Jordan 2003). Jordan (2003) describes how he uses personas in order to focus during the design process. Personas are made up people, usually the types that are perceived that would ideally use the end product. The designer keeps the persona in mind and attempts to create a product or service that they (the persona) would use (Jordan 2003). Personas enable the designer to imagine the product in use and Jordan (2003) advocates that they are a tool "...suitable for bringing inclusive design into the product creation process" (Jordan 2003, p.5). He asserts that designers can imagine disabled people using products and designs and acquire an idea of problems they may encounter. He concludes that the persona approach to design can be successful even "...when the organisation has no formal commitment to inclusive design" (Jordan 2003, p.6). The merits of this type of design methodology are similar to those of scenario based design. Scenario based design is similar to Jordan's (2003) use of personas but the scenarios created by the designer consider more than a singular activity (Carroll 2000). Carroll (2000) describes scenario based design as being able to "...offer a unique leverage on some of the most characteristic and vexing challenges of design work" (Carroll 2000, p.44). It is a method that allows the designer to create or imagine a scenario of their choosing and evaluate how the situation will change if certain factors alter (Carroll 2000).

An example of imagining the world of wheelchair users can be seen in the video *Dreams are the Worst* (1984). The concept is based on Finkelstein's (1975) paper that describes an imaginary world where wheelchair users live together in a village that gives them full management and democratic rights. "...for the villager, being in a wheelchair, is like anyone else in the world" (Finkelstein 1975, p.36). Villagers design the buildings to accommodate only wheelchair users and, as no-one is vertically ambulant, the ceilings and doors are low. Finkelstein (1975) continues with this imaginary world by introducing able-bodied people who have to come and live there "...through no choice of their own..." (Finkelstein 1975, p.36). They acquire bruises

from banging their heads when they use doorways and back injuries because of low ceilings mean they have to stoop when mobilising. Eventually they visit wheelchair using Doctors who write reports about the condition of "...able-bodied people in society" and how "... the bruises and bad backs were *caused* by their physical condition" (Finkelstein 1975, p.36). The story concludes with the able-bodied people arguing that "...perhaps their disabilities could be overcome (and disappear!) with changes in society" (Finkelstein 1975, p.36). Finkelstein's (1975) views of a very different world from the one we live in give a synopsis of how designers might gain an insight into the world of a wheelchair user through their own imagination.

Jordan (2003) considers that once designers understand the difficulties faced by disabled people they can begin to design the products for use by people with varying disabilities. This study agrees with Jordan's hypothesis, but contests that his methods utilised for obtaining the views of the end user are adverse to the social model of disability, the request for inclusion from disabled people and the basic principles of inclusive design. Although Jordan (2003) asserts that he advocates inclusive design, he does not include disabled people themselves in the design process. This is disparate from the views of the participants of this study discussed in chapter 8 and the literature reviewed in chapter 3 that affirm that planners and designers should consult with disabled people themselves.

9.4 Design for Accessibility

Imrie and Hall (2001) maintain that "...designing for the needs of disabled people has never been a significant feature of the development process" (Imrie and Hall 2001, p. 10). They further assert that design texts containing anthropological and ergonomic data (Neufert and Neufert 2000) reinforce architects beliefs that disabled people "...revolve around a range of physiological norms...that reduce the body to a universal type ...characterised by fixed parts" (Imrie and Hall 2001, p.10). This perspective is endorsed by two professionals working in the field of disability access, and with whom the researcher consulted to gain their perspective from the planning and development perspective.

Graves, the Equality and Diversity Officer with Barclays Bank, Poole, and who has had a sight impairment since birth, considers that design professionals frequently

incorporate the needs of a wheelchair user into design projects considering that their requirements satisfy all disabled peoples needs. Graves maintain that this occurs because designers do not identify with disability or inclusive design methodology. He goes on to argue that the situation is compounded further by the international sign for disability is a logo of a person in a wheelchair. The logo is a contentious issue, much debated in disability related circles, where many disabled, and non-disabled people, consider it unsuitable as it portrays the notion that only wheelchair users are disabled.

Brookwell, the Access Surveyor for Bournemouth Borough Council, considers that

...access isn't just ramps and toilets, nor is it rocket science. It is a common-sensicle [sic] approach to making your building accessible to all

(Personal Communication, May 13, 2004)

These views on disability, accessibility and inclusion are encouraging and oppose the views of many planners, designers and local authority employees. Both in and out of her official role Brookwell is involved with several local disability organisations and is a proactive member of a local access group. She advocates inclusive design methodology and worked with Imrie (2003) and a local charity researching an inclusive project that considered the impact of Part M on the design of new housing. In the report Imrie (2003) asserts that builders are limited by innovations in materials and products by suppliers, structural restraints and consumers who consider disability and good design adverse compatriots. He further contends that as with other aspects of design they make no attempt to challenge these acknowledged views (Imrie 2003). Imrie (2003) concludes that

Design innovation in relation to disability is likely to be limited by builders' perception that consumers are conservative in their design tastes, and unlikely to want fixtures and fittings associated with disabled people.

(Imrie 2003, p.11)

Although Imrie's (2003) report discusses the impact of building regulations it also highlights how builders, planners and designers attitudes towards disability issues are influenced by their own attitudes, upbringing, societal and cultural influences. This is concurrent with the data gained from the participants (See Chapter 8), the literature reviewed (See Chapter 3) and the principles of the social model of disability.

9.4.1 User Participation

As previously discussed in this chapter, persona's and scenario based design are methods that designers can utilise to consider disabled people's needs and requirements. However, as formerly stated, it is the contention of this study that these are not satisfactory methods for comprehending the real desires of the end user. The best way to understand these needs is to ask the end user themselves, as they are the experts when it comes to true evaluation of the product they are going to use.

Unlike the field of social science research, design research has few examples of user participation within the complete design process. Salari and Leon (2003) discuss the challenges of using ethnographic participatory methods within the field of design. They contend that this type of methodology is

...more powerful and far reaching than a set of managements teams scanning over second-hand data or reviewing outsourced reports that make reference to a dissatisfied consumer base...

(Salari and Leon 2003, p.12:486)

But they go on to affirm that one of the problems in persuading managers to utilise participatory methods, is that by becoming immersed in the everyday lives of the end users designers will see with their own eyes the constant challenges that poor design presents the user (Salari and Leon 2003). A social scientist would consider this an element of the research findings that could lead to richer data if pursued further, however a designer would believe the information to be detrimental to the design process as they would no longer be singularly accountable for the end product. This disparity between the views of social scientists and designers was a fundamental consideration throughout the development of the design resource that accompanies the inclusive design methodology that this study advocates.

9.5 Inclusive Design Methodology

Inclusive design is a design methodology where the end users are at the fulcrum of the design process. Designing inclusively is not a separate specialism or a new genre of design; it is an approach to designing that enables the designer to

...ensure their products and services address the needs of the widest possible audience, irrespective of age or ability.

(Design Council 2003, p.1)

Research completed by Salford University Research Focus on Accessible Environments (SURFACE) demonstrates that designers are enthusiastic about incorporating inclusive design principles into the design process (Newton *et al.* 2003). However the participants that took part in that study conceded that

- Designers had a knowledge gap when dealing with complex design problems for disability
- Designers have concerns about the DDA particularly part 3 - where the definition of 'reasonable' provision remains uncertain
- Users want to be involved in the design process but feel they have little to contribute

(Newton *et al.* 2003, p.14:562)

The SURFACE research utilised an inclusive design approach and the social model of disability together with emancipatory research methods and concluded that there needs to be "...a national framework for inclusive design education" (Newton *et al.* 2003, p.14:569). The authors (Newton *et al.* 2003) contend that research shows that effective legislation underpinned by practical guidance would be the key to "...designing environments for everyone to use and environments that ultimately improve quality of life" (Newton *et al.* 2003, p.14:569).

As previously stated, RICA describes the ability of inclusive design as being to

...design mainstream products and services so as many people as possible can use them, although there will always be some people who need specialist equipment.

(Ricability 2002, [p. no number])

This concurs with Jordan (2003), Clarkson and Keats' (2003) and this studies acknowledgement that there are practical limitations to inclusive design due to individual disabilities specialist requirements. However, the advantages of inclusive design far outweigh the minor limitations. The principles of inclusive design assist with the production of products and designs that are suitable for all sections of society and design exclusion is minimal or eradicated. In order to persuade managers and decision makers to include inclusive design methodology into the design process, advocates of inclusive design need to promote projects where its methodology succeeds and validate its credibility.

The twentieth century saw the onset of research and development into the field of inclusive design. However, the amount of research has only recently increased with the

advent of a bi-annual conference organised by the Helen Hamlyn Research Centre at the Royal college of Art ('Include' 2005). Attendance at the 'Include' conferences has increased progressively, as understanding of the benefits of inclusive design extends through companies who seek a better understanding of their customers needs ('Include' 2005). Also, the introduction of social issues into the design curriculum and the exploration of user-centred methods, have been contributory factors to the expansion of inclusive design techniques. However, there are few exponents of models or resources to provide a framework for an inclusive design project. The inclusive design 'cube' was developed as a model to encourage the acceptance of inclusive design and to provide a guidance framework (Clarkson & Keates 2003). But, it is a diagnostic tool to assess the potential for expanding the market for a product, rather than a set of guidelines to encouraging user involvement. By contrast, the Royal Society for the encouragement of Arts, Manufacture and Commerce (RSA) has developed an electronic resource for anyone completing an inclusive design project. However, the data on the cards provided only offer an outline about how to obtain further information on a given topic. Whilst the principles of inclusive design are being acclaimed, no one has compiled a resource that contains all of the information contained in the one developed for this study (Chapter 13).

9.5.1 Market Segments

One of the reasons inclusive design methods are shunned by decision makers is the misconception about the market segment their product or design is targeted at. Demographic change is a challenge to the design profession and a need for a more inclusive design strategy is being recognised within the business agenda (Design Council 2003). Although inclusive design knowledge is becoming more prevalent within the design community, the involvement of end users is rarely incorporated in the project budget and timescales (Bellerby and Davis 2003).

Marketer's belief of separating the population into segments is contradictory to the tenets of inclusive design as they believe

...attempting to satisfy all of the market will in fact satisfy the needs of none of the market segments effectively

(Lancaster and Reynolds 1999 cited Bellerby and Davis 2003, p.1:17)

Bellerby and Davis (2003) assert that what decision makers in the design process do not seem to recognise, is that when considering a target population for a product or design, disabled people are inherent within existing market segments by nature of socio-demographic criteria. Age, income and attitudes are used by marketers to classify the population into measurable segments and disabled people are intrinsic to all of these categories although they may not be visible as having a disability. As disabled people are included in existing market segments, it should be recognised by decision makers that embracing inclusive design does not require a special needs market segment.

It should be acknowledged that the costs involved in a design project constitute a major influence on manager's decisions. However, it should also be recognised, by managers themselves that their comprehension of market segments and how inclusive design is of benefit to all members of society, not just disabled people, would lead to better design production which in turn would lead to wider inclusivity which would initiate greater profitability. To understand how adaptable and easily inclusive design methods can be integrated into the design process, the following model has been developed by the researcher.

9.6 PACE model of Inclusive Design

The PACE (Problem, Analysis, Concept and Evaluation) model of inclusive design shows how at all stages of the design process the end user should be consulted. As with Pugh's (1991) model of total design, the PACE model of inclusive design encompasses the whole design process. Pugh (1991) describes his model of total design as having "...a central core of activities, all of which are imperative for any design, irrespective of domain." (Pugh 1991, p.5). The design core, becomes enveloped by the product design specification, obtains additional inputs from discipline-dependent and discipline-independent sources, which produces the product design activity model. As Pugh's model is based around a central core of design activities, the PACE model of inclusive design is centred on consulting with the end user and recommends that at all stages of the design process the end user is consulted for their views. It should be recognised that the end user will not necessarily be able to offer design solutions, but that their comments should assist the designer in their quest for solutions. The object of this is that by consulting with the end user during the design process and seeking advice from

the people who will use the product or design, the final concept will be more suitable for the people who will actually use it.

9.6.1 Development of the PACE model

Design models and PhDs in the field of design have a common theme - requiring a 'novelty' factor to express their content. The PACE model demonstrates graphically how the inclusive design process works. It was developed by considering and evaluating the keywords used in the design process.

All design begins with a problem, solutions are sought and developed and evaluation of the solution occurs, Problem, Analysis, Concept and Evaluation (P.A.C.E). When inclusive design methods are incorporated into the design course the end user is consulted at all stages of the process (Fig 5). The extended PACE model (Fig 6) shows how even during testing, modification and the end use stage, the end user should be consulted.

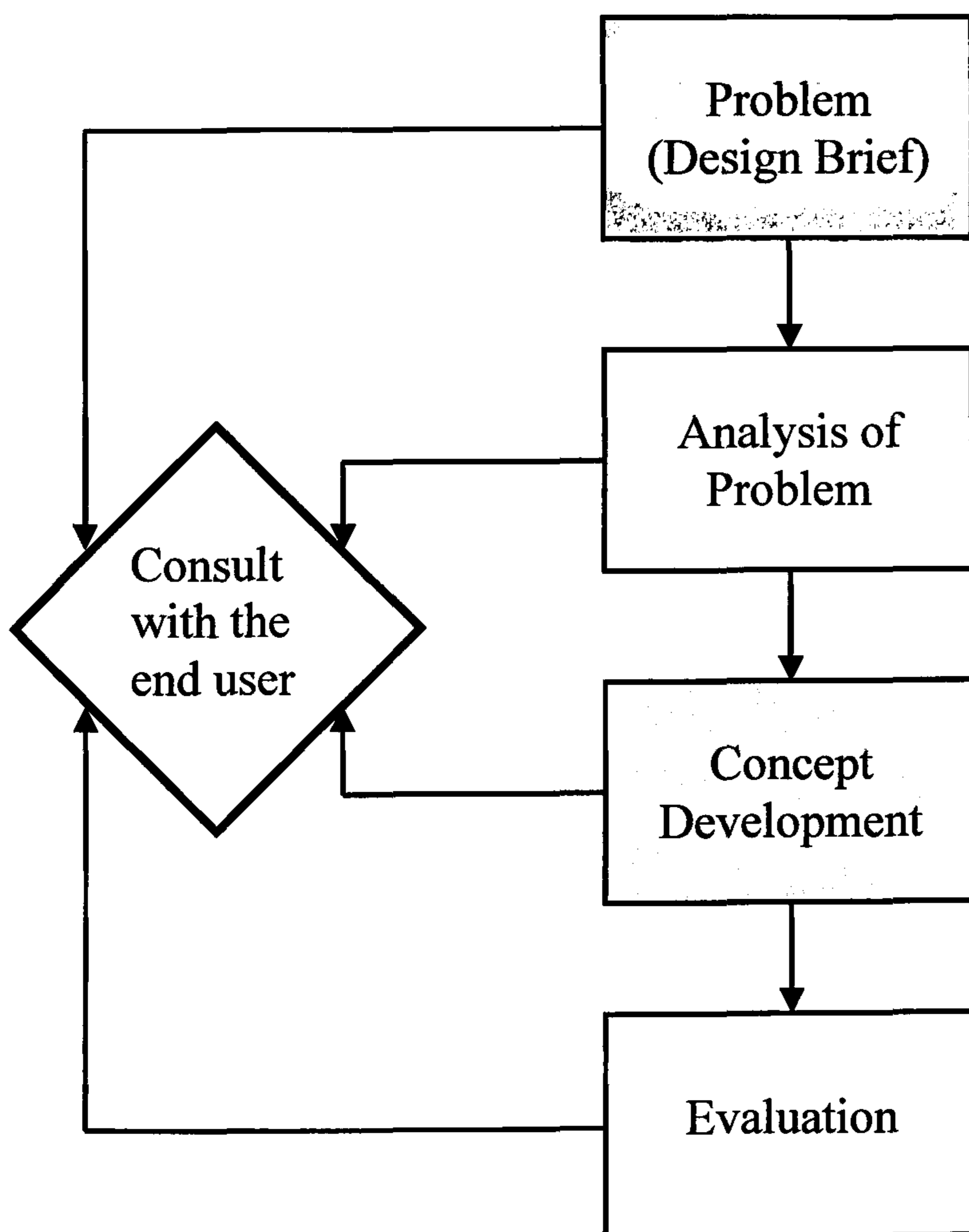


Fig 5 - PACE model of Inclusive Design (Adams 2004)

If the PACE model of inclusive design had been used in the design process for each of the issues raised by the participants of the study (See Chapter 8), it can be hypothesised that their views would have been very different. The discussion in chapter 11 considers how participant's comments might have been divergent to those articulated during the focus groups if inclusive design methods had been utilised. The debate does not consider specific alternative design solutions, it deliberates how, if the experts in the field had been consulted during the design process, the issues raised might have been different.

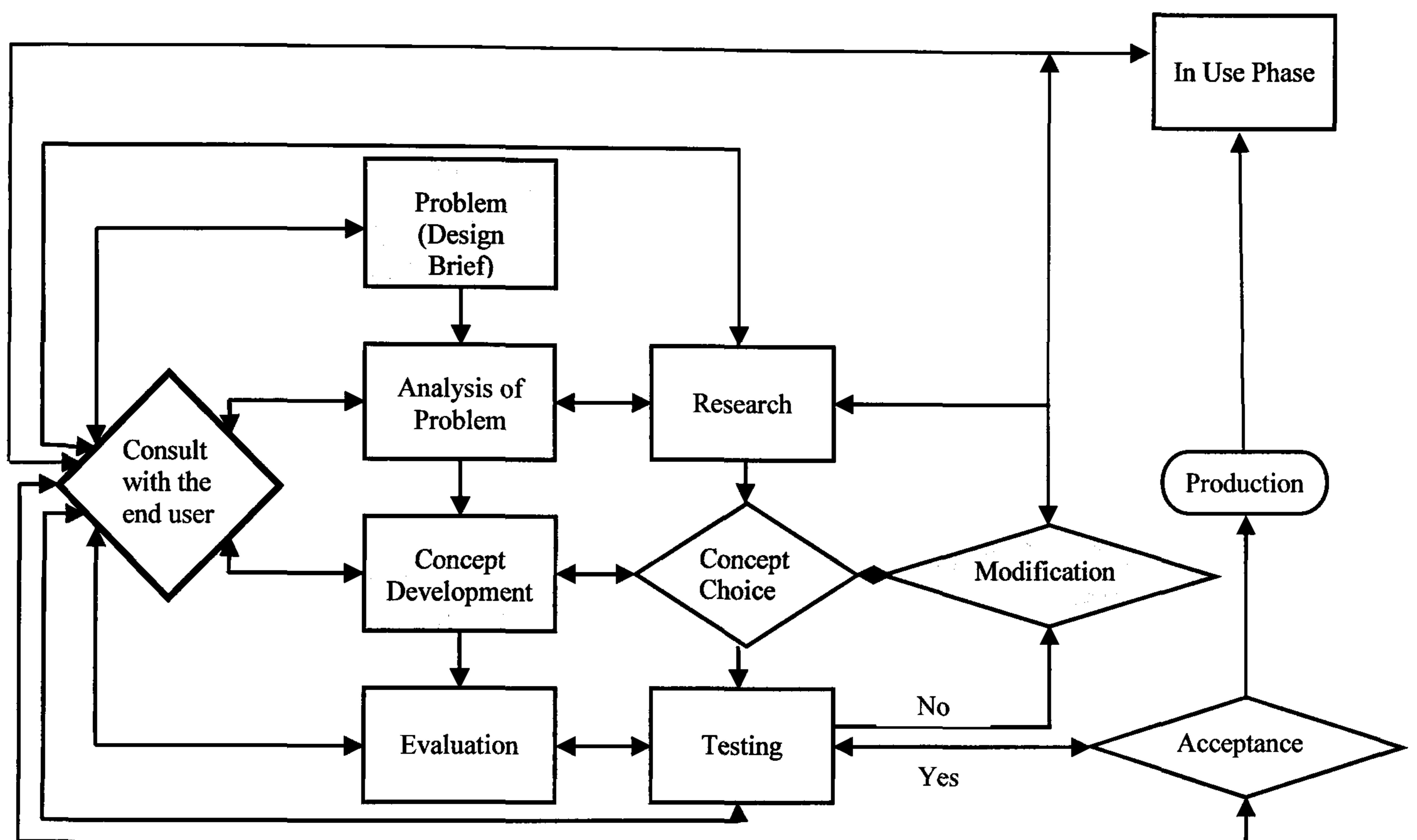


Fig 6 - Extended PACE model of Inclusive Design (Adams 2004)

In addition to understanding how inclusive design methods can enhance the design process and eliminate design exclusion, designers require an understanding of how to communicate with the end user. As a consequence of this a design resource to assist designers with communication techniques has been developed by the researcher. The resource offers designers solutions as to where they can locate information required to support and help with the design process when designing for disability.

For the purpose of this study the end user is presumed to be a wheelchair user and the design resource developed to accompany the PACE methodology is specific to that sector of the disabled community. The resource does consider other disabilities and

makes recommendations about communication with visual impairments, hearing difficulties and cognitive disabilities but the main emphasis of the resource is wheelchair users.

CHAPTER TEN - DEVELOPMENT OF THE DESIGN RESOURCE

This chapter considers the implications and usefulness of a design resource that has been developed to be used in conjunction with the PACE inclusive design methodology. The resource offers designers a collection of data that will enable them to communicate effectively with members of the disabled community in a socially acceptable manner. It also offers suggestions of locations where designers can source information specific to designing for people with disabilities. The resource is divided into ten sections and the discussion examines their content, the reasons for their inclusion and where appropriate the content of each section added to the resource is linked to the participant's comments from chapter 8.

10.1 Participants' Views

The design resource was developed to be used in conjunction with the PACE model and its contents evolved from data obtained from the focus groups and individual interviews. As discussed in chapters 6, 7 and 11, for research in the field of disability to be 'meaningful' researchers need to engage with, listen to, and take advice from, experts in the field - disabled people themselves. As all of the participants of the focus groups had disabilities, and were wheelchair users, it followed that utilising the data they provided in the development of the resource, was appropriate.

On the whole the participants' comments were not gender specific (Marks 1999), except for the remarks about public toilets. Not all of the participants agreed that they should have to pay a charge for a RADAR key. Participant 1f1 stated

...you know the thing that annoys me with these toilets for the disabled? You need a RADAR key, why should we pay for it
(1f1 1996)

This sentiment was echoed by 1m1. Moreover, participants were concerned about the differences in pricing and that the system didn't always work. This was proved by the quote from 2m1 who related the story about how on a trip to London, he and his wife found someone

...camping in the disabled loo and they must have been able to buy a key just like that ... they're supposed to issue them on identification only that they are actually for your use
(2m1 1996)

But it was participant 1m1 who made the gender specific comment, in allegiance with his female peers. He observed that:

...I don't have to pay to go to the toilet do I - as a man

(1m1 1996)

This comment instigated a conversation between group members about women having to pay to use public conveniences, whereas men do not. The conversation was summarised by 1f3 who stated that as "...ladies have to pay to use the loo, so I suppose a one off charge for a RADAR key..."

This was the only gender related comment raised by the group, which implies that issues relating to disability and access are not gender specific. However, many disability researchers and academics would dispute this argument asserting that experiences of gender will have an important effect on an individual's experience of disability (Morris 1991; Barnes and Mercer 2001; Marks 1999). Where able bodied men are generally seen as being strong, self sufficient and predatory, disabled people are often perceived as women are often portrayed, as passive and needing protection (Marks 1999; Greenwell 2003). Differences between people can be seen as natural, leading to divisions of 'male' and 'female' (Greenwell 2003). This division is seen as being the basis for the inequalities between men and women (Clarke and Cochrane 1998). Unfortunately disabled people, whether male or female, are frequently denied the role of nurturer, as they are often perceived as needing assistance (Morris 1991; Marks 1999). As social, economic and political factors (including poverty and gender) influence the maintenance of culture in the majority world, then the portrayal and understanding of disability culture must change in order for cultural representation to assist disabled people to integrate into mainstream society. As previously discussed, designers can influence societies views, through their designs. Currently designers do consider their clients and customers views, but mainly from a profitability view point (Lorenz 1990; Pugh 1991; Sethia 2005). However, by challenging the way the design process is conducted, and by integrating end users into the design course by means of inclusive design, then designers can be instrumental in assisting the disabled population with attaining the inclusion that they desire.

However, it should be acknowledged that the participants who were asked to join this study were invited to enlist to assist the researcher to answer the research questions outlined in chapter 2.

- How can designers become more inclusive?
- How should designers engage with disabled people to ensure their views are incorporated in the final design of products and services?
- If traditional design methodology draws upon approaches which involve end users, would the resulting procedure enable designers to advocate an inclusive paradigm, where the emphasis is on utilising the knowledge of the ‘experts in the field’, the end users themselves?

The aim of this study, therefore, has been to develop a new process for designers to utilise when designing for people with disabilities. Whilst it is recognised that considering cultural implications and issues surrounding citizenship are important to the progression of the disability movement, they are not issues that are a foremost consideration within contemporary design procedures. That is not to say that they should not be, or that they ought to be as extraneous as they are presently considered to be. However, instigating this major sociological change in design thinking will not happen quickly and will undoubtedly meet with some resistance. Although, design practitioners are beginning to recognise the significance of inclusive design principles (‘Include’ 2005) and changes in the design profession are occurring.

The task now is to build on the sense of energy and the initiatives generated by Include 2005 and continue to press for change in the way we design our world
(‘Include’ 2005)

Wilcox (2005) asserts that designers and researchers should work collaboratively rather than designers conducting research, and researchers purporting to understand design techniques from observing how designers work. Wilcox (2005) goes on to describe the only effective method to ensure that designers accept research information.

When researchers are presenting information to designers...it has to be placed into a form that makes sense to designers...take information and be able to visualise it...the nature of design is multi disciplinary
(Wilcox 2005, p.5)

It is hoped that this premise of collaboration between researchers and designers will develop over the next two years, and the results will be presented at ‘Include’ 2007.

10.1.1 Examples of how the Participants Views Influenced the Contents of the Resource

All of the participants agreed that planners and designers don't listen to their views about disability or take their experiences into consideration (Chapter 8). These discussions prompted the development of the PACE inclusive design model and the associated design resource. Whilst the majority of the resource offers specific guidance to designers regarding statistics, where to locate information about disability issues and legislation, some of the sections were developed after taking into consideration comments made by the participants.

