

The Social Implications of Increases in Wheelchair Use

Report by

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Contents

List of Tables, Figures, Graphs and Charts	3
1: Background.....	6
The Research Proposal.....	6
Perceptions and Images of Wheelchair Use.....	10
2: Methodology	20
Investigation between acceptance of outline and final proposals	20
Overview of the research design	20
Application of the research method.....	21
3: The Experience of Wheelchair Provision and Use.....	26
Introduction.....	26
The Wheelchair Service.....	27
Definition of need	34
The social effects of stigma	37
Implications for wheelchair services.....	40
4: The survey	42
The sample.....	42
Key demographics	43
Housing demographics.....	51
Education and employment	54
Wheelchair demographics	55
Attitudes	60
Transport	82
5: Conclusions and recommendations	88
References.....	96
Appendix – Questionnaire.....	100

List of Tables, Figures, Graphs and Charts

Figure 1. Geographical Distribution of Respondents	42
Table 1. Respondent	43
Table 2. Sex Distribution of Wheelchair Users in Survey	44
Graph 1. Age and sex of wheelchair users	44
Table 3. Age Statistics for Respondents and Total Population	44
Table 4. Distribution of medical conditions	45
Table 5. Percent of wheelchair users by disability etiology, pre-1968	46
Table 6. Full-time and part-time wheelchair users	46
Table 7. Crosstabulation of Condition by Use.	47
Table 8. Type of Wheelchairs Provided to Full and Part Time Users	47
Table 9. Marital status	48
Table 10. Age by Marital status	48
Table 11. Living Arrangements of Respondent.....	49
Table 12. Carer Nearby by Household Living Alone	49
Table 13. Marital Status by Household Living Alone.....	50
Table 14. Receives any Disability Benefit	50
Table 15. Ethnic group	51
Table 16. Type of Home.....	51
Table 17. Respondents Living in Residential Homes – Who Filled in the Questionnaire?	52
Table 18. Type of Home by Satisfied with Access Within Home.....	52
Table 19. Home Purpose Built by Home Adapted.....	53
Table 20. Home Purpose Built by Satisfied with Access Within Home	53
Table 21. Home Adapted by Satisfied with Access Within Home	53
Table 22. Attended or Attending Special School.....	54
Table 23. Education Seriously Disrupted	54
Table 24. Employment Status	55
Table 25. Had to Give up a Job	55
Table 26. Use Wheelchair Indoors	55
Table 27. Use Wheelchair Outdoors	55
Table 28. Satisfied with Access Within Home by Wheelchair Use.....	56
Table 29. Respondent has had Training to Use Wheelchair.....	56
Table 30. Length of wheelchair use	57
Table 31. When was the Main Wheelchair Acquired?	57
Table 32. How Many Non-powered Wheelchairs Respondents Possess.....	58
Table 33. How Many Powered Wheelchairs Respondents Possess.....	58

Table 34. How Many Non-powered Wheelchairs by How Many Powered Wheelchairs?	58
Table 35. Type of Main Wheelchair	59
Table 36. Source of Main Wheelchair	59
Table 37. Whether Wheelchair is in Good Working Order	59
Table 38. Whether Respondent Feels Safe Using the Wheelchair Alone	60
Chart 1. Wheelchairs can be liberating for disabled people.....	61
Chart 2. My wheelchair has liberated me.....	62
Chart 3. My wheelchair stops me from doing many things I want to do.....	63
Chart 4. My illness/condition stops me from doing many things I want to do.....	64
Chart 5. Other people's attitudes towards me using a wheelchair stop me from doing many things I want to do.	64
Chart 6. The environment around me makes it hard for me to do many of the things I want to do in my wheelchair.	65
Chart 7. Discrimination against wheelchair users should be dealt with strongly under the law.	66
Chart 8. Wheelchair users should take responsibility for solving their own access problems.	66
Chart 9. The Disability Discrimination Act will help to change attitudes towards wheelchair users.	67
Chart 10. I would enjoy using my wheelchair more if it looked better.....	67
Chart 11. The appearance of a wheelchair affects the way non-disabled people view wheelchair users.	68
Chart 12. Wheelchair users have too little choice in the design of the chair they use.	69
Chart 13. The wheelchair I would like is too expensive for me to buy.	69
Chart 14. The roads where I live are too steep for me to get out of my home in my wheelchair without help.....	70
Chart 15. The roads where I live are too steep for me to get out of my home in my wheelchair with help.....	70
Chart 16. Pavements near my home are inaccessible because they are obstructed.....	71
Chart 17. It's very difficult to use a wheelchair near my home because there are too few dropped kerbs.....	71
Chart 18. I need help to go to <i>local shops</i> as they are difficult to access in my wheelchair.	72
Chart 19. The <i>town centre</i> is easier to access than local shops.	72
Chart 20. The <i>town centre</i> is difficult to access.....	73
Chart 21. I can access <i>out-of-town</i> shopping centres on my own.....	73
Chart 22. There are <i>restaurants</i> I would like to go to, but do not as the <i>toilets</i> are inaccessible.....	74

Chart 23. There are <i>restaurants</i> I would like to go to, but do not because of lack of <i>parking</i> .	74
Chart 24. There are <i>pubs</i> I would like to go to, but do not as the toilets are inaccessible.	75
Chart 25. There are <i>pubs</i> I would like to go to, but do not because of lack of <i>parking</i> .	75
Chart 26. I have difficulty travelling to my local leisure centre.	76
Chart 27. I find it quite easy to get in and out of the leisure centre.	76
Chart 28. I am able to participate in sporting activities.	77
Chart 29. It is necessary to provide special leisure activities for wheelchair users	77
Chart 30. People tend not to talk to me when someone else is pushing my wheelchair.	78
Chart 31. People do talk to me when I am controlling my wheelchair.	78
Chart 32. Other people view me negatively because I use a wheelchair.	79
Chart 33. I view myself negatively because I use a wheelchair.	79
Chart 34. I know a shop where I can get good advice on wheelchairs.	80
Chart 35. I have had good advice on wheelchairs from the Disablement Services Centre.	80
Chart 36. I knew almost nothing about wheelchairs before I got one for myself.	81
Chart 37. If I have a problem with my wheelchair, I know I can rely on the Disablement Services Centre to help.	81
Chart 38. I find the staff at the Disablement Services Centre approachable.	82
Chart 39. I find the staff at the Disablement Services Centre efficient. (N=1042)	82
Charts 40 and 41. Using car	83
Chart 42 Using car with assistance by age, excluding missing and never tried.	84
Charts 43 and 44. Using taxi	84
Charts 45 and 46. Using bus	85
Charts 47 and 48. Using train	85
Charts 49 and 50. Using plane	85

1: Background

The Research Proposal

In 1996/7 while undertaking a study of the housing needs of wheelchair users (Harris, *et al.* 1997), we (Bob Sapey and John Stewart) identified what appeared to be approximately a 100% increase in the numbers of wheelchair users in England and Wales over the previous decade. This led us to consider whether the reasons for such a large increase were known and understood, and whether this had contributed to a change in the social activities and aspirations of wheelchair users. As a result we (Bob Sapey, John Stewart, Carol Thomas and Sandra Wilks) submitted a research proposal to the NHS Executive North West R & D Directorate and received a grant of £81,230 to conduct a study between April 2001 and September 2003 of *the social implications of the increases in wheelchair use* in the north west of England. Glenis Donaldson joined us in April 2001 as a research assistant, seconded from her post as a senior physiotherapist with Blackpool, Wyre and Fylde Community Health NHS Trust. The objectives of this study were:

1. To clarify the trends in wheelchair use and establish if the perceived increase since 1986 is continuing.
2. To establish the relative importance of different explanations for this increase.
3. To ascertain if the personal care, housing and other social needs of wheelchair users have changed during this period of increase.
4. To determine the resource implications of changing needs for service providers and purchasers.
5. To highlight aspects of service provision which are problematic for wheelchair users or other service providers.
6. To develop the research capability of NHS staff within disablement services.

The evidence for the increase in wheelchair use lay primarily in two national studies. In 1986 the OPCS disability surveys had put the figure of wheelchair users in England and Wales at 360,000 (Martin *et al.* 1989). Ten years later Aldersea's (1996) investigation into the NHS Disablement Services showed that the number was then approximately 710,170 in England, about a 100% increase. At this time wheelchair users constituted almost 10% of the 7.2 million disabled people identified by the *Follow-up to the Family Resources Survey* (Grundy *et al.* 1999). A point to note however was that while the number of wheelchair users appeared to have doubled over the previous decade, this was in contrast with a 38% increase in the total numbers of disabled adults in Great Britain between 1986 and 1996/7.

We also had secondary evidence from discussions with providers and purchasers that these changes were occurring, but may have been patterned in a

complex way, such that in 1996 the Morecambe Bay Health Authority had experienced a 15% increase in the number of people issued with NHS wheelchairs whereas by 1999 the Preston DSC believed that the out-turn figures would show this increase to have stopped. Further data from Wirral Health Authority as part of our initial survey of all AHAs and CHCs in the north west region (as suggested by the R&D Committee on acceptance of our outline proposal for this study) indicated a similar trend of referrals increasing at the rate of a 50% over the five years from 1995 to 1999, but that this has slowed down considerably since 1997.

There appeared to be no satisfactory explanation of what had caused this increase. A Department of Social Security study of all disabled people suggested that the rising numbers were linked to the increasing population of older people (Craig and Greenslade 1998), but that study made no attempt to look specifically at wheelchair users. Our examination of Aldersea's study showed increases across the age range hence in addition to demographic changes, there must have been other explanations. Grundy *et al.* (1999) also showed increases across the age range lending support to this interpretation.

Craig and Greenslade (1998) considered that changing attitudes towards disablement may contribute towards the increased numbers of people counting themselves as such, but again the authors did not specifically consider if there was such a link to wheelchair use. Following this idea, it may have been that wheelchairs were becoming more socially acceptable and people were not so self-conscious of being seen in them and in the absence of any clear evidence that conditions leading to ambulant immobility were increasing at a greater rate than other impairments, the validity of this explanation must be seriously considered.

Another possibility is that the increase is as a result of changing prescription and allocation procedures within the NHS as in the past, changing institutional practices in the allocation of wheelchairs had led to such increases. For example, in Canada in the 1940s, a change to allocating wheelchairs to individuals rather than hospital wards had not only led to an obvious increase in the numbers of wheelchairs in use, but also to the presence of wheelchair users in Canadian social and economic life (Tremblay 1996). In this way, a relatively simple change in prescription practice brought about significant social change. Woods and Watson (2002a) point to a similar rise in wheelchair use following the establishment of the National Health Service and universal provision in Britain. However, they also describe how this increase, which was managed by the Ministry of Pensions, resulted in the standardisation and mass provision of inappropriate wheelchairs. The Ministry Model 8 which came into service in 1951 was designed for the occasional older user and fashioned to be amenable to the standardised production process favoured by the Ministry. Woods and Watson (2002a) argue that this was 'a wheelchair designed for the service, rather than the wheelchair user'.

During the 1986/95 period of increase, there had been a change in prescribing practice for wheelchairs, with the Disablement Services Centres training

therapists and nurses to undertake this task and it may well have been that the different perceptions of need by professions other than doctors could have accounted for some of the increase.

A different explanation was that changes in medical practice and health behaviours had resulted in delayed mortality and hence a larger population was surviving to be disabled (Grundy *et al.* 1999), and a sizeable minority may well be wheelchair users. Also, the recent developments in care in the community had resulted in fewer younger disabled people living in institutions and while the numbers of older people in such homes had increased (Oliver and Sapey 1999) there may have been changes in their social behaviour, such as their getting out and about more often. In such circumstances people may be less willing to rely on wheelchairs owned by institutions and therefore would have been referred to the DSCs for equipment of their own. . However this trend has been changing. Between 1999 and 2003 there was a 24% increase in the numbers of 'physically/sensorily disabled adults' under 65 years of age being supported by local authorities to live in residential and nursing homes in England (Department of Health, 2003, Table S1).

The other possibility was that the changing figures may have been partly the result of better research methods, with Aldersea's study being more accurate than the OPCS survey. However, this would not have accounted for the increases that were being reported to us by various DSCs and health authorities. While we have confidence in Aldersea's figures, we should also note that the Audit Commission (2000) reported the total number of wheelchair users for the UK to be only 640,000 with this data having been provided by the Royal College of Physicians, and with Aldersea herself being a member of their external advisory group. There is no further information from the Audit Commission about how they calculated this figure.

Understanding the causes of the variations and possible continuing increase was important because those causes would impact on the planning process in both the purchase and provision of health and social care. Some explanations for the variations and increase in wheelchair use were within the domain, if not entirely the control, of the NHS: for example, the differing practices of health professionals in allocating services. These practices impact on other related agencies such as social-rented landlords (local housing authorities and housing associations) and social services as well as upon other parts of the NHS. Other explanations place the changes entirely outside the control of the NHS, such as demographic trends and changing attitudes. We felt it was necessary for NHS planners to understand the relative significance to the overall picture of each set of explanations, as they have to respond (or not) to the latter, whilst they are the direct generators of the former.