The section on conversation and etiquette was developed from respondents comments about how they didn't consider themselves to be any different now that they had a disability. They wished that people wouldn't treat them differently. 2f1 noted "... people in a manual chair being pushed, people talk to the pusher..." While 2f3 commented

If someone is pushing you then people speak down to you as if you are not there. They talk to the person who is with you. It's off putting, you have only lost the use of your legs, not your head or your tongue – does she take sugar
(2f3 1996)

The element about acceptable and unacceptable terminology was included as participants commented about the use of the terms handicap and disability. Participant 2f1 affirmed "I am disabled by my legs that don't work, not handicapped by it". All of the participants agreed that they preferred the term disabled to the term handicapped. The participants' assertions were summed up succinctly by 1f1 who observed that "I think that handicap is an awful word". While 2m1 argued that

...wheelchair users not wheelchair bound, because a lot of people say wheelchair bound its wheelchair user
(2m1 1996)

Although social science researchers have realised the advantages of focus groups, designers, historically, have not. Wilcox (2005) asserts that designers shouldn't really do research if only from the point of view that they are not trained in the area. He argues that it takes a long period of education to become a proficient researcher, and that as researchers are not designers, so, designers are not researchers (Wilcox 2005). Therefore if designers and researchers work in collaboration as opposed to telling each other how to accomplish elements of their chosen professions, then design research

would be more progressive. Yet, while suggesting designers and researchers to work together, Wilcox (2005) omits to consider the cost, time implications and personality problems that would certainly arise if designers were to relinquish part of the design process to an outsider. That is not to say that in larger design businesses do not employ researchers, but in a small organisations cost is a major implication (Pugh 1991). However, the premise of inclusive design is to include the end user in the design course and to acknowledge their expertise. If research and design are performed by separate departments or individuals then some of the valuable insights into the experience of the end users may be lost via interdepartmental discussions.

10.2 The Design Resource

The following discussion considers the topics included in the design resource, the reasons for their inclusion and their relevance to the end user and the designer. **The reader should note that the dialogue changes between the third and first person as the researcher uses sections from the design resource are used within the text.** The researcher considers that utilising direct excerpts highlights the user friendly approach of the resource.

Porter *et al.* (2003) contends that “...any (inclusive design) resource must be highly visual, with a ‘pleasurable’ interaction for the designer” (Porter *et al.* 2003, p.14:578). The resource has been created with this in mind and it is segregated into ten “...bite sized...” sections (Lebbon 2003, p.3:125) entitled:

- **Introduction and Golden Rule**
- **Conversation Etiquette** – How to talk to people with disabilities
- **User Participation** – Focus groups as the most appropriate method for user participation in inclusive design
- **Acceptable / Unacceptable Terminology** – Terms that are, and are not, socially acceptable to use when communicating with people who have disabilities
- **Disability Definitions and Statistics** – WHO and UPIAS definitions and web links for disability statistics
- **Guidance on Disability Legislation** – An overview of the DDA, Part M of the Building Regulations and disability legislation web links
- **Ergonomics** – Ergonomic web site links and publications

- **Web Links** – A selection of web links to sites specific to disability
- **Overview of Medical Terminology** – An overview of symptoms of some disabilities
- **Glossary**

(Design Resource – Appendix 6)

10.2.1 Introduction and Golden Rule

The design resource has been developed for use by professionals when designing and developing products or completing alterations for disabled people. Its principles are based on the social model of disability and it is intended that the resource will be used in conjunction with inclusive design methods. As previously discussed, the core of inclusive design is that the end user is consulted at all stages of the design process. If this principle is to be followed, designers will require an understanding of how to:

- Converse successfully with people with varying disabilities
- Communicate in ways other than through verbal communication
- Comprehend socially acceptable terminology where disability is concerned
- Obtain information from one or more members of a group
- Locate information that may assist with a solution to a design problem

While it is acknowledged that the resource has been developed for designers to use, its content concern issues to be considered for designing for people with disabilities. Therefore in accordance with recommendations that can be found on the RNIB web site: www.rnib.org.uk the resource utilises size 14 Ariel typeface, 1.5 line spacing and is black text on a white background.

The front cover of the resource shows a diagram that portrays the values of inclusive design and how all phases of the design process should consult with the end user, the experts in the field (Fig 7).

The beginning of the resource contains an introduction and a ‘Golden Rule’ quoted from literature supplied by Disability Wessex “**Always** ask the person concerned – **Never** assume you know best” (Disability Wessex 2003, p.1). This maxim was considered apt to use at the beginning of the resource as it summed up its contents effectively.

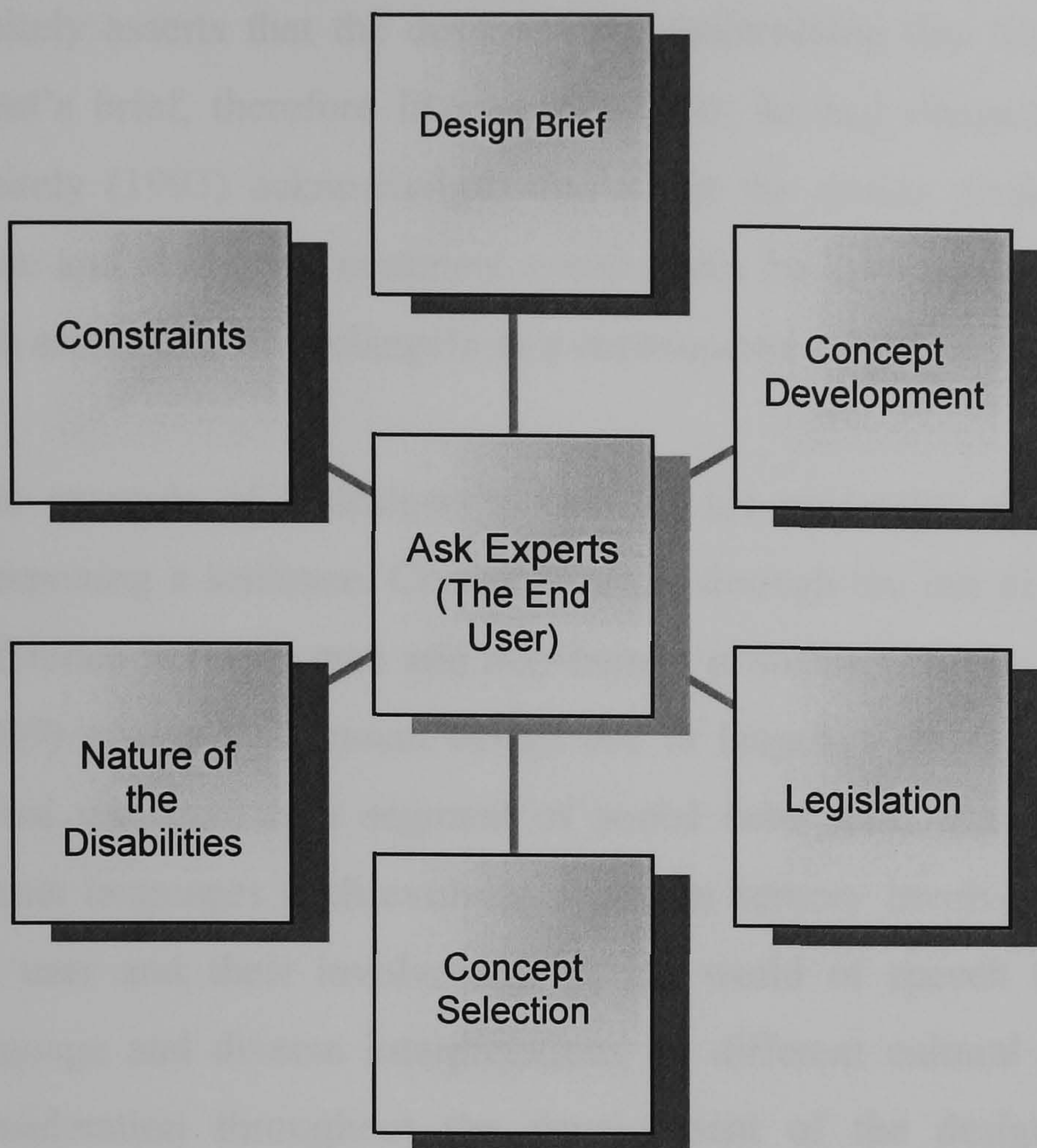


Fig 7 – Front Cover of the Design Resource

10.3 Use of Language

Chapter 3 considers how labels for groups, behaviours and types of people can afford social disapproval. The same dilemma occurs with the use of language and terms used by designers and social scientists which although they have different wording, actually have similar or the same meaning. This diversity in the use of language between different social and cultural groups was a fundamental aspect that had to be considered during the development of the design resource. It was important, as designers and the people they are designing for must communicate effectively so that the end product is beneficial for all.

Whitely (1993) describes the design profession as occasionally being able to “...see its creativity in grandiose terms”. (Whitely 1993, p.43). He recounts a dialogue from a successful designer who stated:

I was in Venice, looking at paintings in churches, and I thought to myself, ‘I am no different from those blokes: if I lie on my back and paint this I am exactly the same’.

(Whitely 1993, p.43)

Whitely asserts that the designer was maintaining that Michelangelo was fulfilling a client's brief, therefore like any designer, he had obligation to his client. However, Whitely (1993) acknowledges that given the design professions insistence about its value and skills, the comment could easily be interpreted that designers are on a par with artists like Michelangelo as a consequence of their mutual creativity.

This example of a designer's view of his profession shows two different ways of interpreting a sentence. Communication through the use of language is the most basic difference between man and non-human primates (Argyle 1969; Ingold 2001). Argyle (1969) asserts that human beings use of language develops from childhood and each verbal utterance is a segment of social behaviour. There are hundreds of different human languages each evolving from the sensory involvement with the world around the user and their involvement in the world of speech (Ingold 2000). The use of language and diverse interpretations by different cultural groups was a fundamental consideration throughout the development of the design resource. As previously discussed the concept of the resource is to enable designers to establish the views and needs of the end user which can then be incorporated into the design specification. To enable successful communication between both parties the language used in the construction of the resource had to be suitable for both cultural groups to comprehend. Ingold (2000) describes language as:

...a system of acquired rules and representations. It is inscribed in the mind of the speaker and is transmitted as a body of information...it is an objective system of rules and regulations for generating well formed and meaningful utterances.

(Ingold 2000, p.393)

An 'utterance' has a hierarchal structure of phonemes, morphemes, words, sentences and paragraphs that are governed by rules (Argyle 1969). These utterances, or language, control and co-ordinate individual behaviour which in turn advances the development of culture (Argyle 1969). Babies learn any language to which they are exposed and as they develop the use of speech they are able to generate an infinite number of sentences. Children do not learn a series of messages; they learn the underlying structure of language without learning the rules (Argyle 1969). Humans' continuing comprehension of language and its construction allows the conveyance of information to others, the ability to offer opinions and the facility to make suggestions about solutions to

problems. This use of language and problem solving ability accelerates the growth of cultural solutions to problems and is a crucial part in the building and transmission of culture (Argyle 1969). Cultures vary, and what is deemed acceptable to one culture may be abhorrent to another whilst there is also "...diversity of cultural eras" (Ravaud and Stiker 2001, p.490). The variety and multiplicity of cultures and the different use of language, where the same word can have a different meaning for different people, means that communication between different groups can be convoluted.

The different meanings of words are something that is pertinent for designers to remember when communicating with people who have varying disabilities. Just because a person is in a wheelchair, it does not mean they have a cognitive disability as well. If a person's speech is not easily comprehensible, should not be assumed that they cannot understand what is being asked of them or that they do not know how to answer the question. How we are spoken to influences how we feel and behave towards the person we are having a conversation with. Eye contact, body language, tone of voice and use of specific terminology shapes how we react and respond.

When talking to a person with a disability it is important to remember first and foremost that they are an individual human being. They are a person with a disability, as opposed to a disabled person. For example, a person is not 'epileptic'; they are 'a person who has epilepsy'. This socially acceptable use of language can often be perplexing, but is important for a designer to be aware of the correct terminology when building a relationship with end user participants. If mutual respect is gained it will help with the collection of the information required, and the end user will feel their contribution has been worthwhile.

When communicating with a person with a disability look and speak directly to that person. Don't be embarrassed when using accepted common expressions that seem to relate to the person's disability. Example: '*see you later*' (to a blind person) or '*got to run now*' (to a person in a wheelchair). Just because they have a disability it does not mean they don't have a sense of humour. The resource offers designers suggestions on how to communicate effectively with people who have varying disabilities so that they can obtain the information they need to develop the end product.

10.3.1 Design Resource – Conversation Etiquette

- **Person with a carer**

If participants bring a companion / carer with them, ensure that the conversation does not specifically occur with the carer to the detriment of the person with the disability; after all, the person with the disability is the expert in the field. Carers may make a valid contribution to the conversation, but they should express their own views, not those of their disabled companion.

- **Wheelchair User**

When talking for some time to a person in a wheelchair, it is advisable sit on a chair. Whenever possible sit in front and at the person's eye level. This avoids giving them neck ache and assists conversation.

- **Hearing Impaired**

When conversing with a person with a hearing impairment look directly at the person, speak clearly, and keep hands and food away from the mouth when speaking. Make sure to sit in good light and not to be 'back lit', leaving it difficult for the face to be seen. To get a person with a hearing impairments attention gently tap their shoulder or wave a hand. Don't shout as it inhibits lip reading and distorts sound accepted through hearing aids. A visual cue can be used to assist conversation or a hearing loop if there is one in the room where the interview is taking place and the participant has a hearing aid.

- **Visually Impaired**

When greeting a person with a visual impairment, ensure introductions include details of where people are standing in relation to the person with the visual impairment. e.g. 'On your left is Miss. Smith'. If the participant needs guiding allow them to take an arm at the elbow, this will enable guiding rather than leading of the participant. To help facilitate conversation be prepared to offer an audible cue. Do not shout, a person with a visual impairment can hear, unless they have a hearing impairment as well.

- **Speech Impairment**

When talking to a person with a speech impediment listen attentively. Encourage rather than correct and exercise patience rather than finishing a sentence. Do not pretend to understand and be willing to repeat or rephrase questions. If unsure of what has been

said repeat speech so that confirmation of accuracy can be obtained. When necessary ask short questions that require a yes or no answer, these can be answered with a nod or shake of the head.

- **Learning Disability**

Take a pen and paper to interviews as if all else fails most people will be happy to write or draw the answer. Use ‘plain English’ rather than confuse participants with long words or academic terminology. Confirm what has been said by repeating it back to the participant, this will ensure the information given and received is correct.

(Design Resource - Appendix 6)

10.4 Obtaining Information from End Users

There are a variety of user participation methods available to designers (Kahmann and Henze 2003). These include:

- Mind mapping
- Controlled testing
- Diary keeping
- Focus groups
- Interviews
- Observation
- Prototyping
- Scenario based design
- Personas
- Storyboarding
- Survey
- Task analysis
- Video prototyping
- Walkthroughs
- Questionnaires

All of the methods listed could be considered for use within the inclusive design process, but this study argues that focus groups are the most proficient method for acquiring data from disabled end users. Focus groups were used to obtain information from the participants in this study and the information acquired was varied and abundant. It should be acknowledged that focus group techniques and follow up interviews employed within social science research projects would delve deeper into the data obtained to achieve deeper and richer knowledge of the subject being researched.

10.4.1 Design Resource – User Participation

The design resource recommends the use of focus groups for obtaining information from end users as they are a qualitative research tool that provides a viable method for obtaining information from end users throughout any design project. They are flexible, easily adaptable, applicable to a wide variety of topic areas and available to all types of people. The strength of focus groups is their ability to bring together a group of individuals who have knowledge about a specific topic or issue. The discussion is guided by an interviewer or moderator who explores verbal and non-verbal responses to questions and comments to discover more about participants' perceptions and views. The group discussion enables a rich gathering of information as participants build on the ideas and responses of others within the group. The use of focus groups would enable designers to obtain information from "...direct interaction with participants" (Langford and McDonagh eds. 2003, p.3) and to further investigate and develop responses and comments to gain a more in-depth understanding of end users views. Designers need to understand the intricacies of focus group methodology so the most suitable process is used to obtain the information they require.

10.4.2 Advantages of Focus Groups

- Significant amounts of information can be obtained quickly and efficiently from a large number of people in a relatively short time
- Qualitative methodology that allows in-depth investigation of issues that cannot be measured or quantified (eg. emotional relationships between user and product)
- Ability to gain in-depth knowledge of the topic being discussed
- Researcher and participant interaction increases understanding and awareness
- Flexibility of the focus group process
- Allows open discussion which can lead to new and unconsidered topics
- Applicable for all topic areas
- Provides immediate feedback
- Detailed overview of several opinions
- Verbal and non-verbal communication can be observed by the researcher allowing underlying messages and subconscious notions to be discussed
- Open for use by any social group
- Relatively cheap research methodology compared to others

10.4.3 Limitations of Focus Groups

- Dominant or quiet group members
- Discussion content – interesting topics for the group may not be of use or interest to the researcher

- Quality of the discussion will be influenced by the group make-up and may range from lively and revealing, to that of little value to the researcher
- Sample may be difficult to recruit
- Venue (cost, location, transport for participants, time of day)
- Time consuming
- Cost

10.4.4 Planning the Research

Pre-determining the objectives of the focus group is necessary as the content of each session will vary and should be tailored to the research objectives. When setting the focus group objectives the designer should be consider

- The required outcomes of the research
- The most appropriate techniques and methods to be used
- The resources available
- Timescales
- Choice of participants

10.4.5 Recruiting Participants

It is important to remember that the research aims will determine the content of the session and the choice of participants. As participants should have reasonable knowledge about the topic to be discussed, they should be chosen from specific user groups (purposive sampling). When planning sessions a number of factors should be considered

- Number of participants attending each session (traditionally 8 – 10 participants are recommended however 4-6 participants for design research sessions allows more time for individual views)
- How / where to contact participants
- Participants fees (approx £25 - £30 per person per session)
- Length of the session (1-3 hours)
- Time of day (outside of office hours is preferred)
- Location of the session
- Depth / breadth of information required

10.4.6 Focus Group Location

Participants will contribute more to the session if they feel comfortable and valued, so the choice and layout of the room is an important factor when organising focus groups. Attention to detail and the creation of a comfortable environment will make a considerable difference. Focus group organisers should be mindful of

- Ease of access (location, transport, level access)

- Comfort for participants (size of room, lighting, temperature, seating, layout of furniture - tables or seating should be arranged to enable face-to-face contact)
- Facilities (toilets, refreshments - using ceramic mugs instead of paper or plastic ones and providing good quality food will help make participants feel valued)
- Disturbance (telephones, noise from other groups, Tannoy® announcements, doorbells)
- Ease of setting up equipment
- Accessibility to visual material
- Accessibility of audible material

10.4.7 Session Content

Free-flowing discussion may be appropriate to obtain the information required and the moderator should anticipate the flow of natural conversation allowing one topic to link to another. However, a moderator's guide is a tool that ensures the information required is obtained. This guide is prepared in advance and outlines the content and structure of the session. It should include

- A list of questions to be asked
- Aids used to encourage discussion
- Preferred duration of discussion time per question

10.4.8 Conducting the Focus Groups

Participants should feel welcome and comfortable when attending focus groups. When participants arrive:

- Receive them courteously
- Register their names / supply name badges (allows familiarisation)
- Show them the way to the room
- Point out facilities
- Offer refreshments
- Allow time for chatting to others and to make themselves comfortable
- Ensure everyone is comfortable

A good introduction will prepare the participants for what is to come and set the tone for the rest of the session.

- Begin by welcoming the participants, thank them for coming and introduce any research staff
- Point out fire escapes and procedures should there be a need to evacuate the building
- Confirm the facilities available (w.c.'s etc)
- Explain how long the session will last and what is hoped to be achieved
- Discuss any consent required, audio taping, video taping, photography
- Talk about any relevant confidentiality issues (Data Protection Act 1998, ethical issues - where necessary)

- Re-iterate how important participants views are
- Ensure everyone understands that individual comfort is important, and that if anyone feels uncomfortable at any time, they should let a member of the research team know
- Refreshments are available at designated breaks

The overall structure of the session should be quite flexible allowing discussion about revealing topics to be extended when necessary. However, if the discussion becomes irrelevant to the research objectives, it is the moderator's task to steer the conversation back to the topic being researched.

10.4.9 Focus Groups with Older Participants

Focus groups with older participants require a different design and organisation of their content. Generally the sessions should include:

- More moderator involvement
- A slower pace
- Shorter in length
- Frequent breaks in the flow of discussion
- Shorter questions – use words older people will understand

N.B. This is not meant to be condescending towards older people, it is to highlight that their needs may be slightly different

10.4.10 Analysis of the Data

It is beneficial if designers are involved in data analysis although it can be a lengthy and complex process. One hour of conversation can take three to four hours to transcribe. When tapes are transcribed, similar comments should be arranged into groups which enable themes and categories of user's needs and requirements to be identified. The process of learning what the participants have really said evolves while the data is being transformed into information and trigger words will often spark creative thinking.

(Design Resource - Appendix 6)

It can be seen that the key benefits of using focus groups for designers is that they interact directly with participants and can explore any comments made while the concept is initially being discussed, rather than having to follow them up at a later date. The moderator can also probe the accuracy of participants' remarks and gain information from both verbal and non-verbal responses. The main advantages of focus group discussions for the end user participant, is that they have the chance to discuss

their views and concerns ‘face to face’ with the designer and also obtain support and interaction from a peer group. This two way open communication enables a rapport between the moderator / designer and the participants which will result in more information being imparted / collected by the respective parties.

10.5 Socially Acceptable Terminology

It is necessary for designers to comprehend the socially acceptable terminology relating to the end users they may consult. What is acceptable to one person / group may not be tolerable for another. The meaning of a word can change by its position in a sentence and combinations of words change meanings. E.g. ‘...Venetian blind...’ is not the same as ‘...blind Venetian...’ and ‘...they are hunting dogs...’ has two possible meanings (Argyle 1969, p.67). A further complication is that words can carry additional information to their descriptive meanings. ‘Yid’ and ‘nigger’ are both socially unacceptable terms as they indicate the user is hostile to the racial groups they refer to (Argyle 1969). In an attempt to improve images of groups through the use of words, alternative descriptions are constantly being developed through societal pressure groups (Hughes 1998; Lewis 1998). Examples of this are: senior citizen, instead of old person, older people rather than elder or elderly and hard of hearing as opposed to deaf person. Whilst it should be acknowledged that ‘no-one gets it right all of the time’, it is important to consider what terms / words may be deemed unacceptable by the participants that the designer hopes to gain information from.

10.5.1 Design Resource - Acceptable / Unacceptable Terminology

In the design resource (Appendix 6) there is a list of current socially acceptable and unacceptable terms for use when talking to people with disabilities. They include:

Acceptable Terms:

Person with a disability
 Disabled people
 Mr. X has a disability
 Disability (as a general term for limited functionality)
 People with (e.g.) spinal cord injury
 Contracted (e.g.) multiple sclerosis
 (Never identify people solely by their disability)
 Blind people-deaf people
 Blind or partially sighted
 Deafness / hearing impairment

Unacceptable Terms:

Cripple, cripples
 ‘The Disabled’
 Defective, deformed, vegetable
 Handicap, handicapped

 Victim of spinal cord injury
 Suffers from multiple sclerosis

 The blind – The deaf
 Blind as a bat
 Deaf and Dumb

Deaf or hard of hearing	Mutt and jeff
Deaf and mute or deaf without speech	Deaf and Dumb
Mental illness	Loony, mad, round the twist
Developmental disability	Retard, moron, idiot, imbecile
A person with restricted growth	Midget, dwarf
Downs syndrome	Mongol
Cerebral palsy	Spastic
A wheelchair user	Wheelchair bound, confined to a wheelchair
Able bodied	Healthy (when used in contrast to disability)
People without a disability	Normal

(Design Resource - Appendix 6)

10.6 Disability Definitions and Statistics

The definitions of disability, handicap and impairment have been discussed in earlier chapters and the views of the participants were conclusive that they disliked the term handicap. The WHO and UPIAS definitions are included within the resource so that designers can see the difference between the classifications made by disabled and non-disabled people.

10.6.1 Design Resource - Disability Definitions

WHO Definitions (World Health Organisation)

These definitions have been criticised by disabled people as they focus on impairment and limitations.

- **Handicap**

A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual

- **Impairment**

Any loss or abnormality of psychological, physiological or anatomical structure or function

- **Disability**

Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being

UPIAS Definitions (Union of Physically Impaired Against Segregation)

These definitions were compiled by disabled people's organisations. The main difference from the WHO definitions is that disability is defined as being socially and environmentally constructed and external to the individual.

- **Impairment**

Lacking all or part of a limb or having a defective limb, organism or mechanism of the body

- **Disability**

The disadvantage or restriction caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities

(Design Resource - Appendix 6)

10.6.2 Design Resource - UK Statistics

Statistics about disability issues can be found at several locations and may be necessary for designers to use within the marketing section of the design process. A depiction of numbers may also convince managers and decision makers that inclusive design is a viable methodology. (It should be acknowledged that these web addresses may need to be updated on a regular basis).

UK Statistics

- **National Statistics Online**

<http://www.statistics.gov.uk/CCI/SearchRes.asp?term=disability&x=13&y=8>

- **OPCS (Office of Population Census and Surveys)**

<http://www.statistics.gov.uk/STATBASE/Product.asp?vlnk=8008>

- **Labour Force Survey**

<http://www.drc-gb.org/drc/InformationAndLegislation/Page356.asp>

- **Number of people with visual impairment**

<http://www.rnib.org.uk/library/research/statsrc.htm>

- **Number of people with hearing impairment**

http://www.rnid.org.uk/html/factsheets/general_statistics_on_deafness.htm

Other links

- **Scottish report commissioned by the Disability Rights Commission**

<http://www.drc-gb.org/drc/Documents/factsbooklet2001.pdf>

- **Analysis of HESA statistics on disability**
http://www.ed.ac.uk/ces/PDF%20Files/TT_0207.pdf

(Design Resource - Appendix 6)

10.7 Disability Legislation

Builders and designers have to adhere to access statutes, codes of practice and building standards (Imrie and Hall 2001). Part M of the building regulations (1999) is the standard that covers access and facilities for disabled people and in May 2004 an updated version came into force. The review of Part M (1999) was shaped by both the impact of the DDA and "...society's developing recognition and understanding of the diversity of human population" (Petherick 2003, p.8). The new Part M is based on standard BS8300 (2001) which is a code of practice for the 'Design of buildings and the approaches to meet the needs of disabled people' (BS8300 2001). Its contents and that of Approved Document (AD) M reflect the acknowledgement that peoples' abilities are multifaceted and changeable and purport that buildings should be "...accessible to, and usable by everyone including disabled people" (Petherick 2003, p.8). The main difference between the new Standard and its older version is the introduction of the principle of inclusive design. References to disability have been removed from the title and the Standard specifies recommendations for buildings and not the people who will use them. However, the AD M that accompanies Part M (1999) explains the relationship between Part M (1999) and the DDA and the implications of the changes that have taken place.

Participants of the study were disdainful with their views about planners and had few comments to make about the legislation surrounding disability and standards for buildings built for accessibility. Thomas (2003) contends that development professionals have limited comprehension of inclusion and how it affects their work. She asserts that many developers still consider inclusive design to be concerned with 'special' and 'add on' facilities for disabled people that will incur unnecessary costs and complications to products and services. It is hoped that the new legislations and Standards will allay these misconceptions and allow an element of legislative backing for disabled peoples request for inclusivity.

Legislation is changing constantly as the implementation of the DDA takes place and development professionals have to keep up to date with new implementations. The new

Part M (2004) recommends that all new Building Regulation applications should include an access statement, but the new Planning and Compulsory Purchase Bill (2004) states that planning applications have to be backed up by a mandatory access statement. It is hoped that this will encourage the designer / builder to expand the access statement for the Building Regulation submission. The implementations of standards and regulations are not always well publicised and have to be sought out by building professionals. Those interpreting the legislation are often relied on to inform applicant's of the requirements, which means that by default it is important that development professionals are continuously trained. The following section of the design resource, its information and web links, will assist designers in accessing the information they require and offer links to future building regulatory changes.

10.7.1 Design Resource - Guidance on Disability Legislation

The DDA provides the legal framework through which a person with a disability may bring an action against an employer or service provider if they feel they have been discriminated against on the grounds of their disability.

It is in eight parts:

1. The meaning of disability
2. Discrimination in employment
3. Discrimination in other areas: The provision of goods, facilities and services
4. Education
5. Public Transport
6. National Disability Council
7. Supplemental
8. Miscellaneous

Useful website: www.hmso.gov.uk/acts/acts1995/1995050.htm

Publications:

Blackstone's Guide to the DDA – Caroline Gooding
ISBN 1854314998

Disability Discrimination Act Inclusion and workbook for building owners, facilities managers and architects – John H. Penton
ISBN 1859460321

Disability Rights Commission – Government body to provide information – www.drc-gb.org

Building Regulations

Approved Document M of the Building Regulations (1999) covers access to, and within, a building for people with disabilities – new build or extensions only

Useful website: <http://www.hmso.gov.uk/si/si1998/19982561.htm>

N.B. Part M is currently being re-written and is likely to pick up on many of the guidelines and specifications included in BS8300. Although the requirements of BS8300 are not presently enforceable by law, it is advisable to work to the stated requirements.

ADM 2004 – published November 2003, came into force 1st May 2004.

British Standard 8300

The British Standard BS8300:2001 is a code of practice that is aimed to support the DDA and gives practical design and building advice.

Useful website: <http://www.bsi.org.uk>
(Replaces BS 5810 and BS 5619)

British Standard 5588

BS5588 is a code of practice for fire precautions in the design, construction and use of buildings. Part 8 deals with means of escape for people with disabilities. This is not included in ADM or BS 8300.

Useful website: <http://www.bsi.org.uk>

New document DD9999 is being developed to give more information and will replace BS 5588

The Special Educational Needs and Disability Act, 2001 (SENDA)

SENDA amends part 4 of the DDA. It relates to educational establishments and establishes legal rights for disabled students in pre and post -16 education.

SENDA has three parts:

1. Relates to Special Educational Needs in England and Wales.
2. Relates to Discrimination in Education in all geographic areas.
 - Chapter 1 – Schools
 - Chapter 2 – Further and higher education institutions and local education authorities

- The role of the Disability Rights Commission
3. Miscellaneous Section

Useful website: <http://www.ukcle.ac.uk/directions/issue4/send.html>

(Design Resource - Appendix 6)

10.8 Ergonomics

Ergonomics are an important factor when designing for human beings as they exemplify the relationship between the person and the equipment and environments they use (Norman *et al.* 1990). Designers should acknowledge that anthropometric data for people with disabilities do not “...revolve around a range of physiological norms...that reduce the body to a universal type ...characterised by fixed parts” (Imrie and Hall 2001, p.10). The participants discussed several issues involving the use of ergonomics during the sections about transport (8.3), personal care (8.4), restricted access to buildings (8.5) and urban accessibility (8.6). It is their contention that ergonomics within the field of design for disability have not been suitably addressed. The design resource offers web links for accessing information to ergonomic solutions when designing for people with disabilities.

10.8.1 Design Resource - Ergonomics

Useful websites:

The Ergonomic society

<http://www.ergonomics.org.uk/>

Ergonomics – The Official Journal of the Ergonomics Society and the International Ergonomics Association

<http://www.tandf.co.uk/journals/tf/00140139.html>

Open Ergonomics - an ergonomics society registered consultancy

<http://www.openerg.com/>

Publications:

Bodyspace: Anthropometry, Ergonomics and the Design of Work – Stephen Pheasant

ISBN 0748403264

10.9 Web Links

Information about disability available on the internet enables designers to access to organisations who deal expressly with disability issues. The following web sites are links to specific organisations that deal with disability issues and designers can use these links to research a variety of topics. (It should be acknowledged that an appraisal of each web link would be beneficial and this concept is discussed later in the thesis).

10.9.1 Design Resource – Web Links

Web Links

Adaptive Environments Centre
www.adaptenv.org

Americans with Disabilities Act
janweb.icdi.wvu.edu/kinder

British Council of Disabled People
www.bcodp.org.uk/

Centre for Accessible Environments
www.cae.org.uk

Centre for Disability Studies
www.leeds.ac.uk/disability-studies/

Centre for Universal Design
www.design.ncsu.edu/cud/index.html

DIAL (Disability Advice Line Services)
www.dialuk.org/uk

The Design Council
www.design-council.org.uk/

Disability Discrimination Act 1995
www.hmso.gov.uk/acts/acts1995/1995050.htm

Disability Rights Commission
www.drc-gb.org

European Institute for Design and Disability
www.design-for-all.org/

Helen Hamlyn Research Centre
www.hhrc.rca.ac.uk/

Human Factors and Ergonomics Society
www.hfes.org

Include
www.stakes.fi/include

International Ergonomics Association (IEA)
www.iea.cc

Joint Mobility Unit
www.rnib.org.uk/jmu/welcome.htm

Joseph Rowntree Foundation
www.jrf.org.uk/

Older Adultdata , Adultdata and Childata (Anthropometric data)
www.virat.nott.ac.uk/PSTG

Phab (Physically Handicapped and Able Bodied)
www.ukonline.co.uk/phab/

RADAR (The Royal Association for Disability and Rehabilitation)
www.radar.org.uk

RIBA (Royal Institute of British Architects)
www.architecture.com/go/Architecture/Home.html

RICA (Research Institute for Consumer Affairs)
www.ricability.org.uk

RNID (The Royal National Institute for the Deaf)
www.rnid.org.uk/

Royal National Institute for the Blind
www.rnib.org.uk/

WHO (World Health Organisation)
www.who.int/icidh

(Design Resource - Appendix 6)

10.10 Medical Terminology

The Design Resource includes a section that offers an overview of various disabilities. It should be emphasised that summary of a disability will not specifically assist with the design process, but it will help the designer in understanding the needs of a disabled person through comprehension of the implications of their impairment.

10.10.1 Design Resource – Overview of Medical Terminology

AIDS (Acquired Immune Deficiency Syndrome)

AIDS is not a disease. It is the term used to describe a person's condition if they contract pneumonia, tuberculosis or other infection or illness which becomes life threatening due to their damaged immune system caused by HIV (Human Immunodeficiency Virus).

Alzheimer's Disease

Alzheimer's disease is a common form of dementia. (See dementia)

Ankylosing spondylitis

Ankylosing spondylitis is a progressive and painful rheumatic disease. It mainly affects the spine but it can also affect joints, ligaments and tendons.

Arthritis

Arthritis is a general term used for inflammation of a joint or joints.

Autism

Children with autism behave in puzzling ways, have difficulty in relating to other people and are unsuccessful at making sense of the social world.

Brittle Bone Disease

Brittle bone disease is thought to be a combination of several disorders rather than a single condition. It is caused by abnormalities in the fundamental structure of the protein part of the bone. Fractures happen easily but healing usually occurs readily.

Cerebral Palsy

Cerebral palsy is caused by damage to, or lack of development in, a small part of the brain that controls movement and posture. This damage can also affect other parts of the brain resulting in other types of disability. Cerebral palsy may affect one or more limbs, cause speech and language difficulties, oral problems such as swallowing difficulties or drooling, convulsions and learning disabilities.

Cognitive functions

Cognitive functions are concerned with the processes of learning.

Cystic Fibrosis

A hereditary and life threatening condition that affects the lungs and digestive system. The lungs frequently become infected and respiratory infections are common.

Dementia

A person with dementia experiences a progressive decline in the abilities to remember, reason and think. There can also be associated physical decline and deterioration can be slow or rapid. Symptoms are unpredictable, and the variability of symptoms differs from person to person.

Down's Syndrome

Down's syndrome occurs when there is a presence of an extra chromosome in the body cells. Down's syndrome characterised by - short stature, a round skull which is flat at the back, small jaws and nose, slack muscle control and / or learning disabilities.

Dyslexia

Dyslexia is often known as 'word blindness' and is characterised by difficulties with reading and writing.

Dysphasia

The loss of ability to speak, read or write.

Epilepsy

A person who has epilepsy is liable to recurrent seizures or fits that are caused by a temporary disturbance of brain function.

Hearing Impairment

Hearing impairments occur when there is an interruption in the processes conducted by the middle or outer ear. People with a hearing impairment will often rely more on other senses particularly that of sight.

HIV (Human Immunodeficiency Virus)

HIV is a virus that damages the bodies defence system so that it cannot fight off certain infections.

Huntington's Chorea

Huntington's chorea is a hereditary disorder of the nervous system. The most obvious symptoms are - involuntary jerking movements, loss of motor control, unsteady gait, loss of concentration and / or memory.

Motor Neurone Disease (MND)

Motor neurone disease is the name given to diseases affecting the motor neurones in the brain and spinal cord. Nerve cells that control the muscles are slowly destroyed which may result in a progressive weakness and paralysis of limbs. Speech and swallowing may be affected however, MND does not affect the senses and the intellect remains unchanged.

Multiple Sclerosis (MS)

Multiple sclerosis is a disorder of the central nervous system that causes both motor and sensory disabilities. Symptoms include – weakness or clumsiness in one or more limbs, difficulty with balance, cramp spasms, speech may be effected and blurring or loss of vision.

Muscular Dystrophy

Muscular dystrophy is progressive, hereditary and results in muscle weakness.

Parkinson's Disease

Parkinson's disease is a progressively degenerative disorder of the central nervous system. Symptoms may increase over time and include – shaking or tremor in a hand or arm, rigidity or stiffness in muscles, slowness and / or difficulty in initiating movement.

Poliomyelitis

Poliomyelitis is a virus infection that can result in damage to part of the brain and spinal cord responsible for the control of voluntary movement.

Spina Bifida

Spina bifida occurs when the spinal region fails to develop properly in the first 25 days of pregnancy. It is characterised by congenital malformations of the central nervous system which can result in a person having paralysed legs, dislocation of the hip and / or water on the brain.

Spinal Cord Injuries

Damage to the spinal cord nerves can result in paralysis.

Quadriplegic – Paralysis of all four limbs.

Paraplegic – Paralysis of the lower limbs and part of the torso.

Stroke

A stroke is a condition in which part of the brain is damaged either as the result of a clot or haemorrhage in a blood vessel in the brain.

Visual Impairment

A person with a visual impairment experiences a reduction in the ability to gather information about their external environment through the sense of sight. They often rely more on their senses of touch and hearing to help them familiarise themselves with the world around them.

(Design Resource - Appendix 6)

10.11 Glossary

A glossary was included in the resource for designers to refer to when they encounter acronyms that they do not understand.

10.11.1 Design Resource - Glossary

Glossary

ADA	Americans with Disabilities Act
BCODP	British Council of Disabled People
BDA	British Deaf Association
BSL	British Sign Language

CIL	Centre for Independent/Integrated Living
DA	Disability Alliance
DAN	Disability Action Network
DDA	Disability Discrimination Act
DIAL	Disability Information and Advice Line
DLF	Disabled Living Foundation
DoH	Department of Health
DPI	Disabled Peoples' International
DPOs	Disable People's Organisations
DRC	Disability Rights Commission
GLAD	Greater London Association of Disabled People
GMCDP	Greater Manchester Coalition of Disabled People
HMSO	Her Majesties Sorting Office
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ILM	Independent Living Movement
Mencap	Charity for people with learning disabilities
NFB	National Federation of the Blind
NLB	National League of the Blind
OPCS	Office of Population Census and Surveys
PAS	Personal Assistance Support
RADAR	The Royal Association for Disability and Rehabilitation
RNIB	Royal National Institute for the Blind
RNID	The Royal National Institute for the Deaf
SCOPE	Charity for cerebral palsy (formerly known as the Spastics Society)
SENDA	Special Educational Needs and Disability Act
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organisation

(Design Resource - Appendix 6)

10.12 A Resource for Designers

As Lebbon (2003) found, there is a necessity for a "...design toolkit" (Lebbon 2003, p. 3:125) for designers to use when designing for disabled people. Lebbon (2003) concludes that the 'toolkit' should contain facts, figures and stimulus material, including visual user interactions, for the designer to draw on. Lebbon (2003) asserts that the data she proposes will be used to produce an electronic database that designers can use to access information. The database will contain information that can be sorted and selected on a job-by-job basis by designers and used as part of presentations for clients. This type of data collection is utilised in ACCESSaBUILD (2003) a piece of software which is described by its manufacturers as an "...essential resource for building designers and managers" (ACCESSaBUILD 2003 [no page number]). ACCESSaBUILD (2003) software summarises information that could be accessed from various other sources and the manufacturers have compiled a database that has

...brought together information from many sources.... The guidance given within the system is not limited to the legislation or even to the British Standards, but includes information on subjects such as colour and tonal contrast which are relatively inexpensive but can make all the difference to people with visual impairments

(ACCESSaBUILD 2003 [No page number])

Using cut and paste techniques the software enables the user to compile access and cost reports for potential clients. There are three main disadvantages with this software:

- No information about gaining updates on the costing for alterations
- No indication about updates on legislative or building regulatory changes
- No requirement to have an understanding of design or building regulations, therefore if used by a novice, excessive and expensive alterations could occur

The software includes three dimensional images of heights of doors, light switches, hand rails, wheelchairs, graphical representations of disability statistics and fact sheets that could be used to develop an aesthetic report. There is also a statement that the manufacturers have:

...brought together information from many sources and added our own experience of conducting access audits and talking to people with disabilities

(ACCESSaBUILD 2003 [No page number])

However, within the software there are no discussions or suggestions that designers should consider consulting with disabled people during access audits or reviews to ascertain their views. Nor is there any information about how to obtain the views of end

users if they are consulted. The software is purely for the benefit of data processing and it is this type of design procedure that conflicts with the discussion in previous chapters and with inclusive design methods

This study agrees with Lebbon's (2003) contention that a collection of data for designers to access is a necessity, but describes the information it has produced as a 'resource'. The resource differs from Lebbon's (2003) toolkit and the ACCESSaBUILD (2003) software as it purports the premise that designers should include end users themselves in the design process as opposed to looking at imagery of the end user or accessing data about them. The resource also differs in its format. It is produced in a hard copy report style rather than compiled into an electronic database as it was deemed that this type of information could be carried around at all times as opposed to being dependent on a computer. Even in today's technology enhanced society not everyone carries a laptop computer with them when outside of the office.

The design resource was developed from a comprehension of the requests of disabled people for inclusion and accessibility within main stream society. This understanding occurred from reviewing the literature, the participants' views and the researcher's personal involvement within the field of disability. It was a combination of information gained from each of these areas that enabled the design resources contents to be developed. The contents are based entirely on the social model of disability and inclusive design principles. For the purpose of validation the design resource was used hypothetically in consideration of each of the categories raised by the participants. It was also given to a sample comprised of disabled people, carers and design professionals with an accompanying questionnaire. The results of the evaluation of the design resource are debated in the following chapter.

CHAPTER ELEVEN - EVALUATION OF THE DESIGN RESOURCE

Chapter 10 examined how the design resource was developed and the necessary information it contains in order to facilitate success for designers when designing for people with disabilities. The following discourse considers the methods of evaluation used to assess the design resource and outlines recommendations for further analysis.

The chapter begins with an analysis of the categories raised by the participants and describes how some of the issues raised would be different if the design resource and inclusive design methods had been utilised. The discussion does not offer suggestions of design solutions, it outlines how the outcome of the data obtained by the participants may have been different if inclusive design methods had been utilised.

In order to evaluate the resource further, a questionnaire was developed for a sample to answer regarding its contents. The questions asked were open-ended and the questionnaire was answered in the presence of the researcher. This was a time consuming process, but the additional conversations that took place during the interviews assisted with a verbal validation of many of the issues raised throughout the study.

The chapter then reflects on the sample chosen to appraise the design resource and considers the merits of a small sample. Due to a time delay between the original focus groups and follow up interviews and the development of the design resource, many of the original participants from phase one of the study were no longer available to be re-interviewed so a new sample had to be organised.

The discussion then examines the comments made by the sample that completed the questionnaire and considers the recommendations that they advocate. The chapter concludes with an overview of suggestions regarding how the resource could be improved and evaluated further.

11.1 Testing the Design Resource

As discussed in previous chapters, one of the difficulties the researcher encountered was time constraints (Phillipa and Pugh 1994). This was never more prevalent than towards the end of the time allotted for the research.

During the summer of 2003, the researcher became acquainted with staff at a small local museum where the team were bidding for lottery funding to make the historic building the museum was housed in, accessible. The researcher spent considerable time with the museum's project officer deliberating the possible alterations necessary to make the building fully accessible. In due course, it was agreed that the resource, which had been developed as part of this study, would be tested during the planning stage of any potential modifications. The suggestion was that the researcher and the project officer would use the resource during the design phase throughout the consultation period with local disabled people. The project officer had extensive knowledge of issues surrounding visual impairments, and it was agreed that 'two heads were better than one' to ensure more aspects of accessibility were considered. Any issues raised through consultation would then be discussed with the firm of architects who would be working on the planned amendments. Unfortunately in the spring of 2004, it was announced that funding grants were to be considerably reduced and the museum was unsuccessful in its funding application. Regrettably it was too late in the PhD research process for the researcher to test the resource in any other way.

Whilst it is acknowledged that the resource has not been critiqued in the field, a suggestion for testing it is outlined in chapter 13. The proposal is that the resource is given to a design student to use while completing a design project about disability. This suggestion was discussed with members of staff from the design department at Bournemouth University, but there were no students undertaking projects around the field of disability at the time.

11.2 Participants Comments and Inclusive Design Methods

Previous chapters have debated the merits of inclusive design and asserted that this study purports its principles. If inclusive design methodology had been used in the design process for each of the issues raised by the participants of the study, it should be assumed that their comments would have been different. The following discussion considers how experiences may have been different if inclusive design methods had been utilised for some of the categories discussed and examines how future legislation will eradicate some of the issues raised.

11.2.1 Transport (See 8.4)

Participant's comments regarding transport included "...not feeling safe" (Participant 1f1) on buses due to the lack of a clamping system. If focus group techniques had been utilised to ascertain disabled peoples views about travel then it is reasonable to presume that safety issues would have been raised (Design Resource - Appendix 6). Had this been the case, this issue would not have been raised as a problem. Fitting a clamping system would ensure more inclusive travel for wheelchair users and provide a more equitable service by the bus company.

The height of the access to taxis and the seating positions were issues raised by several participants. If an able bodied person had to bend to obtain vehicular access, sit with their head on one side or if they had to sit across a vehicle rather than facing the direction they were travelling then they would comment on the inferior service being provided. If these issues had been considered at the design stage, disabled people consulted and ergonomic data re-considered then taxis, like buses, would offer a more equitable service (Design Resource - Appendix 6).

11.2.2 Personal Care (See 8.5)

Whilst their able bodied peers take for granted the ability to use the lavatory when the need arises, disabled people have to plan meticulously a frequent and necessary bodily function. Information about handles, rails, doors, the height of the toilet seat and space for a wheelchair to turn in can all be ascertained from building regulations. However, asking people to demonstrate how these features are used in a practical sense can offer greater insight into the real needs of the end user. An example of considering design features that are not legislatively portrayed is adding a shelf for bags within an accessible toilet. A wheelchair user might have difficulty putting a bag down and picking it up again and a shelf could make life a little easier. The cost would be negligible, and the service provision would be greatly appreciated (Design Resource - Appendix 6).

11.2.3 Restricted Access to Buildings (See 8.6)

Doors that are too heavy to open, cash dispensers that are too high to use and having to complete transactions on the pavement are issues that able bodied people would complain about. No-one would choose to complete a banking transaction outside in the

street, but one participant of the study discussed in detail how she completed her business in this way (Participant 2f2). The new Part M (1999) building regulations will ensure that all new buildings are accessible to all and Part III of the DDA that came into force on 1st October 2004 will enable disabled people to take service providers to court if they do not offer reasonable access to a service. This will also apply to shops that display goods in the centre of aisles if a regular disabled customer is unable to access the service they supply. It is hoped that this type of inequitable service will cease to exist as legislation to assist with equality increases. However, with adaptations to older existing properties, requesting disabled people's views about accessibility would ensure the changes made are suitable for the people who require the alterations (Design Resource - Appendix 6).

11.2.4 Urban Accessibility (See 8.7)

The railway lines that dissect Poole High Street impede many wheelchair users access to shops. They have divided the High Street since the 19th century and cause irritation for able bodied residents and visitors as well the disabled community (See Appendix 5). Since the focus groups took place the advent of holes alongside the tracks has been suppressed by the introduction of a rubberised surface that is not as perishable as concrete or tarmac. However, the crossing is still dangerous to negotiate for disabled people, the elderly, mothers with pushchairs and small children (See Appendix 5). As with the geographical layout of Bournemouth this issue may not be easily resolved, but public consultation through focus groups with local residents and access groups would provide the council with information about access in the High Street (Design Resource - Appendix 6).

11.2.5 Attitudes Towards Disability (See 8.8)

All of the participants agreed that societal attitudes toward disability need to change for equality for disabled people to become a reality. Discrimination and oppression stem from people's ignorance and fear about something that can occur to anyone at anytime (Reilly 2003). The design resource offers designers ways to communicate with disabled people in socially acceptable ways and attempts to portray disability as something not to be feared and rejected, but to be embraced and included within both design and society. As discussed in chapter 9, designers affect the world they design for through their products and services. Their personal values and attitudes are portrayed through their

designs and so influence the world their designs touch. If designers change the way they design to utilise inclusive methodologies then their designs and attitudes will affect the world differently and oppressive and discriminatory traits will begin to dwindle with the assistance of the use of good design practice.

11.3 Societal Changes and Disability

It can be seen from the previous examples that inclusive design methodologies and future legislation for disability can offer different perspectives to issues raised by the participants. The new ADM Building Regulations (2004), the DDA and changes in societal attitudes will offer the disabled community the opportunity to become part of mainstream society and to obtain the equitable existence they strive for. However, it must be recognised that changes will not happen quickly. As previously discussed the DRC had 60 – 70 test cases ready to implement on 1st October 2004 when part III of the DDA came into force. Disability groups all over the country wait to see if precedence will be set to ensure the discrimination and oppression encountered by disabled people are finally supported by legislation. Unfortunately many groups feel that this will not be the case. They consider that the legislative process will not ‘*carry enough weight*’ to enable change and any improvements that might occur through legislation will not alter society’s attitudinal views which are considered to be the biggest problem of all.

Society is developing a “...recognition and understanding of the diversity of human populations” (Petherick 2003, p.8). The DDA has instigated society to re-think disability issues, whether or not the Act can truly help those it was designed to assist remains to be seen, but a change in societies attitudes also has to occur. It is the contention of this study that these attitudinal changes will have to begin through education and this includes design education. Thomas (2003) asserts that:

It is vital that tomorrow’s engineers, designers, architects, planners etc have a full understanding of the need for an inclusive environment. The DDA will increasingly provide disabled people with access rights and it is in the professionals’ interest to understand how to deliver these objectives.

(Thomas 2003, p.16)

There is a requirement for designers to understand the needs of the disabled community. Education establishments are developing courses about disability and inclusive design practices are being introduced into design based courses, but according to Thomas

(2003) many development professionals only have "...a limited concept of inclusion and how it affects their work" (Thomas 2003). The way forward is for advocates of inclusive design to continue promoting the benefits of its principles and for the development of toolkits, databases and design resources to assist development professionals in their understanding of the disabled community and its needs.

11.4 Design Resource Questionnaire

Evaluation of the design resource was required to prove its value for both designers and disabled people and also as part of the academic process for this study. The ideal test scenario to establish the effectiveness of the resource would be to offer it to a final year design student who was completing a project about disability. However, due to time constraints and the availability of final year students; this was not an option. (This is discussed further in chapter 12)

A summative evaluation of how some of the issues raised by the participants could have been altered by using the concepts described in the resource has already been discussed (Bryman 2001). To provide further analysis a questionnaire was developed about the resources contents and given to a sample comprised of disabled people, a carer, a learning disability advocate and a development professional (See Appendix 7). The questionnaire was comprised of open questions which were given to each of the sample to answer in the presence of the researcher. The choice of open questions was made as "...there are no restrictions on the content or manner of the reply other than the subject area" (Robson 1993, p.233).

The advantages of open questions are:

- Flexibility
- Ability to probe information required to depth
- Clear up misunderstandings
- Test the limits of the knowledge of the person answering
- Permit co-operation and rapport
- Enable truer assessment of what the respondent really believes
- Allow unexpected and unanticipated answers and unthought-of relationships or hypothesis to be disclosed

(Robson 1993; Bryman 2001)

These advantages concur with the participatory research paradigm utilized in the first phase of the study and the qualitative methods that the research is recommending designers acknowledge. The disadvantages of open questions are:

- Time consuming
- Difficult to analyse
- Greater effort required from the respondent
- The potential for loss of control for the researcher

(Robson 1993; Bryman 2001)

It was considered that the time needed to discuss the questionnaires and the design resource would offer further insight into the views of the respondents and again concur with one of the basic principles of the study; that of inclusion. Each of the interviews lasted between 1 and 2.5 hours except for one person who, due to work commitments, completed the questionnaire electronically with face to face discussions taking place before and after its completion.

11.5 Sample Selection

The participants from the first phase of the project were not contacted to analyse the design resource for three reasons.

- Re-structuring of social service day centres meant some service users did not attend the day centre anymore
- Changes in participants personal circumstances
- Loss of contact with the day centres used in phase one due to the researchers personal circumstances

However, by coincidence one member of the sample had been involved in the second focus group, but could not remember attending it or any of the information that was discussed.

Although the previous research had focused on wheelchair users, it was decided to ask both wheelchair users and non-wheelchair users to comment on the contents of the resource to find out if it could be used by designers when designing for a broader spectrum of disabilities. The sample was comprised of six people who were asked to complete the questionnaire.

- 2 x full time wheelchair users who were both previously able bodied
- 1 x part time wheelchair users who used a stick to mobilise the majority of the time

- 1 x carer of a person with learning disabilities
- 1 x learning disability advocate
- 1 x development professional

It was recognised that although the sample was small, members were deemed to constitute a fair representation of people to examine the resource. It was decided to consult a carer and an advocate for people with leaning disabilities as opposed to a person with learning disabilities themselves for two reasons.