The NHS is directly responsible for the provision of wheelchairs, hence increased purchasing and provision impacts directly on the service. Furthermore, both the increased awareness amongst wheelchair users of the range of equipment available and an increased assertion of need for more specialised products can have a significant impact on spending. Strategic decision-making could be

improved by an increased knowledge of the nature of the trends so far and how they may continue in the future. Some service users do not seem to be aware of how it all works, as one of our interviewees commented:

I didn't have a wheelchair, not my own, I borrowed my Grandma's until she died and I thought I could keep that wheelchair, I didn't know it was on loan.¹

Other agencies also experience the impact of any increase in wheelchair users. We were aware that in some cases housing associations had spent considerable sums adapting property for wheelchair use when a more expensive wheelchair could have alleviated the need for permanent structural alterations more economically. Though in many cases the wheelchair issued is useless indoors because the wheelchair user has not been allocated a mobility standard tenancy, as one of our interviewees pointed out:

I don't use the wheelchair inside because there isn't enough room. If I sat in the wheelchair inside, two pushes and I'm at the other end of the flat and I have to get out to get in the bedroom and get into the toilet and into the bath and so I might as well use the stick around the flat and use the wheelchair to go out.

There are complex inter-agency issues when one provider does not fully consider the impact of its actions on the services of a parallel provider. For example, local education authorities who do not provide suitable transport for disabled children which can also carry their wheelchairs, cause the NHS to have to double its provision—one chair for home and one for school. We had hoped to be able to establish quantitatively and qualitatively the extent and nature of problems such as these.

We were also aware that there were a significant number of part-time wheelchair users, particularly amongst the older population. With older wheelchair users, such part-time use often takes the form of outdoor use only, whereas in the case of younger amputees, wheelchair use may be episodic, but during those periods wheelchair use would be full-time. Although in both these examples the need to allocate wheelchairs on a long term basis is of prime importance to the NHS, other social needs would have to be explored if this growing area of use was not to adversely impact on the wider welfare system.

While the study should have relevance to a number of state agencies, it could and should also be of value to disabled people. Therefore we proposed at the outset that this study would involve wheelchair users, hence close liaison was sought between the research team and disability organisations in order to ensure the relevance of this work to disabled people. We hoped that the project would also lead to long term collaboration between purchasers, providers and service users in the field of disability research.

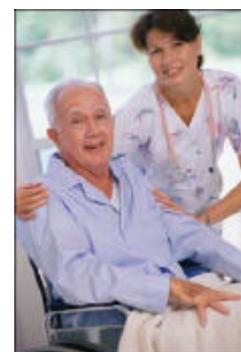
¹ Quotations from our interviewees and survey respondents are always indented and in a distinct font.

Perceptions and Images of Wheelchair Use²



The wheelchair has long been viewed as a necessary, but undesirable piece of clinical equipment. Indeed, the wheelchair is *the* symbol of disability despite it being a minority (less than 10%) of disabled people who are wheelchair users. Wheelchair users have been treated as patients who are subject to expert assessment and prescription rather than as people with preferences and the power to choose. While much may have changed in recent years, the image of a wheelchair user as someone dependent on others is still quite dominant, especially within the care services.

Images such as the one reproduced here, can be found on nursing and residential care home websites and depict wheelchair users as happy and contented in a 'sick role'. The stethoscope around the neck of the woman reinforces the notion of medical dependency and few people would question this link. In some instances the two dependencies - wheelchair and medicine - would certainly go hand-in-hand, but this is not always the case. Indeed, for many wheelchair users their immobility is as the result of impairments which are not treatable and therefore they may have little contact with doctors and nurses. We found that interviewees' experiences of health professionals that should be anachronistic are still prevalent:



It's like when you go to the hospital or the doctors, if you go with anybody cause you're in a wheelchair they don't address you, they look over you and that really infuriates me.

Although there may be much contact with rehabilitation personnel, especially occupational and physiotherapists, the story is often the same:

I felt as if the occupational therapist especially, she just treated me like, she saw the wheelchair and she didn't see me as a person.

Oliver (1993a) has argued that the efforts of the rehabilitation industry to make non-walkers walk again, places a very negative value on the use of a wheelchair. He links these efforts to the assertion of power:

In terms set by the rehabilitation enterprise, walking is rule-following behaviour; not-walking is rule-ignoring, rule-flouting or even rule-threatening behaviour. Not-walking can be tolerated when individuals are prepared to undergo rehabilitation in order to nearly walk or to come to terms with their non-walking. Not-walking or rejecting nearly-walking as a personal choice is something different however; it threatens the power of

² All the images in this chapter have been taken from the internet using a Google search for image files with 'wheelchair' in their title.

professionals, it exposes the ideology of normality and it challenges the whole rehabilitation enterprise.

(Oliver 1993a:16)

This threat to the power of rehabilitation professionals is a central issue in the study of wheelchair use, and the role of the health and welfare services. While the study of wheelchairs and their use has been dominated by medical, managerial and technical considerations, the challenge from the disability movement has been to view the wheelchair user as the person who has the expertise. Not walking ceases to be a medical condition, rather, it becomes a normal part of the range of human diversity. To conceptualise not walking as normal is a significant challenge to the socialisation of rehabilitation professionals, yet for many wheelchair users it is an important aspect of gaining a positive identity, as one of our interviewees commented:



I've actually gained more out of life since I've been in a wheelchair than I did before my accident, I've certainly achieved so much.

The social model of disability, which is a central principle of the disability movement, argues that the limitations faced by disabled people, result not from their impairment, but from the social responses to impairment. The social model makes a clear distinction between meanings of impairment and disability. Confusing the two terms results in a misunderstanding that is unhelpful to any discussion or analysis of disability problems. Impairment refers to the physical problems that may give rise to a person's immobility, while disability refers to the limitations that are caused by the failure of society to take into account the presence of wheelchair users. At a simple level this may be illustrated by steps rather than ramps into buildings, thereby excluding anyone who is unable to negotiate the steps. However it is more complex than this, as there is a widespread belief that people who use wheelchairs may be unable to undertake a range of physical and intellectual tasks.