- As confirmed by both participants who represent learning disabilities, one aspect of communicating with people with leaning difficulties is to not use academic terms or jargon and the design resource contains this type of terminology
- The researcher was not as confident working with learning disabilities as with other disabilities and unsure that an interview would be successful

The participants were asked verbally if they would take part in the study and as with the focus groups in phase one each person was given a code to ensure anonymity. To maintain the continuity of the coding previously used in the study it was decided that the structure of the coding should remain the same. As these were the third set of interviews the first number given was 3. Next a letter denoted the participant's gender and the second number used indicated their place in the interview schedule. e.g. 3f1: third interview, female, first person to be interviewed.

Participants were asked to answer the questionnaire and to discuss any points they wished to raise either as they completed it, or at the end of their analysis. The conversation with each of the participants frequently diversified from the questions being asked about the design resource. However, the additional discussions allowed the researcher personal validation of many of the issues considered during the course of the study. These conversations were noted at the end of the interview and logged in a personal journal.

11.6 Participant Evaluation

The questionnaire began with a statement about the content of the resource and its relevance to the study.

This resource has been developed as part of a PhD study that I am completing entitled 'Wheelchair Access in the Built Environment'. The resource evolved from information I acquired through talking to wheelchair users in the local area about access issues and has been produced for use by designers / planners who are completing projects for people with disabilities. It is hoped that the resource will encourage designers / planners to talk to people with disabilities about their views on access, and consider their comments throughout the design process.

Thank you for agreeing to look at the resource and please be assured your comments will be treated with the strictest confidence.

(Design Resource Questionnaire - Appendix 7)

The questionnaire contained eleven sections and each was discussed with the participant before the questionnaire was completed. The first question asked was - *Is the contents page and page numbering helpful?*

All of the participants said 'yes they were helpful'. Only participant 3f3 elaborated stating:

Yes the contents page is useful in allowing the user to pick out information as required. Although the pages range may help. So it could be Section 1 (name) pages, Section 2 (name) pages 4-6

The second question asked about conversation etiquette – *How do you think this section will help designers / planners communicate with people with disabilities more effectively?*

The answers to this question were different from each participant.

3f1 It may help them remember and realise that they are talking to a 'person' not a 'handicap/disability', and that these people have feelings too, plus dignity. Mutual respect is the key

3m2 It should help because you have to be their equal ideally the eye level should be the same

3f3 Individuals are often nervous of being in situations they are unsure of. This section should help to allow them to concentrate on what they are communicating rather than being concerned with if they are 'doing it right'

3f4 It will help to get better answers that mean something

3f5 Tabulate the text, designers will find that more visually acceptable
No idea if it will be of use, I would like to think it would be, it won't hurt

3m6 It covers everybody – it would help someone who has no experience of disability

Although the comments varied they were all positive about the conversation etiquette section helping designers to communicate with disabled people. The conversations that

accompanied this section all involved participants stating that designers need to understand that disabled people are the same as their able-bodied peers and should be consulted in the same way.

Question three asked about user participation - *This section recommends focus groups as a useful method to obtain information. What are your views on focus groups as a way for people with disabilities to express their views to designers / planners?* Five of the participants agreed that focus groups were a good idea, but participant 3f5 felt that they should be:

... part of the consultation / participation process to qualify information about service provision (3f5)

3m6 You couldn't go wrong with focus groups. Disabled people are the people with the experience of access. But, you must make the content clear use plain speaking and give every body a chance to speak and say their piece

3f4 Remember people with people with learning disabilities can be influenced by:

1. The last thing you say (this is often their choice)
2. The tone of your voice
3. Easily convinced to choose an option you want by your influence.

Use drawings, sketches, photographs or anything else visual if possible and ask questions about that.

Don't re-ask a question if you don't get an immediate answer, give the person time to answer and don't prompt them.

Remember, people who have lived in residential homes have often learnt to have an easy life by telling people what they want to hear. Don't influence peoples answers and remember - give people time.

3f3 I agree that focus groups are a useful resource. The advantages and disadvantages as listed, although the designer/planner needs to be aware that just because a person is disabled it does not mean they are an expert!

(This comment was clarified as meaning 'disabled people are not an expert where design *solutions* are concerned'. It was confirmed by this participant that disabled people are experts in the field of disability and should be consulted throughout the design process.)

3m2 Very good if the impaired listen to what is said – often they don't

3f1 I think they are a good way of 'bouncing' ideas around, and a quick way of ironing out potential problems from the start. It probably saves a lot of hassle later on. Quiet group members could always be approached and coaxed into giving their views on a 1:1 basis

When asked about the acceptable / unacceptable terms section - *are there any terms that you know of that are missing and should be included?* Only participant 3f4 had extra suggestions about terminology

Learning difficulty is often preferred to learning disability. The only problem with this is that it can be perceived (particularly by members of the medical profession) as being related to dyslexia. It is best to ask the person if they have a preference (3f4)

Participant 3m2 commented:

It depends on the person using the language and how the language is used. Things can be made to sound derogatory

Participant 3f3 affirmed:

This section is useful to the user although I do find that a person communicating with disabled people for the first time often gets themselves tied up in knots trying to get the terminology correct and therefore it is something that people should work towards and not be too worried if they say the wrong thing in the initial stages. Obviously in any written document the use of the correct terminology is paramount.

I think the list is comprehensive, but may require review as ‘correct’ words change

Additional discussions about terminology with all of the participants included their dislike of the word ‘handicap’, which was apt as the next question asked – *Definitions – What are your thoughts about the UPIAS definition where the word handicap has been left out or the WHO definitions?*

Participant 3f1 summed up the comments of all the other participants when she stated:

I think the WHO definitions are blunt, and have been put together in words aimed at the ‘normal’ majority rather than the minority to whom the WHO are referring and describing, which leads me back to lack of respect! The UPIAS definitions have that respect.

All of the other participants maintained that the word ‘handicap’ should not be used or even ‘...exist...’ (3f5). Participants 3f5 and 3f6 went on to discuss how they also disliked the word ‘impairment’. Both stated that they did not feel it was a word that they would use and that it would be preferable if it was not necessary for anyone to use the word impairment at any time. Participant 3f3 commented that:

One day maybe we will all just be people with no further classification required! (3f3)

Question six asked - *What would the benefits of a summary of each web site be?* All of the participants thought a summary of each web site would be useful. Regarding the second half of the question which posed the question - *are there any web links that you know of that should be included?* Participants 3f1 and 3m2 had no sites to add. However the other participants suggested:

<http://www.open4all.org> the new DRC website (3f3)

<http://www.dptac.gov.uk/> the website of the Disabled Persons Transport Advisory Committee (DPTAC). DPTAC advise the UK Government on access for disabled people to transport and advice on the built environment (3f4)

Liberty - <http://www.liberty-human-rights.org.uk/> a website that looks at human rights issues (3f5)

‘Through the Roof’ - <http://www.throughtheroof.org>. A Christian disability organisation that is working to change attitudes in churches and wider society towards disabled people and disability (3m6)

Participant 3f1 stated that there were ...some (websites) that I haven’t come across before...

Question seven asked about the overview of Medical Terminology – This section gives the reader an outline of various disabilities. *Do you think there are any others that should be included?* Only participant 3m6 offered the suggestions of ‘Angina and Fibromyalgia (3m6). Conversations that accompanied discussions about this section suggested that an overview of medical conditions and associated terminologies would help designers to understand individual symptoms and to be familiar with terms that they may not have previously encountered.

Regarding the question - *do you have any views on all other sections (Guidance on Disability Legislation & Ergonomics)* three participants had no comment to make while the other three commented:

3m2 The DDA is like the Bible – it is down to interpretation

3f3 These sections are factual. You may want to add about the draft Disability Bill, that will again review the DDA?

3m6 Anthropometric data may be useful

This pack is for use by designers / planners, participants were asked if - *there are any sections that should be added that would help them obtain the views of people with*

disabilities? Participant 3f1; 3f5 and 3m6 had no further comments to make. But 3m2 suggested

It would be ideal if the designers had to live with the disability they were designing for.

3f3 stated that:

The pack provides a good framework for designers and planners and if used correctly should assist in making the final product accessible to all

Participant 3f4 suggested that a section on ‘Total Communication’ may be useful. Total communication is described by Dorset People First as “...about making sure that people have access to the ways of communication that are best for them whenever they need it” (Dorset People First - Dorset Self Advocacy 2004). It is a form of communication that uses gestures, symbols, expressions, photographs and body language and is aimed specifically at helping people with learning difficulties to be more independent and involved in the community.

When asked to comment on *the clarity and overall presentation of the resource* participants stated it was:

Very well presented and easy to understand (3f1)

Easy reading – points are succinct (3m2)

Review of the comments page suggested in question 1 will assist with the use of the document (3f3)

Fine for designers – Quite accessible for people who aren’t designers too (3f4)

Like the way it didn’t start with definitions (3f5)

Clarity is very good – important for clarity for the person you are communicating with (3m6)

Participants were asked if they *had any other comments*. 3f1 and 3m2 had no further comments to make. 3f3 observed that:

The ‘Design Resource for Inclusive Design’ will provide an excellent framework for use by designers and planners

3f4 commented that the resource was “...a bit jargony...”, 3f5 stated she would “...love to read it (the thesis) when it is finished...”. While 3m6 offered a criticism about the DDA:

The DDA doesn’t really cover you, it’s only words. The Government make it look as if they have done a lot and they have done nothing.

3m6 ended his evaluation by reiterating

Don't use board room language when talking to the majority of disabled people, not everyone understands the terminology also it is foxing for people with learning disabilities

11.7 Respondents Views

As previously discussed in chapter 8, access to the disabled community in the area where the research took place was limited. Research and consultation and participation projects are often attended by the same people some of whom have the reputation of having 'set' and specific views about local access issues. Acquiring access to participants to comment on the content and appropriateness of the resource proved, yet again, to be challenging. Once more, time constraints became an issue, as originally a more in-depth analysis of the resource was planned but, due to unforeseen circumstances, this analysis was unable to take place (See earlier discussion).

It was decided to devise a short questionnaire to ascertain respondents' views about the resource. The questions were open ended (Bryman 2001; Blaikie 2000) and the researcher was available at the end of the time required by respondents to fill out the questionnaire, to answer any questions or to discuss any issues raised (Robson 1993). Each of the sections in the resource had an open ended question about its content, e.g. "...are there any terms that you know of that are missing and should be included?" This ensured that the respondents could answer in their own terms and write as much or as little as they felt necessary for each section (Bryman 2001). Although it was time consuming, the decision was made to ensure the availability of the researcher to talk to the respondents after they had filled in the questionnaire. This triangulated methodology (Bottorff 1997; Bryman 2001; Oakley 2000) was used in view of the fact that time was 'running out' and it allowed the researcher to obtain information from the respondents in a short space of time, and collate the data attained (Bryman 2001; Hammersley 1995; Robson 1993).

The comments written and verbalised by the respondents were generally positive even though the researcher did request that they divulge any negative comments. Each respondent was assured that the researcher would not find negative remarks derogatory, but that she needed to know if any improvements could be made to the resource. All of the responses echoed the sentiment that the resource would be of benefit to designers,

and the majority of the ensuing discussions erred away from the design resource and its content, and onto debates about how disability is still not accepted by the majority of society. Although these discussions proved to be of interest, they were not relevant to include in the thesis.

Respondents in any study will come from a variety of backgrounds and have diverse views. Individuals' outlooks on life have to be accepted by the researcher and acknowledged accordingly. If the researcher is considered to be a social actor "...whose activities are party to the reproduction and/or transformation of existing social relationships of exclusion or inclusion, domination or oppression" (D'Cruz and Jones 2004, p.12), then they must be aware of the diversity of the research participants and their status and position in society. Humans' cultural diversity and individuals' inclusion/exclusion from social citizenship (Marshall 1950), has an impact on a range of activities, rights and duties (Lewis 1998). Whilst historically, class, race and ethnicity have been accountable for much social inclusion, it should be acknowledged that the disabled peoples' movement has raised similar concerns regarding disability (Lewis 1998; Priestly 1999). In order for disability research to be 'meaningful' (Stone and Priestly 1996), researchers need to acknowledge disability, citizenship and inclusion/exclusion (Chapter 3; Priestley 1999; Barnes 1991). This principle of recognising peoples' status in society must be acknowledged as part of the interview process.

The respondents who answered the questionnaire about the design resource were an amalgamation of carers, advocates, disabled and non-disabled people yet it was interesting to note that all of the respondents agreed that disabled people are not integrated into mainstream society. Moreover, that irrespective of any legislation, the acceptance of disability has to be brought about by education, training and cultural awareness.

Whilst it has previously been discussed that designers can, and do, influence society through the products and services they create, then perhaps design education should be purporting that by involving end users (specifically disabled end users) in the design process, then design will enable disabled people a further opportunity to influence

societies awareness of their specific cultural issues. Ultimately, this would result in citizenship being enabled through design.

11.8 Conclusion of Evaluation

It can be seen from the participants' comments that they consider the design resource would be a potentially useful tool for designers to use when designing for people with disabilities. The only component that they all agreed could be improved was the web site section where all of the participants recommended that the addition of a summary of the contents of each web site should be incorporated.

On the whole, the underlying factor from the data was that the participants considered that designers need to understand how to communicate with people with disabilities. To do this effectively designers must accept that disabled people are no different from their able-bodied peers in so much as they have opinions, views, requirements and feelings that should be considered. Individual impairments may mean that designers have to accept human imagery as being different from the majority of the population, that they might have to phrase questions differently, use pictures and symbols instead of words and / or have patience when waiting for answers. All of these factors require a little more time for reflection and consideration of the needs of other people to ensure that:

- Designers obtain information that assists them in the production of better products and services that are more suitable for the end user
- The end user (the expert in the field) is consulted enabling a more inclusive design process

CHAPTER TWELVE – FINDINGS AND DISCUSSION

This chapter deliberates the contents of the previous chapters and outlines the limitations encountered while completing the study. The discussion begins by outlining the differences between design research and social science research. This subject has been debated throughout previous chapters as the fields of design and disability are diverse, and understanding their different terminologies has been fundamental to the study. The debate then considers research techniques and how academic rigour guided the research.

The social model of disability is endorsed by this research and the chapter maintains that its basic principles relate with those of inclusive design. Inclusivity and accessibility are issues raised by disabled people and the social model has enabled them a platform to raise awareness of how social issues affect their everyday lives. By contrast, inclusive design could actually assist disabled people in gaining the inclusive and accessible lifestyle they desire. But for designers to truly support the disabled community, they need to accept that disabled people should be included within the design process so that they can convey their ideas and views about the products and services being provided. The dialogue contends that the PACE model of inclusive design and the associated design resource can assist designers with understanding how end users should be incorporated within the design course and how to successfully communicate with disabled people.

The chapter concludes with an examination of the limitations of the study and how cost implications and inexperience of the researcher shaped the research context.

12.1 Design Research V's Social Science Research

A factor that has been discussed during previous chapters is the difference between design and social science methodologies. There is a huge disparity between the two subjects particularly in the use of language and the involvement of 'others' in the research process. Design is a disciplined profession but designers and architects promote their own views and egos through their work. Design research considers many 'inanimate' topics, including material selection, specifications and the product or service itself, which are, on the whole, inorganic. The process of design is regulated, and almost clinical in progression, with the designer using imagination and intuition

alongside quantifiable procedures. The design course has to be regimented to ensure that all aspects of the product or service adhere to health and safety regulations to protect both the end user and the designer. By complete contrast, qualitative social science research is 'people orientated' and considers emotions, feelings and desires. Many methods involve user participation and offer the researcher techniques to consider and convey participant's views. Historically, the design process does not incorporate the views of the people it is intended for. Instead it considers human requirements through ergonomic and anthropometric measurement. Ultimately design is concerned with monetary gain, marketability, brand and designer recognition and the creation of form (Lorenz 1990). Social science inquiry, however, strives to understand the experiences of people and the world in which they live (Holloway 1997).

It is apparent that the differences between the two disciplines are extreme. But, in spite of their differences, it is the contention of this study that they can be integrated to provide a method for designers to involve end users in the design process and to enhance inclusive design principles. Qualitative social science methods were used by the researcher to obtain information during the first phase of the project and focus group methods are recommended for use by designers within the design resource (Appendix 6).

12.2 Research Techniques used in the Study

The use of qualitative research methods enabled data to be collected from wheelchair users themselves as opposed to gaining information '*second hand*' through market research and statistical analysis.

The phase one sample produced more information than was initially expected, which led to the first and second research proposals having to be amended. With supervisory guidance it was decided to concentrate on the views of the wheelchair users and collect richer data about their views of access issues (Chapter 1). This required the researcher to re-evaluate the data and complete a more rigorous analysis of the information obtained.

The analysis of the data involved looking for patterns and meanings, whilst taking care to be objective, and not to make allegations of bias (D'Cruz and Jones 2004). The

method chosen to analyse the data involved using different coloured paper for the transcripts of each focus group, and then utilising different coloured marker pens to highlight the categories and subsequent themes. The use of different coloured paper and pens made the data become ‘more visible’ and, in some way, more tangible. It was only through the use of colour to highlight areas that the data became logical and apparent to someone with a background in design, where visual information is very much part of the design process. This colourful form of content analysis meant that respondents’ views could easily be grouped into themes, and participants views on the same subject identified for discussion (D’Cruz and Jones 2004). Throughout the design process or product development, designers work to a process of “...visualisation of information first of all to take information in and be able to visualise it” (Wilcox 2005, p.5).

The choice of coding used to ensure confidentiality for the participants was suitable for a small study, but if the sample had been any bigger the possibility for confusion can be seen. The first digit showed which focus group the participant took place in. The second digit represented whether the participant was male or female and the third digit depicted where in the order of the focus group the participant spoke for the first time. With a small number in the sample and the coincidence that all members of each gender had a different dialect this method of coding proved to be suitable. Nevertheless, it is acknowledged that if the sample had been larger, or if the accents had not been so pronounced, then comprehension of the audio tapes may not have been so straightforward.

Protecting research participants’ anonymity during dissemination can pose considerable dilemmas to the researcher (French 1993). The use of coding was used to protect the anonymity of the participants, though their gender is recognisable from the ‘m’ or ‘f’ in each individual code (French 1993). As discussed in chapter 8, the researcher purposefully did not discuss specific disabilities as these would have identified the participants should anyone from the day centres read this thesis (Redwood 2006).

Several members of the sample were previously known to the researcher and one of the considerations was that the participants might say ‘*what they thought the researcher wanted to hear*’ rather than what they actually thought or felt. Fortunately this only happened on one occasion during an interview regarding the evaluation of the design

resource. It occurred with the only participant to take part in the evaluation and focus group samples. The comment made was "...if you think of anything else I might have said and didn't just add it afterwards" (3m6, June 2004).

Research findings in quantitative research might be viewed as reliable but not valid, whereas the opposite may be the case for qualitative studies (Oakley 2000). Validity in qualitative research comes from the research findings corresponding to the reality from which it was drawn. In this study, the reality the participants presented was one of inaccessibility, inequality and not being listened to by planners, designers and policy makers. As the concept of inclusive design embraces the notion of designing products and services for all, then designers should be encouraged to adopt inclusive design methods to assist disabled consumers to achieve equality.

One of the topics discussed in chapter 6 is the use of emancipatory and participatory research paradigms. Whilst the research acknowledges the use of emancipatory methods in disability research, this study utilised participatory methods. The reasons for this were:

- Design is a highly disciplined practice that requires specific answers which may not have occurred if a non-designer had guided the research
- The aim of the research, the formulation of a tool to assist designers, required the researcher to make a judgement about the content of the resource as she had the knowledge of 'how designers work' and considered herself to be the expert in that particular field.

The knowledge and design expertise of the researcher and the information gained from the participants who were considered to be the experts in their field was combined to develop the resource. On reflection of this theory, it is now recognised that the researcher was thinking as a designer as opposed to a social scientist embracing participatory techniques or as a true disability advocate.

During the year 2000 the researcher had to take time away from the study due to personal circumstances which resulted in a loss of contact with the day centres and the participants. When the study resumed the day centres were contacted with a letter of

apology and a request to resume discussions with the management, staff and participants. One of the day centres responded positively but the other one did not. Contact was lost again later that year as the day centre, its staff and service users encountered a major restructure at local government level. This meant that the sample for the evaluation of the design resource had to be found from elsewhere and that the original participants who had influenced the resources contents were not consulted.

12.3 Academic Rigour in Research

Stone and Priestly (1996) contest that "...academic rigour should never be compromised in establishing the criteria for what constitutes 'good research'" but that research skills should "...not be taken as a green light to assume knowledge of the needs, feelings and conceptualizations of the research participants" (Stone and Priestly 1996, p.713). They continue by prioritising four aspects of the emancipatory model when completing disability research:

- The contradiction between surrendering control and maintaining integrity
- The tension between accepting our expertise *as researchers* whilst accepting disabled people's expertise as *knowers*
- The problem of collectivising analysis within a social model where that model is not necessarily part of the participants' own understanding of disability
- A recognition that positive outcomes in individual lives need not be the sole criterion of 'good research' where a real contribution can be made in the wider context or the longer term

(Priestly 1999, p.16)

These points were considered in relation to this study:

- The researcher had little or no influence on the choice of research participants who were invited to join the study. Whilst the gatekeepers respected the inclusion criteria, the researcher had nothing else to do with the selection process or the venue for the meetings.
- The central tenet of inclusive design is end user involvement which requires accepting that disabled people have the expertise as *knowers*. The researcher of this study accepted disabled people are the experts in the field of disability. This acceptance stemmed from a life time experience of living along side a peer who was physically disabled and from knowledge gained while working with people with varying disabilities.
- It was found that several participants of the study and many disabled people with whom the researcher met through other experiences, had little or no concept of the social model of disability and '*hid behind*' the medical model while accepting inequitable services. While the majority of the participants acknowledged that their impairments were not what disabled them, some considered their difficulties with access stemmed from becoming physically unable to perform certain tasks.

- The wider context of the research examined how to inform designers and development professionals of the importance of ascertaining the views of end users, specifically disabled people. It is hoped that if designers adopt inclusive design principles, the process will lead to improved policy and practices (Chapters 2 & 13).

The dilemmas of the social relations of disability research and satisfying the requirements of rigorous research approaches are discussed by disability academics including Oliver (1999), Priestly (1999) and Swain *et al.* (2003). Priestly deliberates how arduous it can be to “...satisfy academic peers” (Priestly 1999, p.16) while producing research that is shaped by the research participants. He had to modify a research proposal by removing the word ‘emancipatory’ when a member of the faculty persuaded him that unless changes were made, it would be regarded as too removed from the ‘mainstream’ (Priestly 1997). Bennett (2002) encountered similar difficulties with her proposal for an MA in Design Research for Disability.

12.4 The Social Model of Disability

Chapter 3 examined many of the discriminatory areas encountered by the disabled community and introduced the concept of the social model of disability. The model was formalised by Oliver and Finkelstein and is now the fundamental tenet of the disability movement (Shakespeare and Watson 1997). Finkelstein (1980) anticipated that the post-industrial society in the second half of the twentieth century would herald significant social and economic changes that would advance positive opportunities for the inclusion of disabled people. However many disability writers are not convinced that Finkelstein’s assertions have transpired. Isolation and oppression are still encountered by the disabled community more than in any other minority group (Barnes and Mercer 2003). To compound matters further the social model is now in debate by those who established it as they claim that

...a model which was developed in the 1970s no longer seems as useful at the beginning of the twenty first century

(Shakespeare and Watson 2002, p.23)

Shakespeare and Watson (2002) further assert a new ontology of disability where everyone is impaired. This arises from Sutherlands (1981) affirmation that

...no body works perfectly and that therefore we are all in some way impaired

(Sutherland 1981, p.18)

Shakespeare and Watson (2002) maintain that we should consider the frailty and vulnerability of our embodiment, and that this embodied ontology would denote that there is no difference between disabled or non-disabled people. They further contend that society excludes, disempowers and oppresses people and therefore society ‘disables’ people through discriminatory practices. Shakespeare and Watson (2002) conclude that able-bodied people also deny their vulnerability and put their fears onto disabled people who they then subsequently oppress and exclude and that exclusion and discrimination are where “...the core focus of empowering disability studies should lie” (Shakespeare and Watson 2002, p.29).

While Shakespeare and Watson’s (2002) points of view about a new model of disability are fundamental and innovative, the majority of disability writers, academics and activists are still promoting the social model of disability. This study maintains that while the social model integrates successfully with inclusive design principles, Shakespeare and Watson’s (2002) model could add more credibility to the use of inclusive design. The central principle of the social model of disability allows disabled people to argue that social exclusion affects their life more than their individual impairments do. It is this premise that this study contends is imperative for designers and development professionals to comprehend if inclusive design methods are to be successful in supporting the disabled community in its quest for equality and accessibility. It is this exclusion factor that the PACE inclusive design model and the accompanying design resource attempts to assist in eradicating.

12.4.1 Disability Research and the Social Model

The social model of disability can be seen as a method for focusing on the economic, environmental and cultural barriers encountered by disabled people. Furthermore, a social model perspective recognises that a lack of medical and health services can exacerbate disabled peoples lifestyles. This standpoint also acknowledges that disabled people often feel devalued by a society that continues to oppress, discriminate and exclude people who are viewed, and labelled, disabled. This exclusion and oppression is contested by emancipatory disability research.

Emancipatory research emerged in the early 1990’s and is characterised by seven core principles.

- Control – full involvement by disabled people throughout the research process
 - Accountability – research procedures and practices must be explained to all participating people and organisations. Dissemination must be in appropriate formats
 - Empowerment – research should produce knowledge that will be meaningful for disabled people in their endeavours to overcome barriers
 - The Social Model of Disability – research should adhere to the principles of the social model in a holistic manner
 - The Need for Rigour – research methodology and data collection require logic, rigour and to be open to scrutiny
 - The Choice of Methods – the choice of methods should reflect the needs of the project and be agreed by the disabled participants
 - The Role of Experience – cultural and environmental issues ought to be contextualised by narratives or stories of disabled people themselves
- (Adapted from BCODP 2003)

Whilst these principles are commendable, and do encourage researchers to carry out research for, and with, disabled people, the practicalities of completing research of this nature is not always straightforward to organise. As previously discussed, there are the constraints of academia to consider, as well as locating participants who want to be involved in this kind of research. However, while an emancipatory approach assumes the need for transformation of the social and material relations of research production, the DRC does not recommend emancipatory methods in its 2004 – 2007 research strategy. Instead it states

...social researchers have a responsibility to ensure inclusion in research projects of relevant groups or individuals who might otherwise be excluded for reasons of communication, disability, comprehension or expense

(DRC 2005, p3)

This concept of participation is described by D’Cruz and Jones (2004) as being a methodology that has the potential to

...generate certain ways of knowing but also for its potential to engage with others in a participatory movement towards certain social changes

(D’Cruz and Jones 2004, p.89)

It is this concept of social change that inclusive design can assist with. If disabled people are included throughout the design course, then their expertise can help designers to produce products and services that are more inclusive.