In school, children who use wheelchairs may not be expected to achieve as much as their peers and many teachers and parents may not believe academic achievement to be essential as they do not expect such children to ever go to work. One of our interviewees reflected on the identity she was expected to assume and the future into which she was being socialised:

I'll tell you when I realised for the first time that being disabled wasn't necessarily a good thing, it was, believe it or not, when I was 11. And it was the last year of junior school. The kids went on a holiday. I just assumed that I'd go and I was absolutely devastated when my Mum and Dad said, "No" and I said, "Well why not" and they said, "Because the teachers will



have to help". By that time as far as I was concerned I was physically independent, ...³ but what I hadn't taken into account was that if I couldn't get somewhere in my wheelchair, I would have to be physically carried. ... Up to that point it had not been a problem. If I needed carrying an adult lifted me up and carried me so I didn't see it as somebody doing anything that they shouldn't do, or extraordinary.

... that was the first time it dawned on me that I was any different really, or more importantly that my difference went against me. I'd perceived myself as being different in terms of when I was at school the teachers were still allowed to smack the children and for some reason I always knew that I would never be smacked, ... perhaps it would be frowned upon if a teacher smacked me at school, but that was OK to be different in that way - thank you very much because I didn't want to be smacked. I didn't like the idea that being disabled would stop me from going or doing anything and that was the real first time when it really hit home.

In the 1980s many children with cerebral palsy were taken out of education in order to attend conductive education at the Peto Institute in Hungary (Oliver 1993b). Helping these children to achieve some form of nearly-walking was considered more valuable than helping them to achieve academically. To many rehabilitation professionals it may appear a sacrilege to challenge the aim of helping these children to achieve some form of ambulant mobility, yet for many of the children the level of mobility that they could achieve was not useful and in the process they learned that to use a wheelchair was undesirable. Though one of our interviewees had a different memory of being a child wheelchair user:



My wheelchair was a good cop car and we used to play cops and robbers and the kids, especially the boys, used to love chasing up and down with me. ... [Some] people are afraid of using a wheelchair and I know that my Mum, and I've never really understood her for this, my Mum hates my wheelchair..

The attitudes which sent children to the Peto Institute can be located within a traditional view of disablement. During the 1960s there were also attempts to replace the missing limbs of Thalidomide children with often hideous mechanical prostheses. Alison Lapper, whose statue will grace the 'vacant plinth' in Trafalgar Square, describes the attempts to fit her, when a child at residential school, with metal legs and arms with hooks powered by a canister of compressed gas:

I hissed whenever I moved (*The Independent* 17 March, 2004).

Sayce (2000) discusses what she terms a 'disability inclusion' model in relation to countering the stigma associated with mental ill-health. This model is based upon having strong anti-discrimination legislation to prevent people and organisations

³ The ellipse (...) is used to indicate that words have been edited.



from being oppressive, but also on saying 'no to shame'. The disability movement have long been concerned with promoting a positive image of disability. Many people have written about the way they can incorporate their disablement within a strong self-identity and reject the notion that they are either ill or weak. While there is some public acceptance of this view, typically portrayed by strong images of wheelchair users involved in sporting activities, it is also a view that may be shared by people who would usually be termed as frail and dependent. Wheelchairs no longer need to be seen as symbols of failure, but merely as a means of mobility used by disabled people in a variety of roles, as one of our interviewees commented:

I just see it as a chair with four wheels and I think that's how it should be seen, but I do know that able bodied people or more able people see it differently, and when I'm on my scooter I'm treated differently.



Young and cool



Dancing



Demo



Flying



Fishing



Strolling



Mum



and
being
pushed

While these images show a number of people actively partaking in everyday situations, it is likely that rehabilitation staff are going to focus more on the person's incapacity. The majority of people who are likely to attend a disablement services centre will be over 50 years of age. The mean age of wheelchair users is almost 68 years. The median is higher at 74 years while the mode average of all DSC patients is 81. And that is how some of our interviewees saw it, until it happened to be oneself:

I always thought somebody who was in a wheelchair was always old or you had severe learning disabilities to be in a wheelchair until I ended up in a chair myself.

Two thirds of wheelchair users are women and two thirds are part-time users (Aldersea 1996: part II, p.15). So the typical wheelchair user will be an elderly woman, probably impaired by arthritis, who is able to walk to some extent indoors, but is reliant on someone else to push her around out-of-doors. She is also likely to be issued with a Remploy attendant controlled wheelchair.

This typical chair conveys an image of dependency. However, the women who make up the majority of wheelchair users are not necessarily content to accept this dependent image. As Ann Begg MP says,



Walking is not the be all and end all, but merely one method of movement, but this is hard to convey to people when it is obvious that there are still too many physical barriers making life for those of us in wheelchairs unnecessarily difficult (Reilly 2002: 14).



Challenging the conceptualisation of the wheelchair as a clinical object which denotes dependency is based, as we have said, on a social model of disability. However, while the social model of disability has been extensively developed in the disability studies literature and is very useful in informing the methodology of disability research, it is also necessary to have some understanding of other models that are operating, particularly within the health services. As the social model has developed so too has the individual model of disability. The individual model is by definition that which the social model is attempting to counteract. While the social model defines disability as the disadvantage caused by social responses to impairment, the individual model sets up disability only in terms of limitations caused by impairment. The more sophisticated the definition of the social model becomes, so too does our understanding of the individual model of disability.

However there is a problem within the disability studies literature which is that the individual model is often referred to as a medical model of disability. Many authors use these two terms interchangeably and do not question their meaning. This arises because the individual model of disability is deemed to be informed by a medical view of impairment. This medical view has often been termed the 'personal tragedy' theory.

We believe this to be too simplistic and wish to explore further the different models of disability in order that they may be used in an informed way within this research study. The table below shows certain aspects of several models of disability. Some of these, in particular the lay and medical models do not appear in the disability studies literature, but are helpful in trying to ascertain different perspectives from which people may view the use of wheelchairs.

Model	Beliefs	Causality	Discourse	Practice
Social	Disability is a form of oppression experienced by people with impairments.	Disability is caused by social responses to impairment.	Civil rights and integration.	Rights to services, laws to end discrimination and equality training for practitioners.
Affirmation	Impairments can be experienced positively.	Disability is caused by social responses to impairment.	Pride in impairment and saying 'no to shame'.	Disabled people can promote a positive lifestyle.
Individual	Disability is a limitation experienced by people with impairments.	Disability is caused by impairment.	Identification of 'the deserving' and ever more sophisticated definitions.	A hegemony of care - segregation and special services.
Lay	Disability is a personal tragedy.	Disability is caused by impairment.	Fear of impairment - 'better dead than disabled'.	Pity and charity - disabled people as 'other'.
Medical	Disability is impairment.	Disability is an outcome of accident, illness or genetic malfunction.	Aetiology and the quality and value of life as a factor in determining further intervention.	Scientific research, improved procedures and expertise.