12.5 Inclusive Design Methods

Chapter 9 has discussed the advantages of inclusive design methods and how they are beneficial to the diverse cultural composition of the world in which we live. Inclusive

design is being endorsed as an approach that will facilitate the needs of all of society regardless of age, disability or gender, and the PACE model demonstrates how the end user should be consulted at all stages of the design process. Livingstone, the mayor of London, supports both the social model of disability and inclusive design and has incorporated their principles within his Spatial Development Strategy for the capital. He contends that the needs of all residents of London should be included in all aspects of mainstream life to ensure significant improvements in social inclusion (Livingstone 2004). The Strategic Planning Guidance Implementation Point 28: London's diverse population states:

The Mayor will, and boroughs should, endeavour to ensure that in meeting the principles of inclusive design the spatial needs of London's diverse communities are also addressed.

(Greater London Authority 2004, p.92)

If successful the strategy could potentially be duplicated by other towns and cities throughout the country, leading to councils assisting the disabled community to acquire the accessibility they desire.

The Disability Rights Commission (DRC), an independent body established by Act of Parliament to eliminate discrimination against disabled people and promote equality of opportunity, has set itself a goal of "...a society where all disabled people can participate fully as equal citizens" (Massie 2004, [No page number]). The DRC advocates inclusive design and the chairman Massie (2004) describes its strategies as a "...constantly changing philosophy that guides the way we design our environment" (Massie 2004, [No page number]) as opposed to a fixed set of technical criteria. He concludes that the goal of inclusive design is to create environments that can be used by a diverse range of users therefore the design process should constantly expand to accommodate an understanding of the expectations and requirements of the people it is designed to assist.

If inclusive design is being utilised in the Spatial Development Strategy for London and endorsed by the DRC, then its tenets must be seen as being beneficial to all. This study asserts that inclusive design principles are 'the way forward' for design and that an inclusive and accessible environment is attainable for all.

12.5.1 The PACE model and Associated Design Resource

Newton *et al.* (2003) contend that designers are keen to utilise inclusive design principles and that effective legislation, practical guidance and a national framework for inclusive design education are the way forward to ensure an accessible built environment in the future. However, to date, these concepts are still in the early stages of development (Newton *et al.* 2003; Lebbon 2003). The PACE model of inclusive design demonstrates how the end user should be consulted at all stages of the design process (See Fig 5). It endeavours to display how design exclusion can be eliminated if the advice and opinions of ‘the experts in the field’ is sought throughout the design course.

Newton *et al.* (2003) further assert that end users “...want to be involved in the design process but feel they have a limited amount to contribute” (Newton *et al.* 2003, p.14:562). This study contends that end users, specifically disabled end users, are unsure of their levels of contribution as they have previously been actively discouraged from participating in the design process in any way. The associated design resource offers designers solutions to communication techniques with disabled end users that should help with them realise the importance of their contributions.

Focus groups were recommended as a suitable method for group communication and designers could gain insight into several issues during one session. All of the participants agreed that focus groups were a suitable method for obtaining information from disabled end users, including participant 3f5 who felt that they should be used as part of the information gathering process as opposed to singularly. Designers could use focus groups along with other methodologies, but they were recommended as a singular method for data collection that encourages interaction through personal communication, which this study advocates designers need to consider. During the process of this study the researcher has begun to realise the merits of focus group methodology and how numerous subjects can be discussed in a short space of time. The technique is similar to that of mind-mapping which is a process designers utilise regularly.

It can be seen that on the whole, the participants’ comments about the design resource were positive and they considered that its contents would assist designers with their endeavours to communicate with end users. Communicating with a person with a

disability is not difficult (Morris 1996). A disability does not preclude a personal opinion; however, a person's impairment may mean that obtaining opinions and views may take patience and understanding on the behalf of the researcher. The researcher of this study has had a life time of living alongside someone with cerebral palsy and working with people who have varying disabilities, which has ensured that, for her, the majority of communication with disabled people is not an issue (See Chapter 1). As a result of these personal experiences the researcher is able to identify with many of the comments the participants have made about other peoples' inability to communicate with disabled people. However, the researcher concedes that her experience of communicating with people with learning disabilities is limited and that when this has occurred she has felt embarrassed and unable to communicate effortlessly. The researcher contends both from personal experience and research within this study that the more people converse with people with varying disabilities the easier communication will become. If designers are to successfully design products for disabled people then they must communicate with them to obtain their views as they are the 'experts in the field'. If communication is considered challenging, then designers should embrace the challenge, as they would a design brief, and find a way of combating their own preconceived conceptions, embarrassments and limitations.

During the process of communication it is necessary for designers to realise that there are several socially acceptable or politically correct sayings and statements that should be used. As with all communication individuals may take offence to comments made by others. No-one will '*get it right*' all of the time. However, within the field of disability, as with racial, sexual and gender comments, there are several statements that should always be avoided. These are noted in the resource, but the prominent ones include: handicap, cripple, spastic, moron, defective, mongol, vegetable, imbecile, retard, idiot and normal. (While this study advocates that these terms should not be used they have been heard during the research process). Acknowledging words and terms that are not acceptable will assist with communication skills but '*faux pas*' will occur. As described in the design resource it is important not to be embarrassed to ask if something is misunderstood and to repeat answers to obtain clarification. The designer should remember that their own embarrassment will be recognised by the person they are talking to and that two way communication is necessary for both parties to feel comfortable conveying their views.

The resource also contains sections on suggestions about where designers can access information regarding statistics, legislation, ergonomics and associated web sites. All of the participants agreed that an overview of the content of the web sites would be beneficial and it is recommended that the resource is restructured to incorporate this. As previously discussed the section that contains an overview of medical terminology is not intended to offer designers suggestions or solutions about how to design for a specific disability. It is included give designers a preview of terminology that they may encounter when designing for people with disabilities.

12.5.2 Limitations of the Design Resource

The researcher concedes two limitations with the design resource. One is of promoting it and its contents to designers and the other is that of updating or altering the information it contains. Legislation, standards and web sites are constantly evolving which means that the information in the resource is only accurate for a limited period of time. Possible solutions to this problem are that the resource is linked to a web site where down loads of updated information would be available or that the information is obtainable in printed format. There were two main reasons for developing a printed design resource as opposed to producing an electronic one.

- It was considered that a printed resource could be taken anywhere with the user
 - Not everyone has access to laptops
 - A printed resource can be accessed easier, for an instant reference, than an electronic one
- The researcher did not have the expertise to produce an electronic database or web page; therefore the work would have had to be out sourced which would have incurred a cost

The cost of the printed design resource is negligible compared to that of an electronic equivalent. A printed version contains approximately twenty five sheets of A4 sized paper which could be accommodated in a plastic wallet, ensuring a manufacturing cost of under £10. (It is acknowledged by the researcher that a costing report and feasibility study concerning the validity and marketability of the design resource has not been included in this study, but should be considered essential if the project was to be taken further at a later date).

12.6 Limitations of the Study

The main and most significant limitation of the study was that the researcher was a part-time, self-funding student. This affected the study in a number of ways.

The researcher had to work part time to cover living costs and course fees which meant that days of study were often sporadic as employment did not always consist of regular hours. As a consequence of this, research frequently stopped and started and topics had to be '*re-visited*' to remind the researcher of enquiries that had been previously undertaken. This meant that sometimes the project 'did not flow' or run as smoothly as the researcher had hoped it would. It also caused complications when organising the focus groups, follow up interviews and the resource evaluation interviews as the researchers study time outside of a work context was limited.

As the cost of the research was undertaken by the researcher many activities that would have benefited the project could not be afforded. Examples of this are visits to other universities where inclusive design research and disability studies take place e.g. Leeds, Salford, Bristol, Loughborough, Cambridge and The Royal College of Art. The advantage of visiting these institutions would have been for the researcher to make contact with other researchers in the fields incorporated in this study and to find out '*first hand*' about their research. It may also have benefited the researcher to visit disability organisations outside of Dorset to discuss disability issues, e.g. Greater London Association of Disabled people (GLAD), The Royal Association for Disability and Rehabilitation (RADAR), Centre for Accessible Environments (CAE). However, the resources within Dorset and the surrounding areas and the availability of internet access provided a variety of information for research purposes while affording little or no cost.

Another notable limitation of the study was the researcher's inexperience regarding social science research. The comprehension of the different use of language used by social scientists has been discussed previously but it was an issue that the researcher 'struggled' with throughout the project. It can be seen from previous chapters that the fields of design and social science are widely divergent. Needless to say, the terminology and approach required by each is very different. But to change from a field where the approach was based mainly around feasibility and probability to one where

reality and its diversities are fundamental, was nothing less than a ‘culture shock’ for the researcher. That is not to say that design and designers do not put people and their requirements high in their list of priorities, but rather that designers interact and improve the objects that people utilise as opposed to the people themselves. Dreyfuss & Dreyfuss (2003) clarifies this succinctly.

...what we are working on is going to be ridden in, sat upon, looked at, talked into, activated, operated, or in some way used by people individually or en masse. If the point of contact between the product and the people becomes a point of friction, then the industrial designer has failed. If, on the other hand, people are made safer, more comfortable, more eager to purchase, more efficient – or just plain happier – the designer has succeeded.

(Dreyfuss & Dreyfuss 2003, p.24)

This chapter has discussed the fundamental issues raised during this investigation and considered the limitations experienced throughout the study. Chapter 13 will offer conclusions from the enquiry and recommendations for future progression.

CHAPTER THIRTEEN - CONCLUSIONS AND RECOMMENDATIONS

This chapter provides an overview and conclusions of the study. It begins by considering how legislative processes are, or are not, beneficial to disabled people. Since the advent of the DDA awareness and consideration of disability issues has unquestionably increased, but the value of the DDA is questioned by many disability groups, writers and advocates. The debate within the previous chapters suggests that society's attitudes towards disability have as much, if not more, of an impact on inaccessibility than 'bad design'. As Davis (1997) asserts, and this study supports,

...the 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person
(Davis 1997, p.9)

This premise is central to the social model of disability which, this study advocates, should be combined with inclusive design methods to provide the disabled community the accessible environments they desire.

Inclusive and accessible environments for the disabled community are central tenets of the arguments maintained by disabled peoples' groups, disability writers, academics and advocates. The Disability Rights Commission has set itself a task of striving for a society where all disabled people can participate fully as equal citizens. This study claims that by embracing inclusive design principles, designers can assist with this ambition and assist disabled people to obtain the equitable lifestyle to which they aspire.

The chapter makes a case for inclusive engagement with disabled people within the design course, and proposes a model for this process. It acknowledges that there are several aspects to this, as the research traverses more than one subject. Morris (1991) asserts "...it is not the inability to walk which disables someone but the steps into the building". The study agrees with Morris' (1991) contention but concedes that while environmental inaccessibility is a significant factor in the discrimination encountered by disabled people in their quest for inclusivity, it is societies' attitudes that need to change. If designers embrace inclusive design methods and the principles of the social model of disability, then disabled people would contribute to the construction of the surroundings that they live in and ultimately 'have a say' in the formation of an inclusive and accessible environment.

13.1 Legislation

This study provides some evidence that discrimination and oppression are still encountered by disabled people. Their perceived inequality is less now than it was fifty years ago, but it has not reduced significantly in the ten years since the researcher's interest in disability studies began. At the time of completing this thesis the DDA has been a recognisable Act for ten years. Despite the passing of a decade the Act's value and potential has yet to be fully realised (DRC 2005). Many disabled people, disability activists and academics do not believe that the legislation is 'worth the paper it is written on'. While the effectiveness of the DDA is yet to be seen, new building regulations are assisting in ensuring accessibility for disabled people. Approved Document M (ADM 2004) recommends consulting access groups to assist compiling access statements and the new Planning and Compulsory Purchase Bill (2004) stipulates that designers and development professionals should write access statements to accompany any submissions to local planning departments.

13.2 Societies' Attitudes

The literature reviewed and the data obtained from participants demonstrates that if attitudes towards disability do not change then disabled people will not obtain the equitable and accessible lifestyle they desire. Concern about political and social dimensions of disablement has deepened (Barnes *et. al* 1999), and whilst it has to be acknowledged that legislative frameworks are being developed, it is the attitudinal changes that have to come from re-education and alterations in perception about disability that will really make the difference to the disabled community. As Barnes and Mercer (2003) assert:

The pattern of social participation, or lack of it, experienced by disabled people demonstrates that exclusionary barriers remain deeply embedded in the structures and processes of contemporary societies.

(Barnes and Mercer 2003, p.63)

These configurations of societal constructs are being considered through a new political focus on disability that is being endorsed, in some part, through academic disciplines. To compound this, the growth of disability studies courses and specialist journals in America, Canada, Australia, New Zealand and Britain, has been unprecedented in recent years (Barnes *et. al* 1999). The work of many British disability academics such as Barnes; Oliver; Morris; Mercer; Shakespeare; French; Stone and Priestly has been in response to changes in society's perceptions about disabled people. Furthermore, 'non-

academic writing has been produced by disabled and non-disabled people associated with the disabled people's movement and consequentially this accumulation of literature has assisted in further development of changes in awareness of disability issues and the rights of the disabled community / communities (Barnes and Mercer 2003). However, as Barnes and Mercer (2003) contend, these academics, activists, writers and disability practitioners must consider the following:

- Whose agenda dominates?
- Whose definition of impairment and disability prevails?
- Whose ideology and culture determine policy and practice?
- On what criteria are outcomes measured?

(Barnes and Mercer 2003, p.149)

This enquiry asserts that all of the above should be dictated by disabled people, their philosophies and the principles of the social model of disability. Raising these questions will ensure that disability and impairment are firmly on the academic and political agenda in the majority world. Furthermore it should be recognised that poverty, inequality, political, social, economic and cultural changes are inseparable from the politics of impairment, which in turn can affect anybody at any time regardless of race, gender, age, sexuality or upbringing,

13.3 Inclusivity

This study has promoted the use of inclusive design for assisting people with disabilities with their quest for a lifestyle akin to that of their peers. However, inclusive design principles are not exclusively beneficial for the disabled community. Rather they embrace the diversity of societal construction and enable the creation of an environment that is suitable for all.

It can be seen that the social model of disability has undoubtedly assisted disabled people to explain their experiences and to identify social barriers as the cause of their disadvantages (Shakespeare and Watson 2002). It has also been demonstrated that the principles of the social model integrate with inclusive design methods to create accessible environments for the future. Disability advocates and academics now assert a new model for a social theory of disability, one that considers embodiment and impairment rather than impairment and disability that will make people consider their vulnerability, frailty and mortality and reduce the divide between dis-abled and non-disabled. If this model is developed and adopted as the new social theory for disability

then it will add more credence to the concept that inclusive design should be the innovative paradigm for design education of the future.

13.4 Contribution to Knowledge

The researcher contends that there are several strands to this thesis that are original contributions to knowledge. Including one that was not developed from an original research question, but that transpired during the course of the study (13.4.6). The following discussion considers the research questions outlined in section 2.1 and summarises the information collated regarding each of the research questions.

13.4.1 Designers Should Employ the Practice of Engaging with Disabled People

The first research question posed was – ‘How can designers become more inclusive?’ The DDA combined with an ageing and frailer population are factors that are influencing the need for inclusive design (Bellerby and Davis 2003; See Section 9.5.1). In order to create an effective inclusive design process, then methodological, practical and ethical issues have to be considered, but the crux of the whole process of inclusive design is the involvement of users within the design process (Goodman *et al.* 2005).

It is the overall contention of this study that if designers include the end user in the design process from its embryonic stage through to completion, then products and services created would be of greater benefit to the people they were designed for. Unfortunately including other people, particularly the end user, in the design process is not an established practice, and designers and development professionals will perhaps continue to question its validity. Asking end users for their views and including them in the design process, is a radical and new procedure for the design profession. Researchers and academics at the Helen Hamlyn Research Centre, host a biannual conference of international delegates in an attempt build bridges between researchers, practitioners and companies who have recognised the necessity for inclusive design strategies (Coleman and Macdonald 2003). These conferences were established in 2001, with the advent of the concept that inclusive design would be of benefit for people of all ages and abilities. ‘Include’ 2003 was attended by 160 delegates from 14 countries when the participants were told that they had the opportunity to “...rewrite design history and banish the doctrine of one size fits all” (Frayling 2003 [no page no]). Conversely, ‘Include’ 2005 was attended by a representation of 170 delegates from 19

different countries. Delegates from business, academia and the design profession gathered to establish a more inclusive future where understanding of users of all ages and abilities hold the key to commercial success and social equity. The outcome of the most recent conference is to build on the energy and initiative generated by the conference and to continue to press for change in design methods. However, as Shakespeare and Watson (2002) contend when defending their hypothesis for a new model of disability theory:

It is important to remember that in physics the replacement of Newtonian mechanics by the Einsteinian theory of relativity did not invalidate the former approach, but merely showed its limitations.

(Shakespeare and Watson 2002, p.24)

The same could be said of inclusive design techniques.

By arguing for the inclusion of the end user within the design process this study is not denying designers their expertise. However, it must be considered that the person that will use an end product, or service, will know better than anyone else what they expect and require from the final design. This is not to say that they will offer the most appropriate design solution, but a combination of knowledge from the designer (the expert in their field) and the end user (the expert in their field) will undoubtedly produce a far superior product which has input from multifaceted knowledge.

13.4.2 The PACE Model of Inclusive Design

The PACE model of inclusive design shows the designer how the process of inclusive design works thorough a diagrammatical representation, and illustrates how the end user (the expert in the field) should be central to the design course. It can be seen in Fig 5 that the design process can be split into four basic components. The design ‘*Problem*’, the ‘*Analysis*’ of the problem, the development of a ‘*Concept*’ and the ‘*Evaluation*’ of the product (PACE) and how, during each phase, the end user should be consulted to ascertain their views and expertise. This, in turn, will guide the designer to consider aspects of a product or service that they may not have previously considered. The extended PACE model exemplifies how sub-divisions of these four sections should continue with the notion that the end user should be continuously consulted. It is acknowledged that the inclusion of the end user throughout the design process may be problematic, as ultimately they are not likely to be expert designers or manufacturers, and / or may not be aware of design, product or manufacturing constraints. Equally,

where end users are unlikely to be experts in the field of design solutions, it is improbable that designers will be experts in the field of disability. Therefore, combining the skills and expertise of both contributors, it is hoped that the final product may improve inclusivity, accessibility and equality for a larger section of the population.

13.4.3 A Design Resource for Designers to use with Inclusive Design Methods; Specifically the PACE Model.

The first research question subsequently creates a conundrum for the designer as to HOW they should engage with disabled people, to ensure that their views are considered throughout the design process. This was overcome by producing a unique approach that differs from any other attempt to create a toolkit for designers to use when designing for disabled people. For the first time in the field of design practice this resource

- Informs designers of communication strategies to use specifically when conversing with people with disabilities
- Recommends research methodologies for successful consultation with disabled people
- Offers designers information about where they can source statistical information; legislation and potentially useful web links when completing projects involving disabled people
- Is in a printed format

The design resource that is associated with the PACE model of inclusive design differs from other inclusive design resources or toolkits in one fundamental way. It is based around recommended communication methods for people with disabilities. No other resource or toolkit is formulated in this way. Whilst the RSA (Royal Society of Arts, Manufactures and Commerce) launched a fully accessible, user friendly and multidisciplinary web-based design resource for inclusive design in July 2004, it lacked one integral component. Unlike the design resource developed for this study, the RSA resource does not give specific information about individual disabilities or how to engage with disabled people. Throughout its 1000 links, the emphasis focuses on the aging population. It does however; begin to purport to social research methodologies. Card 2 in the section ‘Understanding real people’ (RSA 2004) states “...ethnography is a method of close observation....the method places great emphasis on behaviour viewed as contextual, as part of its environment, rather than taken from its environment, decontextualised and codified” (RSA 2004, Card 2). Card 5 in the same section

describes user forums as “...not delivering specific or quantified information but has been found to be a very effective method for designers to develop empathy and understanding with potential users of their designs” (RSA 2004, Card 5). Whilst card 13 states that focus groups are “...used to gather raw data on user needs and aspirations in the concept development phase of design” (RSA 2004, Card 13). The cards containing this information include very little else. Consequently, these examples show that the details for user engagement within the RSA web based resource are limited.

During the focus groups participants commented that they consider that planners and designers do not listen to what disabled people have to say, or give serious consideration to their views (Chapter 8). Participant 2f3 commented “...you get someone planning these things; the last person they ask is the person who is going to use the facility”. The design resource developed as part of this study maintains that designers should “**Always** ask the person concerned – **Never** assume you know best” (Disability Wessex 2003, p1), this premise should be integral within the design process to ensure the people who are the experts in the field, have their voices heard. It is this principle that makes the design resource unique and the belief that its utility will be acknowledged as the realisation for the need for inclusive design evolves.

This study has deliberated how any of us can become ‘disabled’ at any time in our lives. Life changes may occur because of old age, temporary illness or the onset of a permanent impairment that cause enduring modifications within our lives. This is something that many people choose not to consider. The researcher concedes that she has always been aware of how unexpected changes in lifestyle have the potential to occur suddenly, due to her personal involvement with disability and also through her employment. Nevertheless, she is also aware that few people consider the possibility of the onset of a permanent impairment and the subsequent life changes. It is only after these life changing events take place, that people say ‘I never thought of disability before’ or ‘I never thought it would happen to me’. One of the issues the researcher has encountered frequently is the inability of many able bodied people to communicate with people with disabilities in a non-condescending manner and it is anticipated that the section in the resource that looks at conversation etiquette will help designers with their communication with disabled end users.

The researcher maintains that disabled peoples views can only be properly established through consultation, but successful consultation by designers can only take place if they have an understanding of individual impairments. It is acknowledged that this contradicts one of the fundamental principles of the social model of disability and rudiments of inclusive living policies (Chapter 10), but if designers do not engage with disabled people regularly or understand how individual impairments can affect communication, then successful participation within the design process with disabled people, may not occur. The resource also outlines the fundamental principles of a variety of disabilities further iterating a constructive foundation for ensuring successful communication.

The resource has also been produced in written format as opposed to an electronic version. Written format documents can be taken anywhere, at any time, and the user would not be restricted by the constraint of requiring a computer to locate the information required. The production of an electronic version is discussed in section 13.5.

13.4.4 Methods Which Facilitate Participation should be Used Within an Inclusive Design Process to Gain Information from End Users

The final research question asked in section 2.1 is – ‘If traditional design methodology draws upon approaches which involve end users, would the resulting procedure enable designers to advocate an inclusive paradigm, where the emphasis is on utilising the knowledge of the ‘experts in the field’, the end users themselves?’

The diversity of the disciplines of design and social science has been discussed, nevertheless, it has been the aim of the study to demonstrate that social research methods can be beneficial to designers when obtaining information from end users, ‘the experts in the field’. This study, and the design resource developed to be used in conjunction with the PACE model of inclusive design; recommend the use of focus groups to ascertain information from end users. There are several advantages to this type of methodology. One is that the designer, as interviewer, has the unique ability to interact with the end user of their product or service. This enables instant further inquiry and the establishment of accuracy and clarification of comments and gestures made by the participants. The flexibility allowed facilitates exploration of issues raised and

questions can be modified, or added, to develop unexpected responses. Furthermore, face-to-face interaction with end users will assist designers in understanding individual needs and the multifaceted requirements of life in a wheelchair.

Another advantage of focus groups is that group members can react to the comments and responses of other group members which is an advantage not found in other design methodologies. This unique group interaction often leads to the establishment of new and innovative concepts that would not have typically transpired. Also, being part of a group of 'like minded' peers can create a feeling of security for participants who may speak more openly and honestly if they feel they are 'not alone' in their views. This honest, open and varied discussion can lead to the detection of data that may not have been discovered through a one-to-one situation.

This study contends that an inclusive process should be used within the design course to 'open up' channels of communication not usually available within standard design methodology. The advantage of participation within the design process means that the end user is instrumental in the conception and creation of the product / service that they will ultimately be the user of. Consultation within the design process through a user inclusive methodology ensures that the views of disabled people, the experts in the field, are instrumental in the development of the final concept.

13.4.5 Designers Influence on Changing Societal Attitudes

A further contribution to knowledge that has surfaced during the duration of the research project is that:

Designers have the potential to influence and to help change attitudes through their work; therefore designers can be instrumental in the quest for inclusion that disabled people desire.

Designers are trained to complete the design process and produce a product which is functional, marketable and profitable. However, it is also a designer's 'privilege' to produce a product that shows their prowess and draw attention to themselves. An example of this might be a building that is constructed with several steps needed to gain access. Rather than the steps having been employed to raise the building above ground level because of the water table levels, it is more likely that the building has been raised to draw attention to it, and consequently, its designer. If this hypothesis is to be

assumed, then designers are in a position to influence the public they design for, and therefore, ultimately have the potential to influence attitudes through their work. This is not to suggest that designers should embark on a ‘moralistic crusade’ to ‘right the world’. However, if designers adhere to inclusive design principles and include the people they design for in the design process (particularly disabled people), then the resulting ‘user friendly’ product / service developed, and the interaction between designer and user, may encourage other people to consider the inclusivity and equality of all. This has the potential to result in changed policies and practices.

13.4.6 Emergent Contribution to Knowledge

The contribution to knowledge that is not linked to an original research question, but which developed during the course of the study, is the necessity for a code of ethics for designers to adhere to when engaging with end users.

As discussed in chapter 7, an investigation within the social world demands an ethical framework or ethical code to minimise the impact of the research process on both the participants and the researcher. The disciplines of health and social care have established ethical codes and frameworks, but design ethics, which relate more to business ethics, do not currently consider engagement with participants throughout the design course, and therefore, no code or framework to promote good practice has been developed. Whilst Goodman *et al.* (2005) acknowledge that there are general ethical guidelines for user research in areas such as psychology and HCI (Human Computer Interaction) they conclude, as the researcher purports, that more specific guidelines need to be developed. The Usability Professionals’ Association (UPA) is an association that brings together advocates from design, technology and research communities who strive for usability and user experience. UPA developed a Code of Professional Conduct that was adopted in September 2005, which is the only form of ethical code, found during research for this study that relates to design. (A recent systematic literature search, in January 2006, established no specific information about designers and ethical standards when working with end users). The UPA Code of Professional Conduct is comprised of seven ethical principles which provide a basis for professional responsibilities and basic tenets of ethical and professional conduct. However, it lacks substance, is open to interpretation, it is only relevant to members of UPA (2005) and is not specific about designers’ responsibilities to participants in research or end users within the design

process. Nevertheless, this recent development demonstrates that members of the design fraternity are acknowledging that designers, as professionals in health and social care, should become morally bound to consider ethical values.

As Butler (2000) contends, codes of ethics (however shaky), need to be contextualised and situated. They need to articulate the occupational / professional, ideological and moral aspirations of the people who create them and who will use them. Butler (2000) further argues that research undertaken by individuals or groups with no particular disciplinary or occupational affiliation could be called social work research, therefore, could necessitate the use of the ethical framework for social work. However, design is a professional discipline, and, as social work theorists have developed a code of ethics, it is the contention of this study that design professionals should develop a framework that is specific to the needs of the design profession.

13.5 Recommendations for Further Research

There are several suggestions for how the research could be developed.

13.5.1 Testing of the PACE Model and the Resource

The PACE model and the resource could be tested by being used by a final year design student completing a project for disabled people. This concept was considered during the duration of this research but it proved to be unfeasible due to time constraints of the researcher and the availability of a final year student completing a project about disability.

13.5.2 Extension of the PACE Model

Fig 6 shows an extended PACE model, but it is conceivable that the model could be extended further using the principles developed by Pugh (1991) and incorporating end user participation throughout the design process.

13.5.3 Further Validation

The resource could be further validated by recruiting more participants to consider its contents and to complete the evaluation questionnaire. This was contemplated during this study, but time and financial resources prevented it from occurring.

13.5.4 Cost of the Resource

A detailed costing analysis could be completed.

13.5.5 Development of the Resource

As previously discussed the resource has been developed in a printed format. However, its contents have the potential to be included in an electronic format and be linked to web pages.

13.5.6 The Creation of a Code of Ethics for Designers for use when Engaging With End Users

As previously discussed in section 13.4.6, there are currently no codes of ethics or ethical frameworks for designers to adhere to when completing research or design projects with end users or disabled people. Whilst it is acknowledged that the development of a code or framework of ethics for designers is not a task to be undertaken during this project, it is recognised that further research and work in this area is investigated.

13.6 Dissemination

The findings of this study were presented to an audience of approximately sixty international delegates at the 5th Qualitative Research Conference in Health and Social Care held at Bournemouth University (See Appendix 8). The abstract stated

Popular constructions of disability have established a relatively powerless and deviant status for the disabled population compared to their able bodied peers. Regulatory controls and legislation require that builders and designers are sensitised to the needs of disabled people, but even with the advent of the Disability Discrimination Act (1995), there is no legislative process to endorse the disabled communities request for a fully inclusive and accessible lifestyle.

In the field of design research social and participatory paradigms are new concepts and the power balance between researcher / researched relationships is still weighed in the favour of the researcher. It is this relationship that this paper addresses. Traditional design methodology is combined with social science research methods to advocate an inclusive design paradigm, where the emphasis is on utilising the knowledge of the ‘experts in the field’, disabled people themselves, throughout the whole design process.

(Adams 2004)

In October 2005 the author presented some of the findings of the study at two Disability Seminars which were held in Bournemouth. The seminars were held for businesses within the local conurbation, and in excess of a hundred local organisations, which make up a Local Partnership Forum, were invited to attend. The author's presentation was regarding the importance of consultation with disabled people and the concept that the experts in the field of disability are disabled people themselves (Adams 2005).

At the time of writing the author is drafting two articles based around findings from this present study for submission to Disability Now and for The Access Journal. The article for Disability Now is based on the Social Model of Disability and its impact on disabled people in the twenty first century where access to local services is concerned. While the article proposed for The Access Journal discusses the utilisation of access groups during the design / planning processes.

A further article is being drafted for submission to The Access Journal and Disability and Society, outlining the differences between social research and design research methodologies. The author maintains that an integration of the two very different methods would afford an inclusive design strategy that would be beneficial, not only to disabled end users, but to designers as well.

As a consequence of this study, the author has been involved in the development of a research proposal submitted to the Joseph Rowntree Foundation in collaboration with Professor Rob Imrie - Royal Holloway University of London and access groups from Carlisle, Waltham Forest and Bournemouth. The project is titled 'Disability and Mobility in the Built Environment', and if successfully funded will enable the researcher to further explore transport issues raised in this study, which combined with a research project being completed at a local level, will lead to further dissemination opportunities. It is further anticipated that during the latter part of 2005 the author will be involved with the submission of a proposal based around Disability, Mobility and the Built Environment to the Economic and Social Research Council (ESRC).

13.7 Conclusion

The research question has changed since the project began in 1996, where the original proposal was to establish the views of wheelchair users, carers and planners and to

develop a questionnaire to ascertain peoples' views about accessibility. The change in the direction of the study is discussed in chapter one and the researcher considers that the final outcome of this enquiry is more beneficial than the original proposal. It is contended that if designers include end users in every stage of the design process, the products and services created will be of greater benefit for those they were designed for.

The limitations of the project are outlined in section 12.5. As a consequence of the necessity for the researcher to work part time while completing the study, the research was occasionally 'hampered' in its progression and avenues that may have been beneficial to the project were not pursued due to financial constraints. However, it is deemed that the PACE model and associated design resource have the potential to be used by development professionals to complete successful designs for people with disabilities. The researcher considers that inclusive design is not detrimental to anyone, and its principles should be adhered to by designers as a matter of course. This study shows that design reflects culture, and the eradication of disabled peoples' inaccessibility and inequality within society can, and should, be influenced by designers, the products they produce and the processes they use.

A further limitation the researcher experienced was her naivety surrounding philosophical perspectives and methodologies in social science research. Section 12.5 discusses the diversities between design and social science research and how the divergences amid the two fields were nothing less than a 'culture shock'. It is the anomaly between the two disciplines that this research has attempted to bridge.

By utilising inclusive design principles designers will assist a larger sector of the population than they have done previously, consequently affecting more peoples' lives, and therefore in due course, increasing profitability. PACE and its associated resource offers new strategies for designers who work with, and for, people with disabilities. The discussion has shown that ultimately designers can be instrumental in the changes to the accessibility and equality to which disabled people aspire.

CHAPTER FOURTEEN – THE LAST WORD

My PhD journey has been fortuitous, enlightening and disappointing. It has been fortuitous because my work life has validated many of the issues raised within the thesis that could not have been completed ordinarily in the timescales allowed for a part time study. Enlightening, because of the knowledge I have gained and the people I have had the privilege of meeting and working with and disappointing because in the last decade I have seen limited improvement in the discrimination experienced by disabled people.

It was difficult to know how to summarise a research project that spanned three diverse topics, but the final quote at the end of this chapter from the Dalai Lama (1998) embraces the issues raised by all three succinctly.

I believe that my views of the design process have changed very little as I have always alleged that *'form should follow function'* and that while I understand aesthetics are significant, a functional product, to me, is more important. That is why one of my Professors at undergraduate level told me "...you'll never make it as a designer, you should teach it instead" (Personal Communication, 1996). Discovering inclusive design methods reaffirmed my belief that designers should consult the end user for their input during the design process. While inclusive design principles incorporate design for all, I truly believe that its methods can specifically help the disabled community with their quest for inclusion. Ken Livingstone has incorporated it within his Supplementary Planning Guidance for London to ensure that the capital is made more accessible to disabled people. The Royal College of Art incorporates an inclusive design research unit and has held two inclusive design conferences in 2001 and 2003, with the next one planned for April 2005. Local access officers are starting to promote the use of inclusive design methods in an attempt to ensure design for all and the DRC is endorsing its evolving philosophies to create an environment that can be used by a diverse variety of users.

Whilst I acknowledge that the concept of inclusive design is growing, I also consider that designers should embrace social science methodologies to facilitate the inclusion of end users within the design process. Social science and design may initially appear to be at opposite ends of a spectrum, but, both disciplines have outcomes that involve people.

If designers could accept that they are not necessarily the expert in every aspect of the product or service they are designing and that utilising the expertise of the end user is not derogatory to their design prowess, then they could receive notoriety as a designer for people. That is not to say that the end user is an expert in all aspects of the product or service being designed either. There has to be a '*happy medium*' where both parties can work together to develop a result that is usable, effective, marketable and required.

After eight years of research I firmly believe that the two disciplines of design and social science can be entwined to produce an inclusive design methodology that will help disabled people gain an accessible environment. However, no matter how stridently designers and development professionals' support, develop and employ inclusive design methods and ultimately construct accessible environments, disabled people will not achieve an equitable lifestyle as their able-bodied peers until society's attitudes towards disability change. Even in the twenty first century society in this country still views disabled people with pity and disdain.

The biggest problem that we, the disabled have is that you, the able-bodied, are only comfortable when you see us as icons of pity

(Morris 1991 p.192)

Morris concludes:

Our disability frightens people. They don't want to think that this is something which could happen to them. So we become separated from common humanity, treated as fundamentally different and alien. Having put up clear barriers between us and them, non-disabled people further hide their fear and discomfort by turning us into objects of pity, comforting themselves by their own kindness and generosity

(Morris 1991 p.192)

If Morris's (1991) assertion is correct, and I believe that it is, then society has a long way to go before disabled people attain the equitable and accessible standard of living they desire. Attitudinal changes may take generations before disability is accepted and disabled people are truly integrated into mainstream society. However, I believe equitability is attainable, but the changes needed cannot be dictated by legislative processes alone. Re-education and greater understanding of the diversity of people's lives is the key to removing the discrimination and oppression disabled people encounter, and that process will take time.

...I always believe we are the same; we are all human beings. Of course, there may be differences in cultural background or way of life, there may be

differences in our faith, or we may be of a different colour, but we are human beings, consisting of the human body and the human mind. Our physical structure is the same, and our mind, and our emotional nature are the same. Wherever I meet people, I always have the feeling that I am encountering another human being, just like myself. I find it is much easier to communicate with others on that level. If we emphasise specific characteristics, like I am Tibetan or I am Buddhist, then there are differences. But those things are secondary. If we can leave the differences aside, I think we can easily communicate, exchange ideas and share experiences.

(Dalai Lama 1998, p.xi)

APPENDIX 1 – LETTER FROM THE WHEELCHAIR CLINIC

South and East Dorset **NHS**
Primary Care Trust

St Leonards Community Hospital
Nr. Ringwood
Hampshire
BH24 2RR

Tel: 01202 584200
Fax: 01202 895945

14 November 2001

Miss Stephanie Adams

Dear Miss Adams

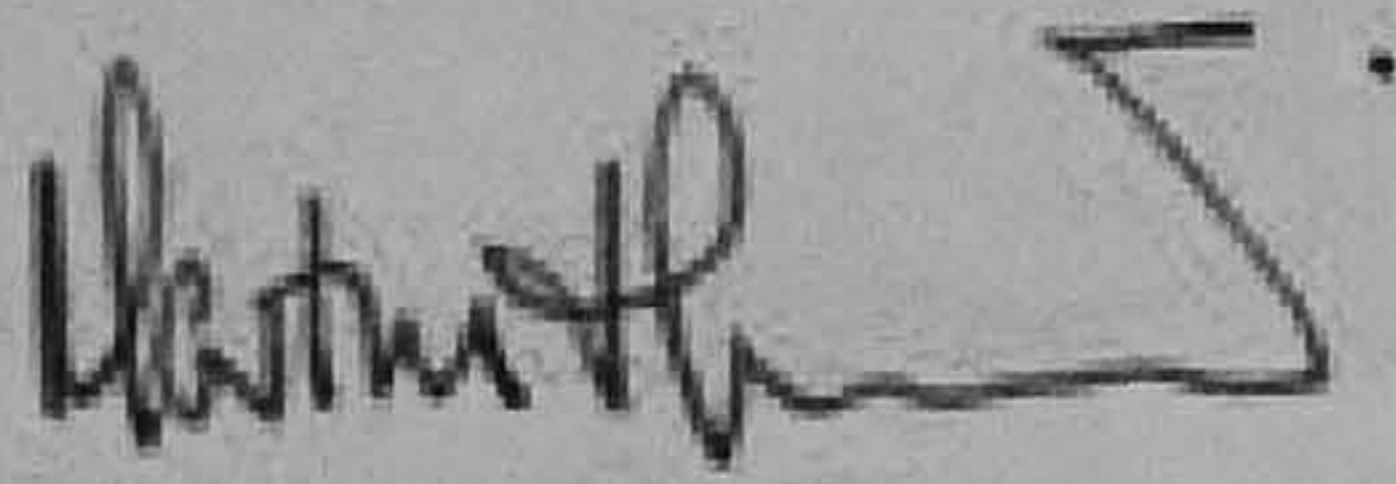
East Dorset Wheelchair Service

Thank you for your letter of 13 November.

I am unable to give you specific details of the number of patients who have been provided with wheelchairs in the Poole and Bournemouth local authority areas. However, for the overall area for which we are responsible, which covers the local authority areas of Bournemouth, Christchurch, East Dorset, Poole and Purbeck, there are currently 11,244 patients registered with us, all of whom are supplied with some type of wheelchair by this Service.

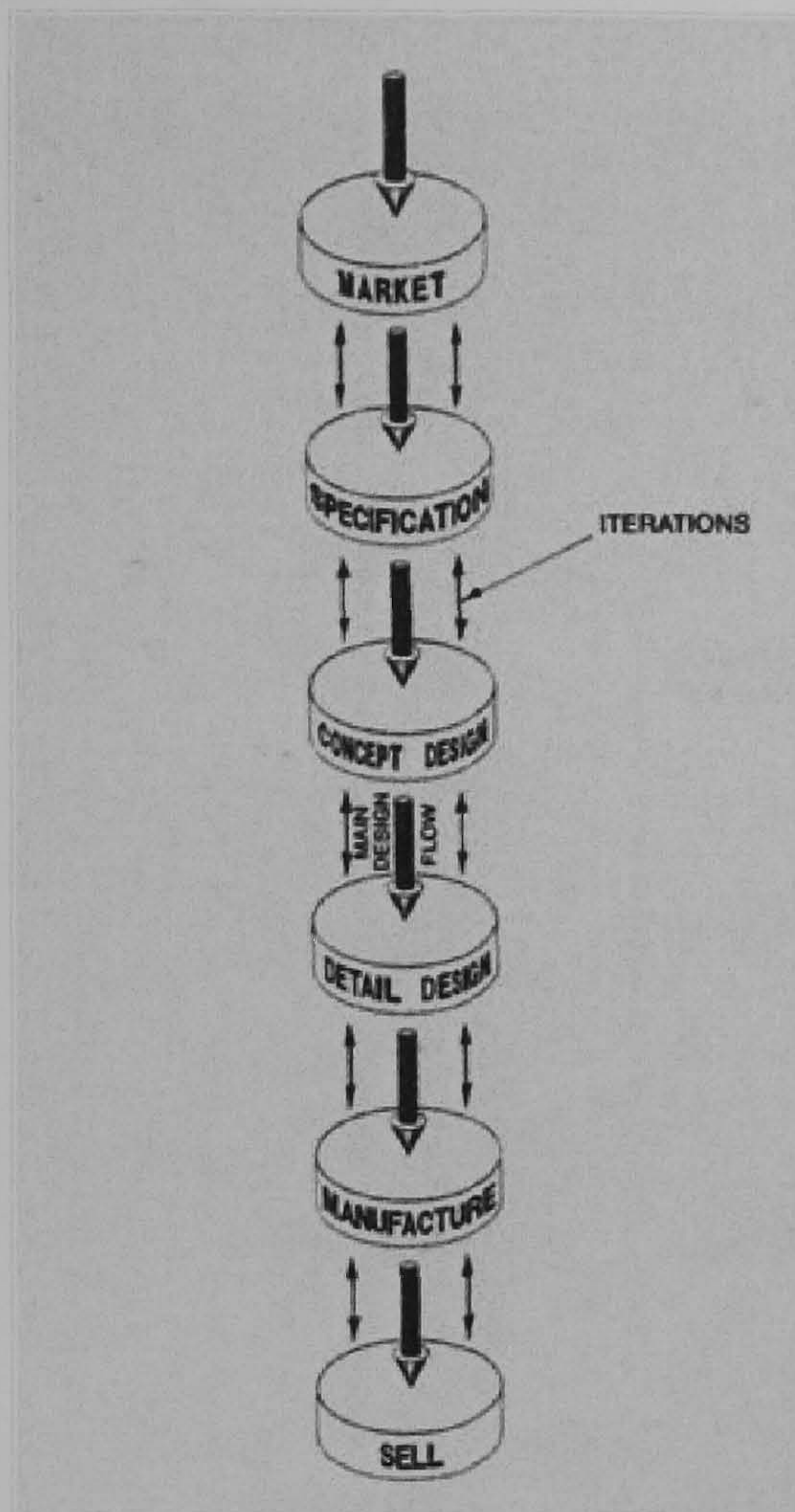
I hope this information will be helpful, and wish you every success with your project.

Yours sincerely

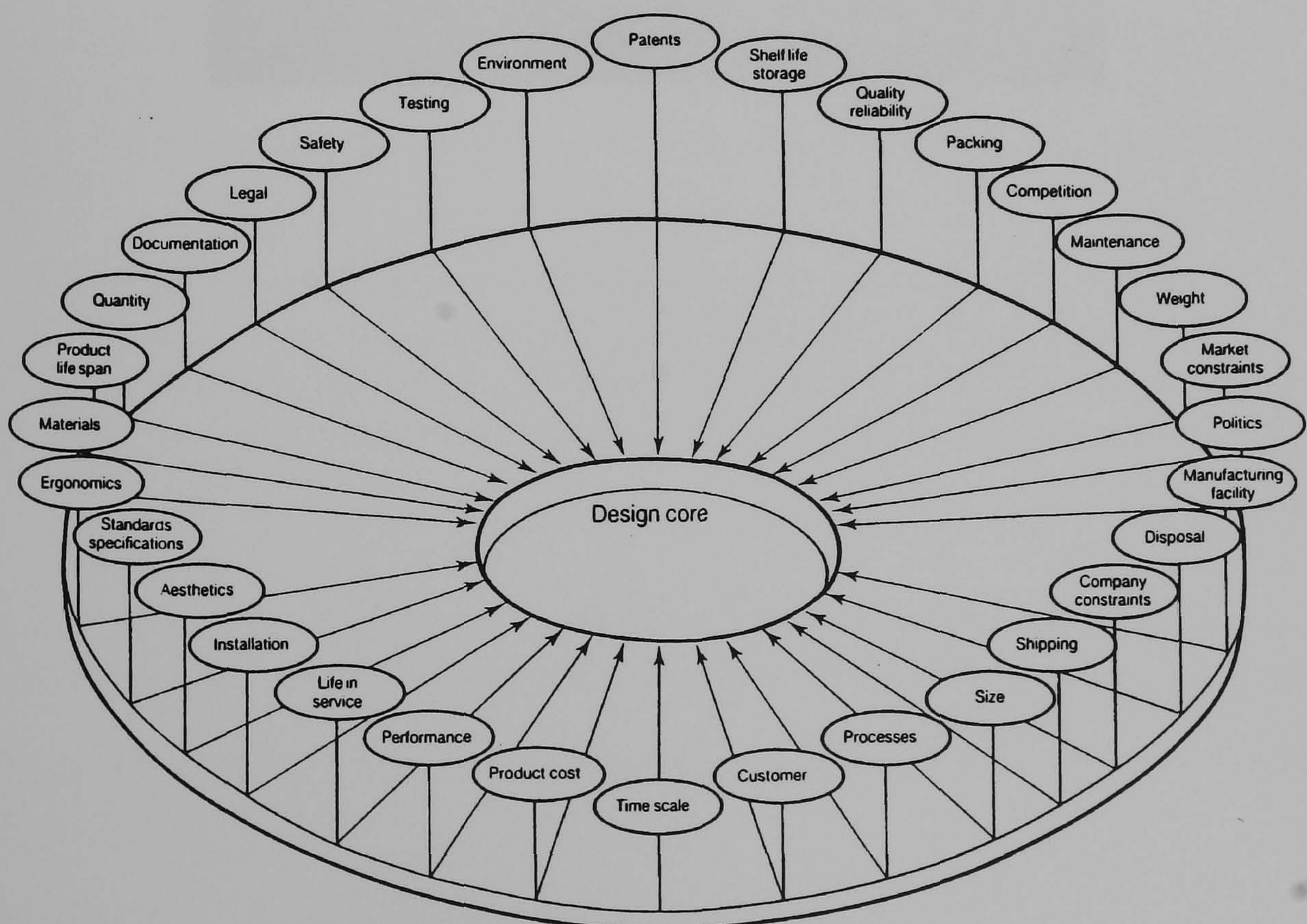


Martin Howlett
Disability Services Manager

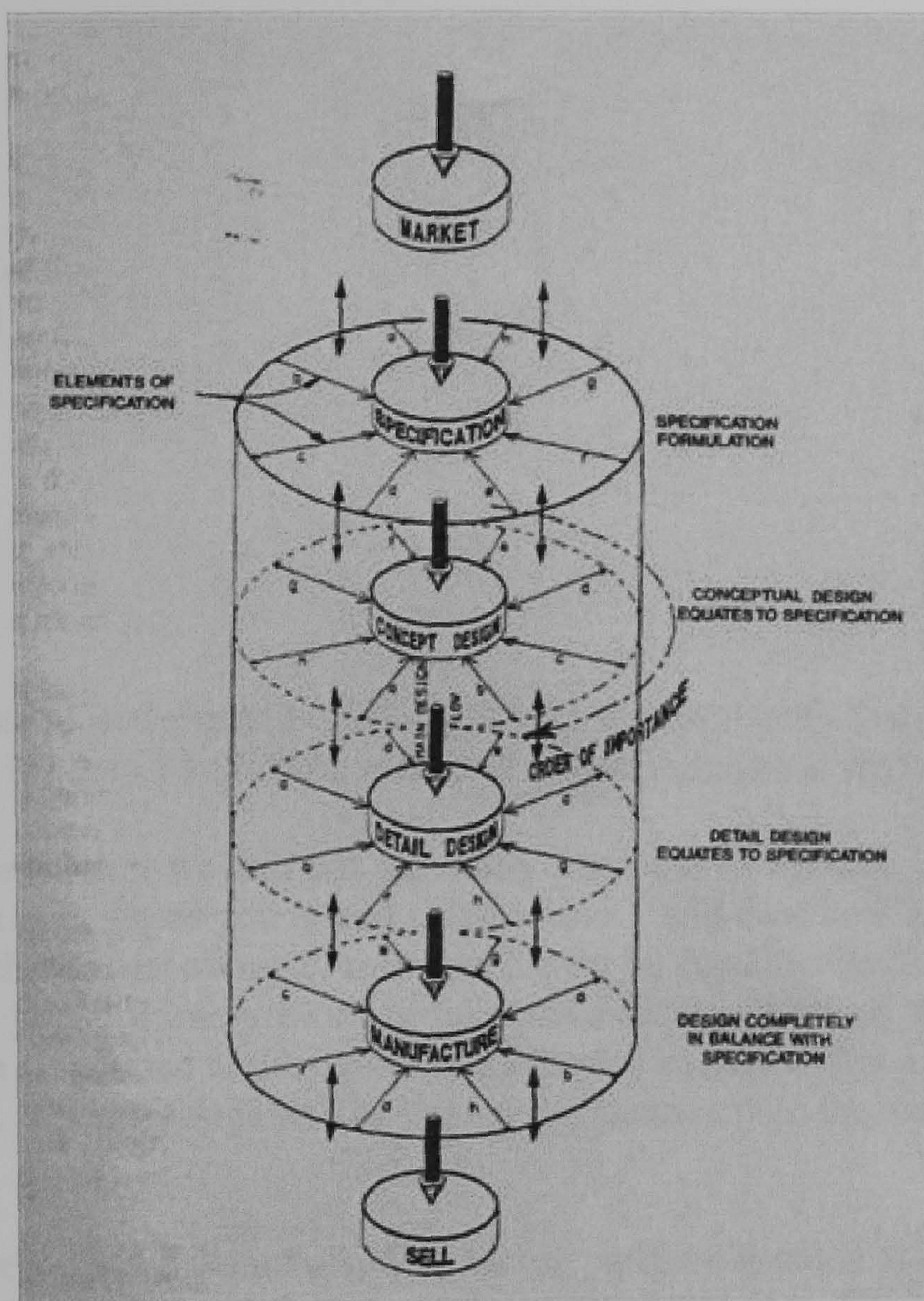
APPENDIX 2a – PUGH’S DESIGN CORE (Pugh 1991)



APPENDIX 2b - PUGH’S PLATES (Pugh 1991)



APPENDIX 2c – THE DESIGN CORE ENVELOPED BY THE PRODUCT DESIGN SPECIFICATION (Pugh 1991)



APPENDIX 3 – CONSENT FORMS FOR PARTICIPANTS

S K Adams (C/o D. Eels)
IHCS
First Floor
Royal London House
Old Christchurch Road
BH12 3NA

Fourways Day Centre
Constitution Hill
Poole
Dorset

3rd June, 1999

Dear

I am writing to ask if you would be willing to take part in a study that is the basis for my Ph.D. The study is about wheelchair users and access in the built environment in Dorset.

During a group interview we will talk generally for about 45 minutes about access issues within the area where you attend a day centre. I will then hold further individual interviews, which will last about 20 minutes. It may be possible that I will ask you if I can re-interview you. All interviews will take place during 1999 and the early part of 2000 and will be conducted at the day centre attended by you and at a mutually convenient time. The meetings will be held at day centres with the managers permission.

There are no foreseeable risks involved by taking part in this study and it is purely voluntary. Participants can withdraw from the study at any time should they wish to, and are under no obligation to explain why they have ceased to take part in further discussions.

Individual identities will be kept confidential by allocating each client with a number/letter and the address allocated to each client will be the day centre they attend. It will be necessary for me to tape the interviews and all tapes will be destroyed at the end of the study. Clients may have a copy of the transcript of the interviews should they request one.

If you are willing to take part in the study please sign and return the enclosed consent form to the manager of the day centre or the instructor assigned to assist with the study.

Thank you for your time, and I look forward to having the opportunity to discuss this project with you.

Yours sincerely

Stephanie Adams
Research Student

.....
.....

I have read this letter and consent to participate / I have read this letter and do not wish to participate.
(Delete as appropriate)

Signature:

Date:

S K Adams (C/o D. Eels)
IHCS
First Floor
Royal London House
Old Christchurch Road
BH12 3NA

Boscombe Centre
2A Owls Road
Boscombe
Bournemouth
Dorset

30th June, 1999

Dear

I am writing to ask if you would be willing to take part in a study that is the basis for my Ph.D. The study is about wheelchair users and access in the built environment in Dorset.

During a group interview we will talk generally for about 45 minutes about access issues within the area where you attend a day centre. I will then hold further individual interviews, which will last about 20 minutes. It may be possible that I will ask you if I can re-interview you. All interviews will take place during 1999 and the early part of 2000 and will be conducted at the day centre attended by you and at a mutually convenient time. The meetings will be held at day centres with the managers permission.

There are no foreseeable risks involved by taking part in this study and it is purely voluntary. Participants can withdraw from the study at any time should they wish to, and are under no obligation to explain why they have ceased to take part in further discussions.

Individual identities will be kept confidential by allocating each client with a number/letter and the address allocated to each client will be the day centre they attend. It will be necessary for me to tape the interviews and all tapes will be destroyed at the end of the study. Clients may have a copy of the transcript of the interviews should they request one.