The affirmation model (Swain and French 2000) is a way of explaining a phenomenon that is very apparent within disability arts, that of people taking a pride in their impairment and making use of it within their public performances. This is quite different to the 'freak show' in which people were paid to be the subject of the 'gaze' of others, rather it is the assertion that having an impairment is certainly not a negative and maybe even a positive. The lay model which we have included in this list is intended to reflect the opposite of the affirmation model. It reflects a popular, but not necessarily thought-out, view of disability. One of the parent-carer interviewees in our study explains from experience:

I didn't know about cerebral palsy, but perhaps he [the doctor] assumed that I did and so really, it was quite a body blow because all I thought of, as lay people do, is wheelchair! That's it, what does the future hold and any hope that you might have had is dashed again. ... I think when we first had [name], when we found out we wished she was dead. Definitely, I'll be honest about that, we wished that she wasn't around any more. We didn't want this child and why was it us? What had we ever done wrong and why couldn't it happen to somebody else?

What is left is the medical model which we wish to distinguish from the individual and lay models. It is clear from a casual observation of medical practice that

some impairment is created as a bi-product of life saving interventions and hence it would be wrong to view medicine as entirely synonymous to an individual model of disability. Yet it does exhibit some features of the individual model when decisions are made about not offering treatment because of a perceived low quality of life, and social model writers often accuse doctors of retaining power over social welfare decisions. On the other hand, doctors often say they want to provide treatment rather than to gate-keep welfare services and they will also usually seek to withdraw from any involvement with incurable conditions. Effectively, medical practitioners are already too busy trying to treat the 'treatable'. This means that the medical model is far more complex than casual inter-changeability with the individual model might suggest.

The wheelchair has not always been a piece of clinical equipment. According to Cooper (1998: 2):

In ancient times, dependence characterised the lives of those who were disabled. Fortunate people relied on servants or family members to carry them on litters. Others went off to die. Being carried on a litter was not necessarily stigmatising since it was the preferred mode of transportation for the wealthy and well-born.

Cooper goes on to give a brief history of the wheel chair:

The earliest record of a wheelchair was incised in stone on a sixth century AD Chinese sarcophagus. By the European Middle Ages, the litter had been supplanted by the wheelbarrow. The wheelbarrow, while rather undignified and still requiring another's power was convenient. The rolling chair was developed during the Renaissance as a heavy cushioned armchair with a reclining back and front legs equipped with casters. ... Later, Louis XIV used a *roulette* (a wheelchair of the period) while recovering from an operation. This popularised the roulette among the French court.

The modern wheelchair, like much else, is a creation of the Enlightenment for as the 18th century progressed, various governments began to finance the development and provision of wheelchairs especially for war veterans. The main advances in the technology of the wheelchair appear to have been led by disabled people, many of whom have set up the companies that produce wheelchairs today (Everest & Jennings; Quickie; Top-End; Magic-in-Motion; Halls Wheels and Eagle Sportschairs). The disabled survivors of successive major conflicts have prompted these advancements through their campaigning for inclusion in mainstream society (Cooper 1998).

Woods and Watson (2002b) argue that there is a need to take a social constructionist approach to understanding the relationship between the wheelchair as a technological product and disabled people. Different groups of actors will have different perceptions of the same objects. Ann Begg MP views her wheelchair positively and calls it her 'liberator' because it freed her from pain and the risk of fracture (Reilly 2002). Whereas Philip Olds, an ex-police officer

who killed himself, believed his wheelchair disqualified him from his male identity (Morris 1992). Woods and Watson conclude that:

a wheelchair is not merely a medical device, nor is it just a means of mobility. Wheelchairs are political. This political nature goes beyond the public into the realm of the private. Wheelchairs are highly personal devices.

The interviewees we have quoted from in these opening chapters have spoken about their perceptions of being disabled people who are wheelchair users. In using the discourses of individual, lay and social models they convey the diversity of experience and aspiration which characterises today's wheelchair users.

In Chapters 3 and 4 we shall extend this discussion through analysis of the interviews and the responses to our postal questionnaire survey.

2: Methodology

Investigation between acceptance of outline and final proposals

Following the acceptance of our outline proposal and the recommendations of the R&D Committee we wrote to the chief executives and chief officers of 16 AHAs and 31 CHCs in the North West RHA area requesting audit and other research data that might be available. We received replies from nine AHAs and six CHCs. Of the AHAs;

- Five had no information to provide.
- One sent data which shows a 50% increase in referrals over the period 1995-99.
- One sent two audit reports of limited value to our study.
- One sent the report of an opinion survey of wheelchair users which does not offer any explanations of wheelchair use or need.

Of the CHCs,

- Two stated they had no relevant information.
- One sent an executive summary on equipment provision.
- One sent an old report on young disabled people's experience of equipment and services.
- One sent an old report and an up-date on children and young people's experience of equipment and services.
- One sent a report on the state of waiting lists.

Overview of the research design

The research was planned in three stages.

1. An analysis in the first 3 months of the project of the electronic records of the Preston Disablement Services Centre which held data on 24,739 people.
2. In-depth interviews of wheelchair users with the objective of creating a questionnaire which can be used to survey the needs of further wheelchair populations. We planned for this stage to be undertaken by a seconded NHS therapist who would be registered for a higher degree (this would form the main part of our capability building contribution).
3. The questionnaire developed in stage 2 would be posted to a wider population of wheelchair users.

Application of the research method

Stage 1

The analysis of the DSC dataset was undertaken in order to confirm and evaluate the trends in referrals for wheelchairs and in order to provide a sampling frame for the second stage of the research. We intended to examine the trends in wheelchair referrals and investigate correlations which may exist between variables such as dates of referral, age, sex, location, ethnic origin and diagnosis.

Our analysis of the DSC data base was presented in October 2001. The analysis of the dataset yielded only limited information, which was partly due to the data having been collected for management rather than research purposes. However, of the data believed to be of analytic interest, most was unusable because it was incomplete. What we did manage to use from the DSC data set provided us with some basic demographic information which is reported in chapter 5. The geographical location of wheelchair users was difficult to determine from the dataset. The postcodes contained a large number of errors, including the insertion of spaces, and our attempts to recode them always resulted in the loss of about 7,000 patients from the data. That kind and size of methodological problem was not envisaged prior to the study.

We had intended that the DSC data set should give us a base-line from which to establish how far the survey we were to undertake would be representative of the whole patient group. As the DSC data on age and sex was reliable, that was considered sufficient for a test of representativeness.

The DSC data on medical condition was unusable, hence it was decided to ask a question about it on the survey questionnaire to give us a much better profile of the users of the service than is currently available.

Our examination of the DSC data set did highlight ways in which the data could be collected more rigorously in the future. For example, the omission of data on ethnicity was deliberate in as much as an individual had been misled about the requirements of the Data Protection Act, 1998. Since discovering this the DSC are now recording that information.

Stage 2

Stage 2 was a qualitative investigation into the nature and character of wheelchair use and the social life of wheelchair users. This stage produced information which was used to design the questionnaire that was then applied to a sample of DSC wheelchair users in order to quantify the issues identified in the qualitative stage.

As disabled people have privileged knowledge of why they use wheelchairs, it was only through in-depth interviews that we were able to gain insight into the lived experience of wheelchair use. We needed an understanding of the different explanations which users themselves offer about the acceptability or otherwise of wheelchair transport, in order to prepare a social survey which would allow a

large sample of wheelchair users to be able to express themselves in the limited format of the questionnaire.

We hoped that by talking to users we could assess the changing role of stigma in connection with wheelchairs. Their consciousness of 'difference' and 'acceptance' may also be a crucial element in increasing use, which explanations based on demographic models cannot access. In order to make sense systematically of a range of wheelchair user experience we needed to interview a relatively large group, for qualitative work.

This stage was undertaken by Glenis Donaldson as the field work component of her MPhil. As there was insufficient knowledge at the outset to design a structured questionnaire, this stage followed a grounded theoretical approach combined with themes and topics that were thought to be relevant. We considered it important when recruiting the research assistant that she be able to listen to the answers of the 'unasked questions', and develop the interviews the accordingly. In all 33 interviews were tape recorded, transcribed and then analysed using Atlas-ti.

Stage 3

The information gathered through the analysis of qualitative study at stage 2 was used to devise a questionnaire which would provide quantification of the social circumstances and attitudes of wheelchair users. We also hoped that the instrument could be developed in such a way as to make possible monitoring and evaluation of other DSC populations.

The main themes from the qualitative stage were:

Identity as a wheelchair user

- Aesthetics of wheelchair
- Discrimination – models of disability; group identity; new social movements
- Impairment/ age/ onset – loss
- Perception of impairment by self and others – stigma; reflexivity
- Self esteem
- Social activity – starting family; sexuality; partners; carers, children; social life; employment; education; sport
- Social changes and increase – causal relationship

Control

- Choice
- Exploitation
- Inclusion
- Income
- Independence
- Individualism
- Knowledge – professionals; ICT
- Social services

Utilitarian issues

- Access – environment; goods and services
- Consumerism
- Funding, financing
- Housing
- Part time/ full time user
- Prescription policy
- Transport
- Voucher scheme
- Wheelchair design and build quality

Therapy

- Medical professions and models
- NHS v private
- Occupational therapists, physiotherapists, alternative therapists
- Radical therapy
- Rehabilitation

We then entered a long process of questionnaire design as follows:

- Initial design
- Mock up
- Consultation with expert reviewers
- Modify
- Consultation with steering group
- Modify
- Pilot
- Modify
- Post to sample

The process was intended to check the reliability of the questionnaire before sending it to a random sample (nearly 5,000) of wheelchair users on the Preston DSC data base. This generated a response of 1,226 (approximately 25%). A response of this size should provide a reliable indication of the circumstances of the population of wheelchair users in the north west.

There are three kinds of problems with other research into the circumstances, experiences, views or attitudes of wheelchair users: they either have generalised from very small samples (for example Robinson 1987; Furnham and Thompson 1994); or they have failed to reach a representative sample particularly in terms of age (for example Aspinall *et al.* 1996) or they have restricted themselves to younger people (for example Cox 2001).

While these may provide some interesting insights into aspects of wheelchair use, the only large scale survey of wheelchair users that we are aware of, was the Audit Commission's (2000) investigation, *Fully Equipped*, into 'the provision of equipment to older or disabled people by the NHS and social services in England and Wales'. Whilst this explored the experience of the provision of equipment, our survey focused on the social implications of wheelchair use and is, to the best of our knowledge, the largest one as yet conducted in the UK which samples from the broadest available population of wheelchair users. Grewal *et al.* (2002) conducted a similar sized social survey of disabled people, but their study is restricted to people of working age, focuses on employment issues and is not solely of wheelchair users.

The responses was analysed using SPSS. The data was initially entered into SPSS and then we ran frequencies to check for erroneous values in each variable. These were then checked against the questionnaires and certain common errors were detected and corrected. A 10% sample was then completely checked and again, any patterns of errors were further investigated and corrected. As a consequence of these stages of checking, we are confident that the final data set used for analysis contains no significant errors.

3: The Experience of Wheelchair Provision and Use

Introduction

The qualitative stage of this study took place between 2001 and 2003. The research team set a target to interview 50 wheelchair users living in the north-west region. Unfortunately this figure proved to be unrealistic due to the limited response from potential interviewees within the two year time frame. In total 33 interviews were successfully completed and each interviewee received a £50 gratuity payment. It was decided that semi-structured interviews would be used to explore the views and experiences of wheelchair users. Although several key themes were identified by the researchers and steering group committee at the start of the project, the inductive nature of the research allowed interviewees to define issues that were of importance to themselves, hence a successful interview did not depend on the completion of a 'proforma'. In practice the interviews came to a 'natural end' when the interviewee felt that he/she had exhausted all relevant aspects of the given themes.

The selection of interviewees was performed in such a way as to achieve a partially stratified and random sample of the north-west wheelchair user population. This task required collaboration between researchers and personnel from Preston Disablement Services and the procedure took the following form. Descriptive data, in coded form, of all wheelchair users in the north-west region was made available to a researcher in the Department of Applied Social Science at Lancaster University. Potential candidates were then selected using criteria based on age, sex and geographical area. A coded list of potential interviewees was then sent back to the Disablement Services Centre. Potential interviewees were contacted by the centre. User anonymity was maintained up to the point at which the interviewee responded positively to the request to be interviewed and supplied their personal details to the university researcher.

The findings in this chapter are based on the 33 interviews. Each interview lasted between one and two and a half hours. All the interviewees used a wheelchair, some on a part-time basis, others were full-time users. All but one of the interviews took place in the interviewee's home. Some interviewees encouraged their partners to participate in the discussion whilst at other times the presence of 'others' seemed to inhibit responses. Although little attempt was made to control the characteristics of the interview group, examination revealed that there was a low response from ethnic minority groups, with only one person out of the 33 from an ethnic minority. There was also little response from wheelchair users living in east Lancashire. The one interviewee from there suggested that most wheelchair users in this area would perhaps feel that the researcher was working undercover for the Benefit Agency in an attempt to reveal fraudulent claims, hence their reluctance to cooperate.