If you are willing to take part in the study please sign and return the enclosed consent form to the manager of the day centre or the instructor assigned to assist with the study.

Thank you for your time, and I look forward to having the opportunity to discuss this project with you.

Yours sincerely

Stephanie Adams

Research Student

.....
.....

I have read this letter and consent to participate / I have read this letter and do not wish to participate.
(Delete as appropriate)

Signature:

Date:

APPENDIX 4 – INTERVIEW GUIDE

Questions for first interviews at Fourways

Transport

Buses Do you use public transport buses at all and if you do how do you find them?
The problem from the group chat we had seemed to indicate that it was as much the drivers being inconsiderate as anything else – would you agree?
Do you think it would help if they were ‘re-educated’?

People carriers used for transporting outside of Fourways

Ignoring the uncomfortable journey due to bus design, would you say that again re-education of the drivers would help?

Taxis How would you like to see the service provided by taxis improved?
If this means a huge van, do you think this would effect the ‘stigma’ of disability?

While on the subject of stigma - Terminology

Do you prefer to be termed disabled or handicapped? (Mention WHO definition)
How much do you think your opinions about disability and how disabled people have changed since becoming disabled?

Civic Centre

How often do you use the civic centre? Housing benefit, benefits, council tax, meetings
Ramps
Lifts – have you been in the lift, is the button behind you? Is this the case in all lifts?
Toilets?

Toilets

Do you have a radar key?
Do you know where all the disabled toilets are in Poole?
1. Bus station
2. Quay
3. By Smiths
4. Opp. Jessops
5. By indoor market
6. On way to quay (top of high street)
7. Poole Park (2X?)
Rails, sinks, towels, loo rolls, lighting, big enough, doors, hygiene

Cafes / Pubs

Good ones? Bad ones?
Improvements?
General attitude of staff?

Cinema / Theatre

Any comments

Shops

Good ones

Bad ones (Supermarkets in particular)

Improvements

What % of shops can not be accessed?

Do you think the DDA will help in October?

How do you find the staff on the whole?

Railway Lines

How big a nightmare are they?

Can you suggest how to improve them?

Kerbs

Are there any good kerbs I can look at?

Do you find the tactile crossings a 'pain'?

Are the drop kerbs narrower on corners? Are drain grills ever a problem?

Your favourite subject – Planners

What are your views on planners?

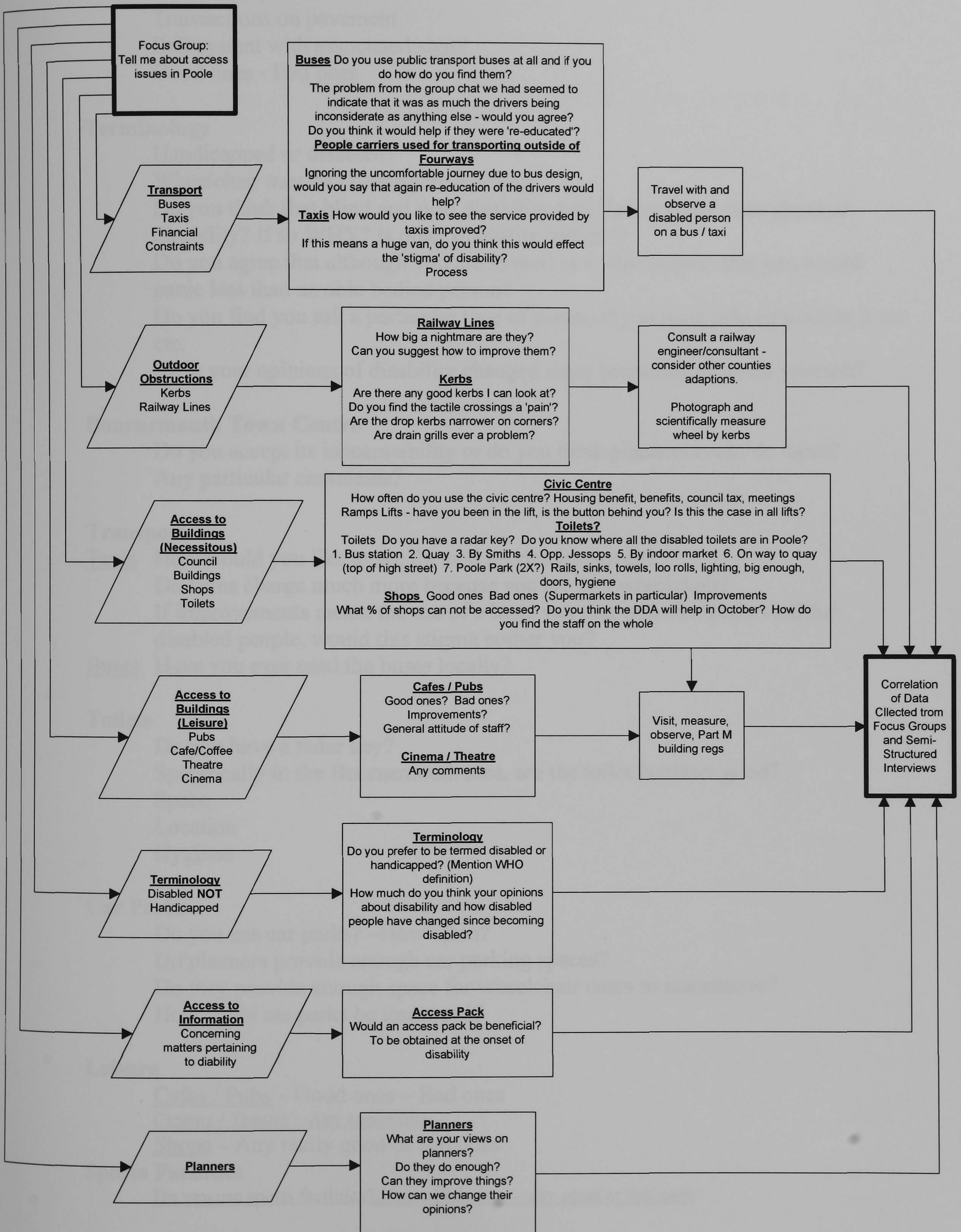
Do they do enough?

Can they improve things?

How can we change their opinions?

Is the whole thing really a case of re-educating people or educating them in the first place to disability?

ISSUES RAISED BY THE POOLE FOCUS GROUP



Questions for first interviews at Owls Road

Banks / Building Societies

Doors heavy
Transactions on pavement
Bell system with associated sign?
Good ones - Bad ones

Terminology

Handicapped or disabled?
Wheelchair user NOT wheelchair bound?
Do you think that blind and deaf disability gets 'better press' than physical disability? If so WHY? Is other disability 'tidier' ?
Do you agree that although you are termed as a 'fire hazard' that you would panic less than an able bodied person?
Do you find you ask a particular type of person if you need help eg parking a car etc.
Have your opinions of disability changed since becoming disabled yourself?

Bournemouth Town Centre

Do you accept its inaccessibility or do you think planners could do more?
Any particular comments?

Transport

Taxis How would you like to see the taxi service improved?
Do firms charge much more because you are in a wheelchair?
If improvements meant the use of a huge van that was obviously used for disabled people, would this stigma bother you?

Buses Have you ever used the buses locally?

Toilets

Do you have a radar key?
Specifically in the Bournemouth area, are the toilet facilities good?
Space
Location
Hygiene

Car Parks

Do you use car parks? –How often?
Do planners provide enough car parking spaces?
Do they provide enough space for wheelchair users to manoeuvre?
How could car parks be improved?

Leisure

Cafes / Pubs – Good ones – Bad ones
Cinema / Theatre – Any comments
Shops – Any really good or bad ones

Sports Facilities

Do you use sports facilities? If so which ones – any good or bad ones

Planners

Your favourite subject

What are your views on planners?

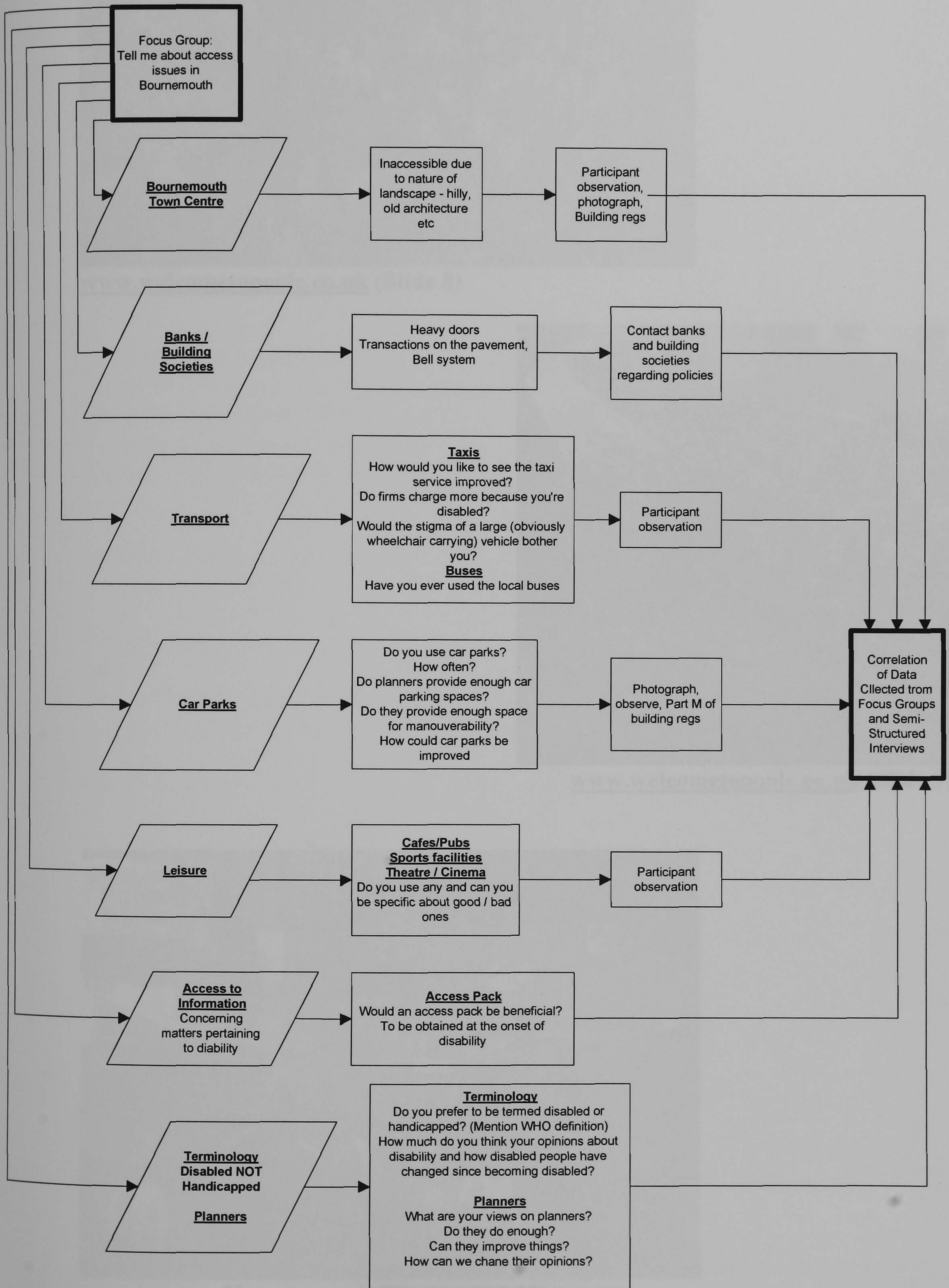
Do they do enough?

Can they improve things?

How can we change their opinions?

Is the whole thing really a case of re-educating people or educating them in the first place to disability?

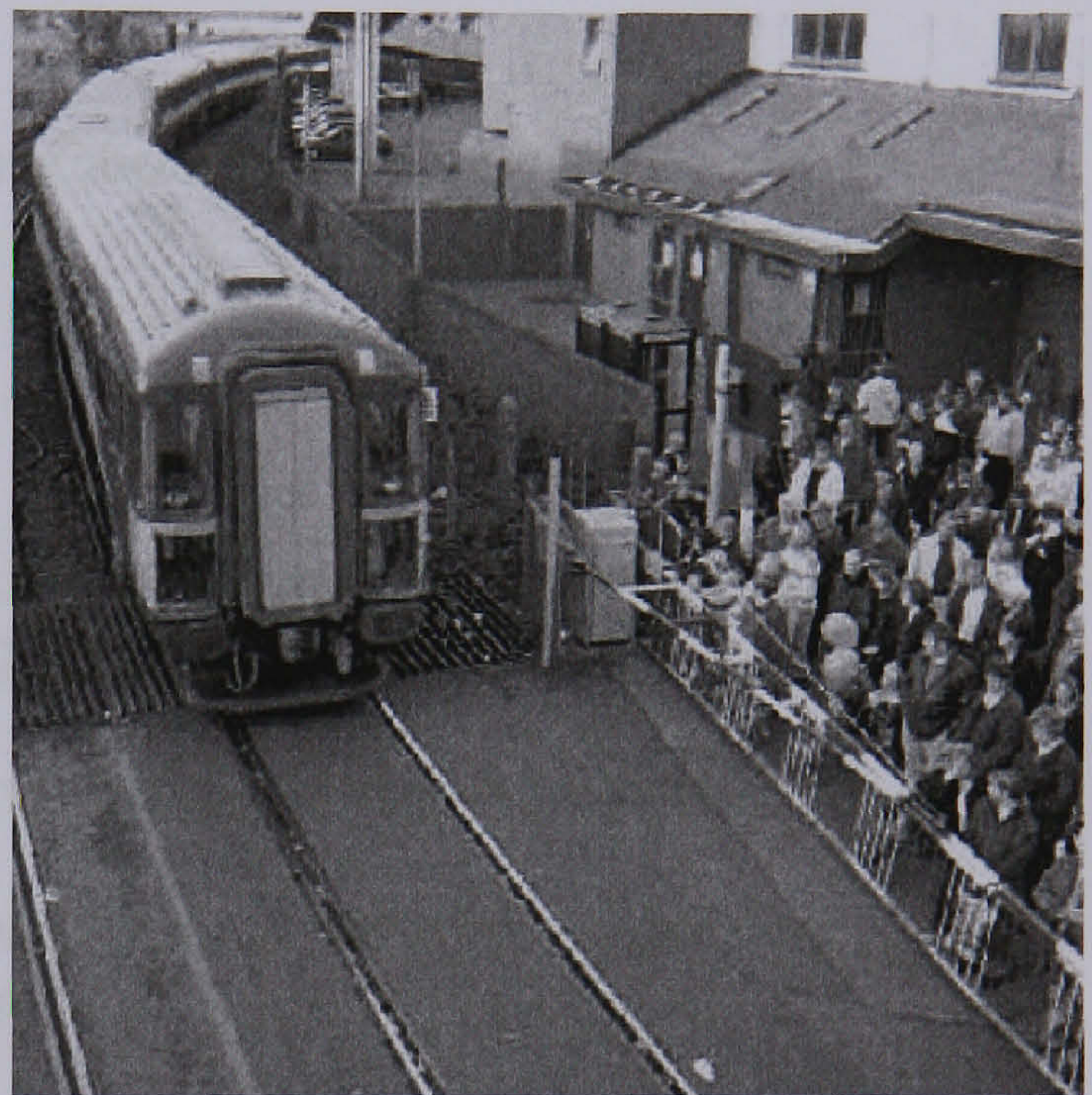
ISSUES RAISED BY THE BOURNEMOUTH FOCUS GROUP



APPENDIX 5 - IMAGES OF POOLE HIGH STREET



www.welcometopoole.co.uk (Slide 8)



www.welcometopoole.co.uk (Slide 9)



www.imagesofdorset.org.uk (Picture 023-12)

APPENDIX 5b – PHOTOGRAPHERS CONSENT TO USE IMAGES OF POOLE HIGH STREET

OK, now I see!

Yes, you can use the photos in your thesis.

Regards,

David Anderson

=====

Broadstone Net - <http://www.broadstone.net>

Bulletin Board - <http://www.broadstone.net/cgi-bin/yabb/YaBB.cgi>

Welcome to Poole - <http://www.welcometopoole.co.uk>

-----Original Message-----

From: Stephanie Adams [mailto:SAdams@bournemouth.ac.uk]

Sent: 15 June 2004 12:33

To: David Anderson

Subject: RE: Photographs

Hi David, sorry, I also contacted John Allen and have put the wrong URL in the message I sent to you! Many apologies.

The photographs I am describing are on the www.welcometopoole.co.uk site and are number 8 - people crossing the railway lines in the High Street and number 9 a train crossing the High Street.

Steph Adams

From: David Anderson [mailto:dta@nildram.co.uk]

Sent: Mon 14/06/2004 18:35

To: Stephanie Adams

Subject: RE: Photographs

Hi there Stephanie,

You've got me a bit confused! In the links below you have one of my sites www.welcometopoole.co.uk and Images of Dorset by John Allen www.imagesofdorset.org.uk.

So I'm not really sure which photo you are referring to! Could you please check again and send me the URL? It sounds like it might be Images of

Dorset, but John has over 1,200 photos on his site!

Regards,

David Anderson

=====
Broadstone Net - <http://www.broadstone.net>
Bulletin Board - <http://www.broadstone.net/cgi-bin/yabb/YaBB.cgi>
Welcome to Poole - <http://www.welcometopoole.co.uk>

-----Original Message-----

From: Stephanie Adams [mailto:SAdams@bournemouth.ac.uk]
Sent: 14 June 2004 07:41
To: dta@globalnet.co.uk
Subject: Photographs

Dear Mr. Anderson, I am a doctoral student at Bournemouth University and am in the last few weeks of completing a research project that has examined wheelchair access within the built environment around Poole and Bournemouth. Several of the participants of the study commented on the problems they encountered when accessing Poole High Street. During an internet search to look for photographs of the railway crossing in Poole High Street I came across two photographs of yours at www.welcometopoole.co.uk <<http://www.imagesofdorset.org.uk/Dorset023/12.htm>>

I was wondering if you would allow me to use copies of two of the photographs, number 8 - level crossing and number 9 - train crossing the high street in the appendix of my thesis as they show not only the level crossing, but also the amount of people who use the crossing on a regular basis.

I look forward to hearing from you.

Stephanie Adams

Hi Stephanie,

You are most welcome to use the picture in your thesis, there is no charge for this usage.

Hope you manage to complete and submit the thesis (both I and my partner have gone through the same pain, so know only too well how much of a slog it can be!)

All the best,

John Allen

Images of Dorset
43 Fairfield Rd
Wimborne
Dorset
BH21 2AJ

Tel: 01202 889 761
Email: j.allen@imagesofdorset.org.uk
<<mailto:j.allen@imagesofdorset.org.uk>>
Web: <http://www.imagesofdorset.org.uk/>

-----Original Message-----

From: Stephanie Adams [<mailto:SAdams@bournemouth.ac.uk>]
Sent: 14 June 2004 07:40
To: sales@jpallen.co.uk
Subject: Photographs

Dear Mr. Allen, I am a doctoral student at Bournemouth University and am in the last few weeks of completing a research project that has examined wheelchair access within the built environment around Poole and Bournemouth. Several of the participants of the study commented on the problems they encountered when accessing Poole High Street. During an internet search to look for photographs of the railway crossing in Poole High Street I came across a photograph of yours at www.imagesofdorset.org.uk/Dorset023/12.htm <<http://www.imagesofdorset.org.uk/Dorset023/12.htm>>

I was wondering if you would allow me to use a copy of the photograph in the appendix of my thesis as it shows not only the level crossing barriers rising, but the amount of people who use the crossing on a regular basis. I look forward to hearing from you.

Stephanie Adams

APPENDIX 6 – DESIGN RESOURCE

A Design Resource for Inclusive Design

Contents

Page 3 Introduction and User Stories

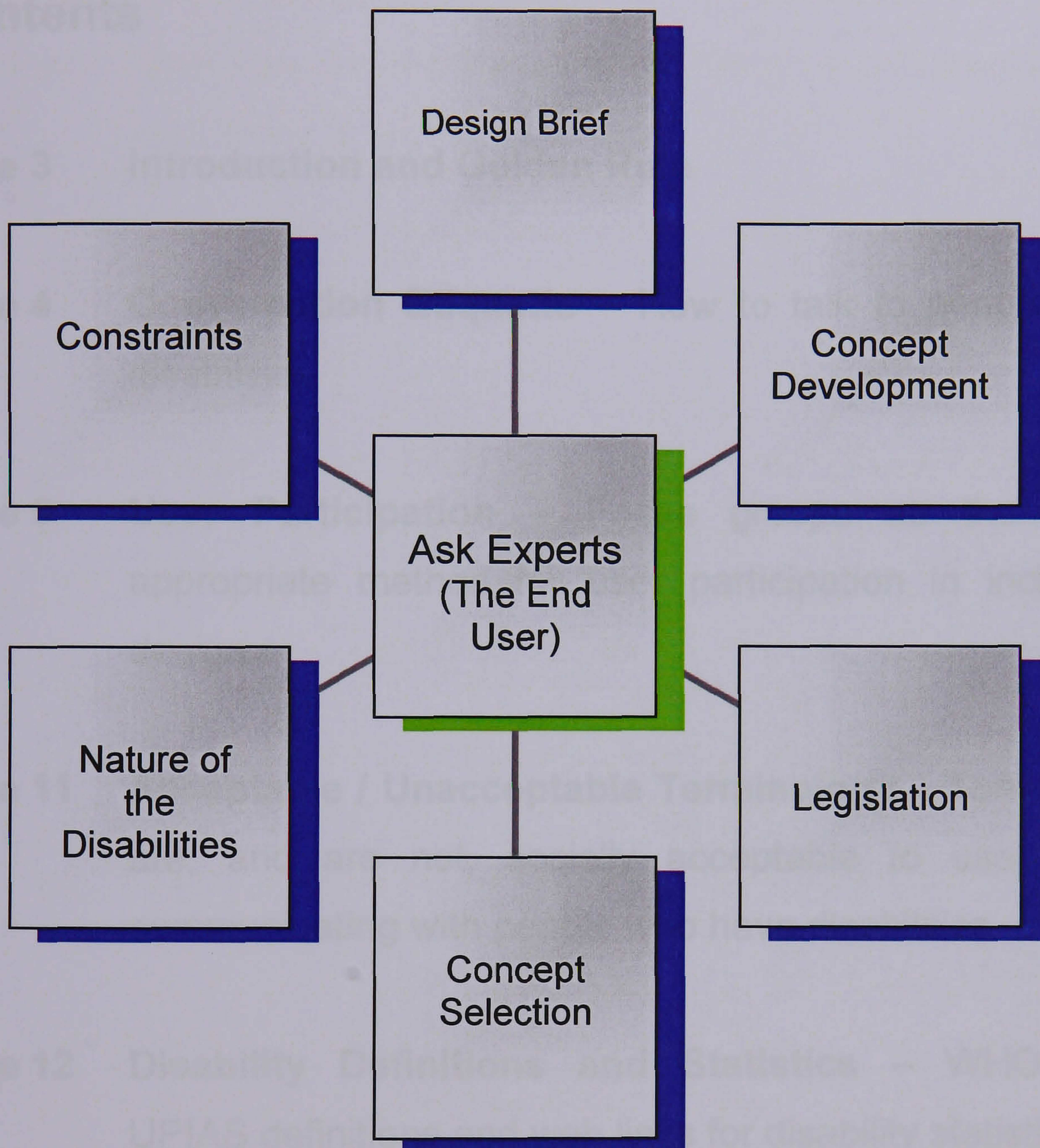
Page 4 Design Process with
appropriate and inappropriate terminology

Page 5 Ask Experts (The End User)

Page 6 Unacceptable Terminology

Page 12 Disability Statistics – WHO and
UPIAS definitions for disability statistics

Page 14 Guidance on Disability Legislation – An overview of
the ODA, Part M of the Building Regulations and
disability legislation web links



A Design Resource for Inclusive Design

Contents

- Page 3** **Introduction and Golden Rule**
- Page 4** **Conversation Etiquette** – How to talk to people with disabilities
- Page 6** **User Participation** – Focus groups as the most appropriate method for user participation in inclusive design
- Page 11** **Acceptable / Unacceptable Terminology** – Terms that are, and are not, socially acceptable to use when communicating with people who have disabilities
- Page 12** **Disability Definitions and Statistics** – WHO and UPIAS definitions and web links for disability statistics
- Page 14** **Guidance on Disability Legislation** – An overview of the DDA, Part M of the Building Regulations and disability legislation web links

Page 17 Ergonomics – Ergonomic web site links and publications

Page 18 Web Links – A selection of web links to sites specific to disability

Page 20 Overview of Medical Terminology – An overview of symptoms of some disabilities

Page 24 Glossary

Introduction

This design resource has been developed for use by designers when designing and developing products or completing alterations for disabled people. It is based around the principals of the social model of disability and inclusive design methodology.

The Golden Rule

Always ask the person concerned – **Never** assume you know best
(Disability Wessex 2003)

Conversation Etiquette

How we are spoken to influences how we feel and behave towards the person we are having a conversation with. Eye contact, body language, tone of voice and use of specific terminology shapes how we react and respond.

When talking to a person with a disability it is important to remember first and foremost that they are an individual human being. They are a person with a disability, as opposed to a disabled person. For example, a person is not 'epileptic', they are 'a person who has epilepsy'. This socially acceptable use of language can often be perplexing, but is important for a designer to be aware of the correct terminology when building a relationship with end user participants. If mutual respect is gained it will help you to collect the information you require, and the end user will feel their contribution has been worthwhile.

When communicating with a person with a disability look and speak directly to that person. Don't be embarrassed if you use accepted common expressions that seem to relate to the person's disability. Example: 'see you later' (to a blind person) or 'got to run now' (to a person in a wheelchair). Just because they have a disability it does not mean they don't have a sense of humour.

- **Person with a carer**

If a person brings a companion / carer with them ensure that you do not converse specifically with that person and ignore the person with

the disability, after all, the person with the disability is the expert in the field. Carers may make a valid contribution to the conversation, but they should express their views not those of their disabled companion.

- **Wheelchair User**

When talking for some time to a person in a wheelchair, sit on a chair. Whenever possible place yourself at the person's eye level and in front of them. This avoids giving them neck ache and assists conversation.

- **Hearing Impaired**

When conversing with a person with a hearing impairment look directly at the person, speak clearly, and keep hands and food away from the mouth when speaking. Make sure that your mouth is in good light and you are not 'back lit', leaving it difficult to see your face. To get their attention gently tap their shoulder or wave your hand. Don't shout it inhibits lip reading and distorts sound accepted through hearing aids. A visual cue can be used to assist conversation.