This chapter identifies three aspects of data as disclosed by the interviewees:

- views about the prescription and provision of wheelchairs;

- views held about the hierarchical division between different groups of wheelchair users;
- views about the stigma associated with being a wheelchair user.

That tripartite demarcation was made in order to aid our understanding of the social reality of impairment, disability and disablement as related through the experiences of wheelchair users.

The Wheelchair Service

The pattern of provision has become increasingly varied since the service underwent decentralisation in April 1991, coincidentally at the same time as the introduction into the NHS of the purchaser/provider split. The introduction of the NHS and Community Care Act, 1990 and reforms of the NHS changed the service pattern in the north-west region (Aldersea 1996). The result of these changes was to make Preston Disablement Services Centre the provider to several regional purchasers. This pattern continued up to 2002 when the introduction of new NHS reforms and the creation of strategic health authorities and local care trusts marked another era of change. Local trusts were given the opportunity to develop alternative services, which would reflect local needs, an example is the provision of an independent service to wheelchair users in the Chorley and South Ribble districts.

The timing of the study (2001) was therefore opportune because potential interviewees could be selected from each geographical area contained within the North-West Regional Health Authority; North-West Lancashire, South Lancashire, Morecambe Bay, and East Lancashire, thus reflecting the new arrangements. Each of these authorities had secured varying levels of service contract agreement with the Disablement Service Centre. Those varying contracts had a bearing on the type of service provision offered to individuals, reflecting not only in the waiting times for assessment and delivery of wheelchairs, but also type of wheelchair supplied. These two factors act as the basis of a postcode lottery, where people living in one area receive a different service those in others. This problem was identified by Aldersea (1996) who noted the lack of national criteria for setting standards of practice, however she also pointed to the flexibility this allowed in meeting individual need:

... the greater ability of the devolved service to respond to local need increases rather than removes the necessity of setting national standards and guidelines.

(Aldersea 1996: part II p. 2).

Due to the qualitative nature of this part of the study, it is difficult to identify inequality of service provision between different geographical areas. However, it is possible to identify some of the consequences of inappropriate service provision, in particular the creation of the dependency of wheelchair users on family health and welfare services. The cumulative effects of dependency on the wheelchair user are also considered.

The interviewees illustrated this point when reporting their experiences of attempting to gain an 'appropriate' wheelchair from the Disablement Services Centre. Particularly poignant is the experience of a 53 year old woman living in social rented housing in Barrow who describes herself as being 'depressed'. It soon becomes clear that there are several key elements influencing her depression: the loss of her independence and subsequent dependence on her family, health and welfare services; her own perceived failure to comply with the medical expectation to adapt and manage her impairment; and her loss of identity as woman, mother and wife. These have contributed to a lack of her self esteem and a feeling of 'lack of worth' resulting in social isolation. When asked if she was 'happy' with the wheelchair that she had been prescribed she states:

I'd like an electric one, but because there is a five year wait, I think that I'll be dead by the time that my name comes up on the list. I can put up with the one that I have got now until I can sort it out.

By 'putting up with' an attendant controlled wheelchair her lifestyle is described in terms of dependency on others, usually family members, to take her out and to perform everyday tasks. Dependency on others has a 'domino effect'. She 'feels like a kid' when taken out by her son. She also tells how her reaction to dependency causes her to experience stress.

Well there are things I can't do like I used to do and it gets me down ... things like going out, going out to work, which I used to enjoy, but I don't go out now.

Not having access to the right type of wheelchair, and loss of employment and independence have resulted in her experiencing life as a role reversal from an adult to a child-like state. Dependency on others is one of the main contributors to her low self esteem. A combination of factors: the limitations imposed upon her by her impairment, pain and fear that her legs will let her down when she attempts to use crutches; restricting environmental barriers causing poor access to her local community; and lack of employment have led to experiences of isolation and depression, and to her social withdrawal.

...he watches his programmes and I watch mine but we enjoy it because if we hadn't telly we'd have nothing because I still wouldn't go out because I'm always frightened of falling over or getting stuck somewhere, you know. And I just don't want that.

This narrative illustrates how the experience of impairment and continued dependency on health and welfare services can be perpetuated through the lack of adequate social provision and support. The Labour government has taken a broad view of health inequalities and acknowledges the importance of both cultural and material factors on people's health. The 1998 green paper *Our Healthier Nation* emphasised the many diverse influences – social, economic, environmental and cultural – which work together to produce ill health (Department of Health 1998: para. 2.3).

Factors affecting health				
Fixed	Social and Economic	Environment	Lifestyle	Access to Services
Genes	Poverty	Air quality	Diet	Education
Sex	Employment	Housing	Physical activity	NHS
Ageing	Social exclusion	Water quality	Smoking	Social Services
		Social environment	Alcohol	Transport
			Sexual behaviour	Leisure
			Drugs	

Adequate provision could facilitate a state of independence and perhaps help a movement away from the 'sick role' (Parsons 1951), a role which this woman seems to have accepted.

Historically the provision of powered wheelchairs by the wheelchair services has been subject to budget constraints. Selection of recipients is based on 'strict criteria drawn up by each service to suit local needs and the budget available' (Aldersea 1996: part II, p. 24). Several studies have been used to inform the criteria. The 1991 Bradford Study (cited in Aldersea 1996) examined the cost benefits of supplying the wheelchairs and found that disabled people aged 20-44 years:

... are most likely to achieve independent mobility when they have an occupant-controlled powered chair. Older people who live alone (age 75+) can also achieve independent mobility but are less likely to use this for essential activities, e.g. shopping, but can become less socially isolated. Those in the 45-75 age group benefit by becoming less dependent upon their carer(s) – this appears to have benefits for user's and carer's health and mental state. (Aldersea 1996, part II, p. 27)

Aldersea also identifies factors which may limit the potential benefits of powered wheelchair use – carers' attitudes and environmental factors. Whilst these factors are of importance, what that study omits is the wheelchair user's voice. In our interviews some wheelchair users, in reflecting upon their own lives, did not talk about the benefits of the wheelchair as a mobility aid as they were unable to envisage this due to their experience of dependency and limitation of lifestyle brought about by inappropriate wheelchair provision. This point is illustrated by two interviewees.

One interviewee told the story of a 13 year old girl who lives in the Lancaster area. Her deteriorating condition meant that she became a wheelchair user in a short period of time.

This is her livelihood, this is her legs, this is what she has to be in twenty-four seven, this is what she has to be in every day of the week.