- **Visually Impaired**

When greeting a person with a visual impairment, introduce yourself and others who may be with you giving details of where people are standing in relation to the person with the visual impairment. Example: On your left is Miss. Smith. If they need guiding allow them to take your arm at the elbow, this will enable you to guide rather than lead. To help facilitate conversation be prepared to offer an audible cue. **Do not shout, they can hear you.**

- **Speech Impairment**

When talking to a person with a speech impediment listen attentively. Encourage rather than correct and exercise patience rather than finishing a sentence for them. Do not pretend to understand and be willing to repeat or rephrase questions. If you are unsure of what has been said repeat their speech so that they can confirm the accuracy. When necessary ask short questions that require a yes or no answer, these can be answered with a nod or shake of the head.

- **Learning Disability**

Take a pen and paper with you to interviews as if all else fails most people will be happy to write or draw the answer. Use 'plain English' rather than confuse participants with long or academic terminology. Confirm what has been said by repeating it back to the participant, this will ensure the information given and received is correct.

User Participation

Focus groups are a qualitative research tool that provides a viable method for obtaining information from end users throughout any design project. They are flexible, easily adaptable, applicable to a wide variety of topic areas and available to all types of people. The strength of focus groups is their ability to bring together a group of individuals who have knowledge about a specific topic or issue. The discussion is guided by an interviewer or moderator who explores verbal and non-verbal responses to questions and comments to discover more about participants' perceptions and views. The group discussion enables a rich gathering of information as participants build on the ideas and responses of others within the group.

Advantages of Focus Groups

- Significant amounts of information can be obtained quickly and efficiently from a large number of people in a relatively short time
- Qualitative methodology that allows in-depth investigation of issues that cannot be measured or quantified (eg. emotional relationships between user and product)
- Ability to gain in-depth knowledge of the topic being discussed
- Researcher and participant interaction increases understanding and awareness
- Flexibility of the focus group process
- Allows open discussion which can lead to new and unconsidered topics
- Applicable for all topic areas

- Provides immediate feedback
- Detailed overview of several opinions
- Verbal and non-verbal communication can be observed by the researcher allowing underlying messages and subconscious notions to be discussed
- Open for use by any social group
- Relatively cheap research methodology compared to others

Limitations of Focus Groups

- Dominant or quiet group members
- Discussion content – interesting topics for the group may not be of use or interest to the researcher
- Quality of the discussion will be influenced the group make-up and may range from lively and revealing, to that of little value to the researcher
- Sample may be difficult to recruit
- Venue (cost, location, transport for participants, time of day)
- Time consuming
- Cost

Planning the Research

Pre-determining the objectives of the focus group is necessary as the content of each session will vary and should be tailored to the research objectives. When setting the focus group objectives the following should be considered:

- The required outcomes of the research
- The most appropriate techniques and methods to be used
- The resources available

- Timescales
- Choice of participants

Recruiting Participants

The research aims will determine the content of the session and the choice of participants. As participants should have reasonable knowledge about the topic to be discussed, they should be chosen from specific user groups (purposive sampling). When planning sessions the following should be considered:

- Number of participants attending each session (traditionally 8 – 10 participants are recommended but 4-6 participants for design research sessions allows more time for individual views)
- How / where to contact participants
- Participants fees (approx £25 - £30 per person per session)
- Length of the session (1-3 hours)
- Time of day (outside of office hours is preferred)
- Location of the session
- Depth / breadth of information required

Focus Group Location

Participants will contribute more to the session if they feel comfortable and valued, so the choice and layout of the room is an important factor when organising focus groups. Attention to detail and the creation of a comfortable environment will make a considerable difference.

Factors to be considered are:

- Ease of access (location, transport, level access)

- Comfort for participants (size of room, lighting, temperature, seating, layout of furniture - tables or seating should be arranged to enable face-to-face contact)
- Facilities (toilets, refreshments - using ceramic mugs instead of paper or plastic ones and providing good quality food will help make participants feel valued)
- Disturbance (telephones, noise from other groups, Tannoy ® announcements, doorbells)
- Ease of setting up equipment
- Accessibility to visual material
- Accessibility of audible material

Session Content

Free-flowing discussion may be appropriate to obtain the information required and the moderator should anticipate the flow of natural conversation allowing one topic to link to another. However, a moderator's guide is a tool that ensures the information required is obtained. This guide is prepared in advance and outlines the content and structure of the session. It should include:

- A list of questions to be asked
- Aids used to encourage discussion
- Preferred duration of discussion time per question

Conducting the Focus Groups

Participants should feel welcome and comfortable when attending focus groups. When participants arrive:

- Receive them courteously

- Register their names / supply name badges (allows familiarisation)
- Show them the way to the room
- Point out facilities
- Offer refreshments
- Allow time for chatting to others and to make themselves comfortable
- Ensure everyone is comfortable

A good introduction will prepare the participants for what is to come and set the tone for the rest of the session.

- Begin by welcoming the participants, thank them for coming and introduce yourself (and any other research staff)
- Point out fire escapes and procedures should there be a need to evacuate the building
- Confirm the facilities available (wc's etc)
- Explain how long the session will last and what you hope to achieve
- Discuss any consent required, audio taping, video taping, photography
- Talk about any relevant confidentiality issues (Data Protection Act 1998, ethical issues - where necessary)
- Re-iterate how important participants views are
- Ensure everyone understands that individual comfort is important, and that if anyone feels uncomfortable at any time, they should let a member of the research team know
- Refreshments are available at designated breaks

The overall structure of the session should be quite flexible allowing discussion about revealing topics to be extended when necessary. However, if the discussion becomes irrelevant to the research objectives, it is the moderator's task to steer the conversation back to the topic being researched.

Focus Groups with Older Participants

Focus groups with older participants require a different design and organisation of their content. Generally the sessions should include:

- More moderator involvement
- A slower pace
- Shorter in length
- Frequent breaks in the flow of discussion
- Shorter questions – use words older people will understand

N.B. This is not meant to be condescending towards older people, it is to highlight that their needs may be slightly different.

Analysis of the Data

It is beneficial if designers are involved in data analysis although it can be a lengthy and complex process. One hour of conversation can take three to four hours to transcribe. When tapes are transcribed, similar comments should be arranged into groups which enable themes and categories of user's needs and requirements to be identified. The process of learning what the participants have really said evolves while the data is being transformed into information and trigger words will often spark creative thinking.

Further Reading

Barrett, J. and Kirk, S., 2000. Running focus groups with elderly and disabled elderly participants. *Applied Ergonomics*, 31, pp. 621-629.

Data Protection Act, 1998,

www.hmso.gov.uk/acts/acts1998/19980029.htm

Kreuger, R.A., 1998. *Moderating focus groups – focus group kit 4*. Thousand Oaks: Sage Publications.

Langford, J. and McDonagh, D. eds, 2003. *Focus Groups – Supporting effective product development*. London: Taylor & Francis.

Morgan, D., 1988. *Focus groups as qualitative research*. London: Sage Publications

Morgan, D., 1993. *Successful focus groups – advancing the state of the art*. London: Sage Publications.

Morgan, D., 1998. *The focus group guidebook – focus group kit 1*. Thousand Oaks: Sage Publications.

Acceptable / Unacceptable Terminology

Acceptable Terms:

Person with a disability

Disabled people

Mr. X has a disability

Disability (as a general term
for limited functionality)

People with (e.g.) spinal cord injury

Contracted (e.g.) multiple sclerosis

(Never identify people solely by their
disability)

Blind people-deaf people

Blind or partially sighted

Deafness / hearing impairment

Deaf or hard of hearing

Deaf and mute or deaf without
speech

Mental illness

Developmental disability

A person with restricted growth

Downs syndrome

Cerebral palsy

Unacceptable Terms:

Cripple, cripples

'The Disabled'

Defective, deformed,
vegetable

Handicap, handicapped

Victim of spinal cord injury

Suffers from multiple
sclerosis

The blind – The deaf

Blind as a bat

Deaf and Dumb

Mutt and jeff

Deaf and Dumb

Loony, mad, round the twist

Retard, moron, idiot,
imbecile

Midget, dwarf

Mongol

Spastic

A wheelchair user

Wheelchair bound,
confined to a wheelchair

Able bodied

Healthy (when used in
contrast to disability)

People without a disability

Normal

Disability Definitions and Statistics

WHO Definitions (World Health Organisation)

These definitions have been criticised by disabled people as they focus on impairment and limitations.

- **Handicap**

A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual

- **Impairment**

Any loss or abnormality of psychological, physiological or anatomical structure or function

- **Disability**

Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being

UPIAS Definitions (Union of Physically Impaired Against Segregation)

These definitions were compiled by disabled people's organisations. The main difference from the WHO definitions is that disability is

defined as being socially and environmentally constructed and external to the individual.

- **Impairment**

Lacking all or part of a limb or having a defective limb, organism or mechanism of the body

- **Disability**

The disadvantage or restriction caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities

UK Statistics

National Statistics Online

<http://www.statistics.gov.uk/CCI/SearchRes.asp?term=disability&x=13&y=8>

[OPCS \(Office of Population Census and Surveys\)](#)

<http://www.statistics.gov.uk/STATBASE/Product.asp?vlnk=8008>

[Labour Force Survey](#)

<http://www.drc->

[gb.org/drc/InformationAndLegislation/Page356.asp](http://www.drc-)

[Number of people with visual impairment](#)

<http://www.rnib.org.uk/library/research/statsrc.htm>

[Number of people with hearing impairment](#)

[http://www.rnid.org.uk/html/factsheets/general statistics on deafness.htm](http://www.rnid.org.uk/html/factsheets/general_statistics_on_deafness.htm)

[Other links](#)

Scottish report commissioned by the Disability Rights Commission

<http://www.drc-gb.org/drc/Documents/factsbooklet2001.pdf>

Analysis of HESA statistics on disability

http://www.ed.ac.uk/ces/PDF%20Files/TT_0207.pdf

Guidance on Disability Legislation

Disability Discrimination Act 1995 (DDA)

The Disability Discrimination Act 1995 (DDA) provides the legal framework through which a person with a disability may bring an action against an employer or service provider if they feel they have been discriminated against on the grounds of their disability.

It is in eight parts:

1. The meaning of disability
2. Discrimination in employment
3. Discrimination in other areas: The provision of goods, facilities and services
4. Education
5. Public Transport
6. National Disability Council
7. Supplemental
8. Miscellaneous

Useful website: www.hmso.gov.uk/acts/acts1995/1995050.htm

Publications:

Blackstone's Guide to the DDA – Caroline Gooding

ISBN 1854314998

Disability Discrimination Act Inclusion and workbook for building owners, facilities managers and architects – John H. Penton

ISBN 1859460321

Disability Rights Commission – Government body to provide information – www.drc-gb.org

Building Regulations

Approved Document M of the Building Regulations (1999 ed) covers access to, and within, a building for people with disabilities – new build or extensions only

Useful website: <http://www.hmso.gov.uk/si/si1998/19982561.htm>

N.B. Part M is currently being re-written and is likely to pick up on many of the guidelines and specifications included in BS8300. Although the requirements of BS8300 are not presently enforceable by law, it is advisable to work to the stated requirements (November 2003).

ADM 2004 – published November 2003, came into force 1st May 2004.

British Standard 8300

The British Standard BS8300:2001 is a code of practice that is aimed to support the DDA 1995 and gives practical design and building advice.

Useful website: <http://www.bsi.org.uk>

(Replaces BS 5810 and BS 5619)

British Standard 5588

BS5588 is a code of practice for fire precautions in the design, construction and use of buildings. Part 8 deals with means of escape for people with disabilities. This is not included in ADM or BS 8300.

Useful website: <http://www.bsi.org.uk>

New document DD9999 is being developed to give more information and will replace BS 5588

The Special Educational Needs and Disability Act, 2001 (SENDA)

SENDA amends part 4 of the DDA. It relates to educational establishments and establishes legal rights for disabled students in pre and post -16 education.

SENDA has three parts:

1. Relates to Special Educational Needs in England and Wales.
2. Relates to Discrimination in Education in all geographic areas.
 - Chapter 1 – Schools
 - Chapter 2 – Further and higher education institutions and local education authorities

- The role of the Disability Rights Commission

3. Miscellaneous Section

Useful website: <http://www.ukcle.ac.uk/directions/issue4/send.html>

Ergonomics

Useful websites:

The Ergonomic society

<http://www.ergonomics.org.uk/>

Ergonomics – The Official Journal of the Ergonomics Society and the International Ergonomics Association

<http://www.tandf.co.uk/journals/tf/00140139.html>

Open Ergonomics - an ergonomics society registered consultancy

<http://www.openerg.com/>

Publications:

Bodyspace: Anthropometry, Ergonomics and the Design of Work –
Stephen Pheasant

ISBN 0748403264

Ergonomics: Standards and Guidelines for Designers

ISBN 0580153916

Web Links

Adaptive Environments Centre

www.adaptenv.org

Americans with Disabilities Act:

janweb.icdi.wvu.edu/kinder

British Council of Disabled People

www.bcodp.org.uk/

Centre for Accessible Environments

www.cae.org.uk

Centre for Disability Studies

www.leeds.ac.uk/disability-studies/

Centre for Universal Design

www.design.ncsu.edu/cud/index.html

DIAL (Disability Advice Line Services)

www.dialuk.org/uk

The Design Council

www.design-council.org.uk/

Disability Discrimination Act 1995

www.hmso.gov.uk/acts/acts1995/1995050.htm

Disability Rights Commission

www.drc-gb.org

European Institute for Design and Disability

www.design-for-all.org/

Helen Hamlyn Research Centre

www.hhrc.rca.ac.uk/

Human Factors and Ergonomics Society

www.hfes.org

Include

www.stakes.fi/include

International Ergonomics Association (IEA)

www.iea.cc

Joint Mobility Unit

www.rnib.org.uk/jmu/welcome.htm

Joseph Rowntree Foundation

www.jrf.org.uk/

Mencap

www.mencap.org.uk

Older Adultdata , Adultdata and Childata (Anthropometric data)

www.virat.nott.ac.uk/PSTG

Phab (Physically Handicapped and Able Bodied)

www.ukonline.co.uk/phab/

RADAR (The Royal Association for Disability and Rehabilitation)

www.radar.org.uk

RIBA (Royal Institute of British Architects)

www.architecture.com/go/Architecture/Home.html

RICA (Research Institute for Consumer Affairs)

www.ricability.org.uk

RNID (The Royal National Institute for the Deaf)

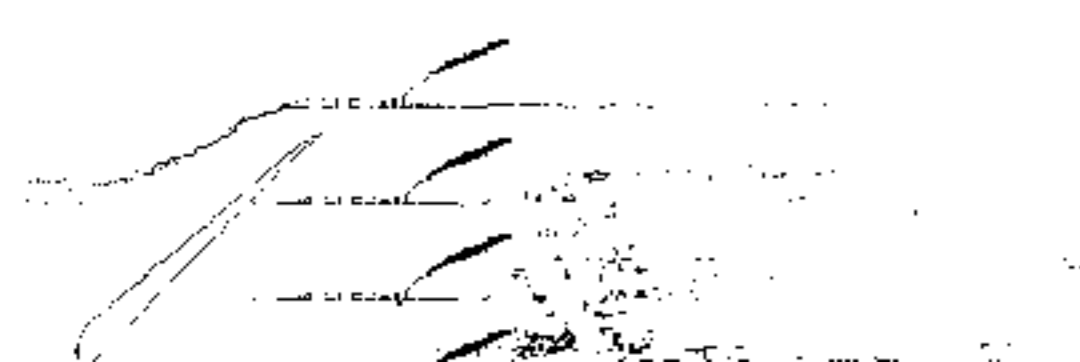
www.rnid.org.uk/

Royal National Institute for the Blind:

www.rnib.org.uk/

WHO (World Health Organisation)

www.who.int/icidh



Overview of Medical Terminology

AIDS (Acquired Immune Deficiency Syndrome)

AIDS is not a disease. It is the term used to describe a person's condition if they contract pneumonia, tuberculosis or other infection or illness which becomes life threatening due to their damaged immune system caused by HIV (Human Immunodeficiency Virus).

Alzheimer's Disease

Alzheimer's disease is a common form of dementia. (See dementia)

Ankylosing spondylitis

Ankylosing spondylitis is a progressive and painful rheumatic disease. It mainly affects the spine but it can also affect joints, ligaments and tendons.

Arthritis

Arthritis is a general term used for inflammation of a joint of joints.

Autism

Children with autism behave in puzzling ways, have difficulty in relating to other people and are unsuccessful at making sense of the social world.

Brittle Bone Disease

Brittle bone disease is thought to be a combination of several disorders rather than a single condition. It is caused by

abnormalities in the fundamental structure of the protein part of the bone. Fractures happen easily but healing usually occurs readily.

Cerebral Palsy

Cerebral palsy is caused by damage to, or lack of development in, a small part of the brain that controls movement and posture. This damage can also affect other parts of the brain resulting in other types of disability. Cerebral palsy may affect one or more limbs, cause speech and language difficulties, oral problems such as swallowing difficulties or drooling, convulsions and learning disabilities.

Cognitive functions

Cognitive functions is concerned with the processes of learning.

Cystic Fibrosis

A hereditary and life threatening condition that affects the lungs and digestive system. The lungs frequently become infected and respiratory infections are common.

Dementia

A person with dementia experiences a progressive decline in the abilities to remember, reason and think. There can also be associated physical decline and deterioration can be slow or rapid. Symptoms are unpredictable, and the variability of symptoms differs from person to person.

Down's Syndrome

Down's syndrome occurs when there is a presence of an extra chromosome in the body cells. Down's syndrome characterised by - short stature, a round skull which is flat at the back, small jaws and nose, slack muscle control and / or learning disabilities.

Dyslexia

Dyslexia is often known as 'word blindness' and is characterised by difficulties with reading and writing.

Dysphasia

The loss of ability to speak, read or write.

Epilepsy

A person who has epilepsy is liable to recurrent seizures or fits that are caused by a temporary disturbance of brain function.

Hearing Impairment

Hearing impairments occur when there is an interruption in the processes conducted by the middle or outer ear. People with a hearing impairment will often rely more on other senses particularly that of sight.

HIV (Human Immunodeficiency Virus)

HIV is a virus that damages the bodies defence system so that it cannot fight off certain infections.

Huntington's Chorea

Huntington's chorea is a hereditary disorder of the nervous system. The most obvious symptoms are - involuntary jerking movements, loss of motor control, unsteady gait, loss of concentration and / or memory.

Motor Neurone Disease (MND)

Motor neurone disease is the name given to diseases affecting the motor neurones in the brain and spinal cord. Nerve cells that control the muscles are slowly destroyed which may result in a progressive weakness and paralysis of limbs. Speech and swallowing may be affected however, MND does not affect the senses and the intellect remains unchanged.

Multiple Sclerosis (MS)

Multiple sclerosis is a disorder of the central nervous system that causes both motor and sensory disabilities. Symptoms include – weakness or clumsiness in one or more limbs, difficulty with balance, cramp spasms, speech may be effected and blurring or loss of vision

Muscular Dystrophy

Muscular dystrophy is progressive, hereditary and results in muscle weakness.

Parkinson's Disease

Parkinson's disease is a progressively degenerative disorder of the central nervous system. Symptoms may increase over time and

include – shaking or tremor in a hand or arm, rigidity or stiffness in muscles, slowness and / or difficulty in initiating movement.

Poliomyelitis

Poliomyelitis is a virus infection that can result in damage to part of the brain and spinal cord responsible for the control of voluntary movement.

Spina Bifida

Spina bifida occurs when the spinal region fails to develop properly in the first 25 days of pregnancy. It is characterised by congenital malformations of the central nervous system which can result in a person having paralysed legs, dislocation of the hip and / or water on the brain.

Spinal Cord Injuries

Damage to the spinal cord nerves can result in paralysis.

Quadriplegic – Paralysis of all four limbs.

Paraplegic – Paralysis of the lower limbs and part of the torso.

Stroke

A stroke is a condition in which part of the brain is damaged either as the result of a clot or haemorrhage in a blood vessel in the brain.

Visual Impairment

A person with a visual impairment experiences a reduction in the ability to gather information about their external environment through the sense of sight. They often rely more on their senses of touch

and hearing to help them familiarise themselves with the world around them.

Glossary

ADA	Americans with Disabilities Act
BCODP	British Council of Disabled People
BDA	British Deaf Association
BSL	British Sign Language
CIL	Centre for Independent/Integrated Living
DA	Disability Alliance
DAN	Disability Action Network
DDA	Disability Discrimination Act
DIAL	Disability Information and Advice Line
DLF	Disabled Living Foundation
DoH	Department of Health
DPI	Disabled Peoples' International
DPOs	Disable People's Organisations
DRC	Disability Rights Commission
GLAD	Greater London Association of Disabled People
GMCDP	Greater Manchester Coalition of Disabled People
HMSO	Her Majesties Sorting Office
ICIDH	International Classification of Impairments, Disabilities and Handicaps
ILM	Independent Living Movement
Mencap	Charity for people with learning disabilities
NFB	National Federation of the Blind
NLB	National League of the Blind
OPCS	Office of Population Census and Surveys
PAS	Personal Assistance Support
RADAR	The Royal Association for Disability and Rehabilitation

RNIB	Royal National Institute for the Blind
RNID	The Royal National Institute for the Deaf
SCOPE	Charity for cerebral palsy (formerly known as the Spastics Society)
SENDA	Special Educational Needs and Disability Act
UPIAS	Union of the Physically Impaired Against Segregation
WHO	World Health Organisation

A Design Resource for Inclusive Design

This resource has been developed as part of a PhD study that I am completing entitled 'Wheelchair Access in the Built Environment'. The resource evolved from information I acquired through talking to wheelchair users in the local area about access issues and has been produced for use by designers / planners who are completing projects for people with disabilities. It is hoped that the resource will encourage designers / planners to talk to people with disabilities about their views on access, and consider their comments throughout the design process.

Thank you for agreeing to look at the resource and please be assured your comments will be treated with the strictest confidence.

A Design Resource for Inclusive Design

Is the index page and page numbering helpful?

Conversation etiquette page 4 – How do you think this section will help designers / planners communicate with people with disabilities more effectively?

User participation page 6 - This section recommends focus groups as a useful method to obtain information. What are your views on focus groups as a way for people with disabilities to express their views to designers / planners?

What do you think of the acceptable / unacceptable terms section page 11 - are there any terms that you know of that are missing and should be included?

Definitions page 12 – What are your thoughts about the UPIAS definition where the word handicap has been left out or the WHO definitions?

Web links page 18 – Are there any web links that you know of that should be included? What would the benefits of a summary of each web site be?

Overview of Medical Terminology page 20 – This section gives the reader an outline of various disabilities. Do you think there are any others that should be included?

Do you have any views on all other sections (Guidance on Disability Legislation page 14 & Ergonomics page 17).

This pack is for use by designers / planners, do you think that there are any sections that should be added that would help them obtain the views of people with disabilities?

Please comment on the clarity and over all presentation of the resource.

Any other comments.

Thank you for your time.

APPENDIX 8 – POSTER ABSTRACT SUBMISSION

Abstract Submission for The 5th Qualitative Research Conference

Ms. Stephanie Adams
PhD Student
Bournemouth University

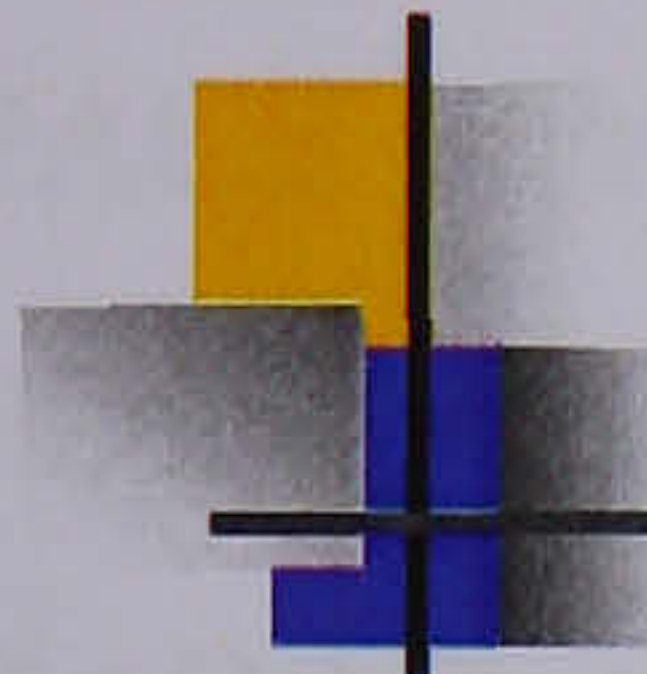
sadams@bournemouth.ac.uk

Disability and the Built Environment - Poster Presentation (Disability and Vulnerability / Socio-Economic Issues)

Disability and the Built Environment

(Based on a PhD thesis to be completed October 2004)

Stephanie Adams – sadams@bournemouth.ac.uk

- 
- Popular constructions of disability have established a relatively powerless and deviant status for the disabled population compared to their able bodied peers. Regulatory controls and legislation require that builders and designers are sensitised to the needs of disabled people, but even with the advent of the Disability Discrimination Act (1995), there is no legislative process to endorse the disabled communities request for a fully inclusive and accessible lifestyle.
 - In the field of design research, social and participatory paradigms are new concepts and the power balance between researcher / researched relationships is still weighed in the favour of the researcher. It is this relationship that this paper addresses. Traditional design methodology is combined with social science research methods to advocate an inclusive design paradigm, where the emphasis is on utilising the knowledge of the 'experts in the field', disabled people themselves, throughout the whole design process.

GLOSSARY

ADA – Americans with Disabilities Act

ADM – Approved Document M

BCODP – British Council of Disabled People

BSC – British Standards Council

CAE – Centre for Accessible Environments

DDA – Disability Discrimination Act

DPI – Disabled Peoples International

DRC – Disability Rights Commission

EDRA – Environmental Design and Research Association

ESRC - Economic and Social Research Council

GLAD – Greater London Association of Disable People

ICIDH – The International Classification of Impairment, Disability and Handicap

MND – Motor Neurone Disease

OPCS – Office of Populations, Census and Surveys

PACE – Problem, Analysis, Concept and Evaluation

PDS – Product Design Specification

RADAR – The Royal Association for Disability and Rehabilitation

RIBA – Royal Institute of British Architects

RICA – Research Institute for Consumer Affairs

RNIB – Royal National Institute for the Blind

SENDA – The Special Educational Needs and Disability Act

SURFACE – Salford University Research Focus on Accessible Environments

UPIAS – Union of Physically Impaired Against Segregation

VOADL Voluntary Organisations for Anti Discrimination Legislation

WHO – World Health Organisation

PARTICIPANTS CODING

The participants coding system was devised as follows:

The first number signifies the number the focus group or the participants' inclusion in the design resource evaluation; the letter denotes the participant's gender; the final number indicates the sequence in which the participants spoke during the focus group.

1f1	1m1	2f1	2m1	3f1	3f4
1f2	1m2	2f2	2m2	3m2	3f5
1f3	1m3	2f3	2m3	3f3	3m6

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