She started to lose feelings in her legs so she's permanently in a wheelchair. She got measured up for a new chair last July. The wheelchair never came until after Christmas. There

is six to seven months growth in [between, which] meant that when she did eventually get the wheelchair, the wheelchair did not fit. The wheelchair was badly made and was falling to bits.

The provision of a poor quality wheelchair again creates dependency on others. The importance of a wheelchair which meets both the physical and social demands of everyday life is made apparent. Another interviewee who had a head injury at a young age tells of the consequences of being prescribed a wheelchair which he felt was inadequate for his needs, but due to his speech impairment the prescribing agent does not listen to his views. The provision of an attendant controlled wheelchair further disables him and is instrumental in creating dependency on others.

I used to have a push wheelchair, yes, but when I was still in college I did say I wanted an electric one. I couldn't speak, could I, and being sat in a wheelchair I couldn't ask anybody to push me to the toilet.

Years later he still reports how his life is restricted by provision which still fails to meet his need.

You're more concerned with the battery capacity and how far you can go, you'd like one with a bigger battery. I would like one of them, those sort of like badger cars ... All my life (hesitates) Oh I don't know, it depends on them and what they say.

'Depends on them and what they say' gives an insight into the professional role in the creation of dependency and power relations. This occurs through the limitation of the user's role in the choice of an appropriate wheelchair. Through the course of this man's interview it became clear that a combination of his age at the time of the injury, his lack of speech, and the professional dominance of others have resulted in an absence of personal involvement when important decisions are being made about his needs. This process has continued throughout his adult life and has not helped him establish autonomy.

The power which health and social service professionals are seen by wheelchair users to wield over them is evident in many interviews. The following extracts are about alterations to wheelchair users' own homes to make them more accessible:

There was a meeting, it was very informal and I was never quite sure whether what I said, or if the meeting we were having, was going to be like the final decision type of thing. That's not to say the OT was bad or anything because everything is fine. It's just, perhaps not how I would have quite wanted it. I'd have been willing to pay a bit extra to have it done exactly to my specifications.

A similar account was given by another interviewee:

I was sat in the kitchen and they were wandering round the house, and upstairs, deciding on what they were going to do, and I'd no say in it, and it was like they were the adults and I was the child.

One interviewee generalises the point about being excluded by people who are supposed to be meeting the needs of service users, but seem uncaring and incompetent:

They just tell you what's going to be done, there's no discussing it with you, that's what infuriates me about social services. I mean they're just pen pushers at the end of the day, civil servants. It doesn't take brains to be a social worker and I don't think half of them know what they're doing anyway. And when you ring anybody to speak about anything you get passed round, and the left hand doesn't know what the right hand is doing and that infuriates you. And I think it infuriates you more so when you're in a position like this.

The interviewee's contact with social services had, presumably, occurred in the context of an individual needs-led assessment under the NHS and Community Care Act, 1990, but assessment does not necessarily lead to provision, as we shall note. However, ignoring wheelchair users' needs and wishes, by not asking directly what they might be, was not confined to those in the public service:

If I'm prepared to wait sixteen months for one [a wheelchair], yes, but I'm not. Initially how I got to have a scooter was that in my early twenties without consultation of any kind this local charity suddenly appeared with an electric chair for me. I mean by 'suddenly appeared' I was only told about it about two weeks before I got one, but I hadn't been consulted at any point about what might be suitable.

Aldersea highlights the lack of resources available to meet the demands of the user group. The report cites the following reasons for service inadequacy:

- An increase in the number of new clients registered each year, the majority being over 65 years of age.
- An increase in the severity of disability of many of those now being assessed for a wheelchair.
- An increase in the cost of equipment, due partly to price increases but also to the widening range of equipment available and loss of benefits enjoyed from volume purchasing.

(Aldersea 1996: part II, pp. 1-2)

These facts immediately place service providers in the role of gatekeepers to scarce resources. To supply an equitable service within the limited resources provided, the Disablement Services have been issued with a rationale and administrative guidelines on the selection and provision of a wheelchair. The categories are:

1. The long term full time user – no walking ability

- High Activity – Independent mobility and lifestyle. Appropriate equipment reduces dependence on others and improves quality of life.

- Restricted Activity – Unable to self-propel. Independent mobility with powered wheelchair. May require attendant for outdoor mobility. Degree of independence in basic daily needs.
- Low Activity – Limited or nil ability to self-propel. Dependent for many basic daily needs.

Hence the level of activity of the user will determine the type of wheelchair supplied.

2. The long term occasional user – (limited walking ability)

- Variable walking ability due to fluctuating condition. High degree of independence but requires wheelchair to maintain level of independence and quality of lifestyle.
- Ability to walk a short distance. Requires wheelchair on regular basis for outdoor use or to enhance quality of life for user and carer.

3. Short term temporary users

- Normally independently mobile. Immobile due to accident or operation. (May include terminal care).

(Extracted from *Wheelchairs: guidelines for purchasers and providers based on categories of users* November 1995, reproduced in Aldersea 1996.)

In these guidelines need has been defined in terms of the categorisation of users' mobility status. The interviews reveal how the categorisation of wheelchair users by mobility status still tends to be biased toward the more active user. People who have spinal injuries and who received treatment at tertiary or specialist centres seemed to be more informed and had more say in the choice of their wheelchair. It should not be forgotten that this group of wheelchair users are likely to be younger and therefore more assertive. Also, within the specialist centre they are part of a group of people with spinal injuries and therefore not as isolated as people with many other conditions. Many within this group also had financial security gained through compensation or employment.

In the ideological climate which stresses competitive individualism, independence is fore-grounded, thus reducing the respect afforded to people who are dependent (Sennett 2003). Becoming a wheelchair user is synonymous with dependency, but the individual model discourse of categorisation also distinguishes levels of dependency. Liggett (1988: 192) suggests that when practices 'operate by producing and managing identities', such as sub-groups based on impairment within administrative guidelines, this process binds both disabled and non-disabled people to their respective identities. It was possible within the interviews to identify attitudes that reinforce the hierarchy created by this system. At the top of the tree are people who have a spinal injury and have retained the use of their upper limbs and their ability to self-propel; lower down the tree are those people who have a congenital impairment and who are more likely to use a powered wheelchair.

Both sexes tended to report instances of resistance to cultural stereotypes, in particular interviewees were anxious to stress their resistance to using an electric wheelchair. Powered wheelchair users were described as being perceived as 'more dependent and less socially acceptable' than manual wheelchair users. This seemed to form the basis of people's desire to retain as much physical independence as possible.

There seems to be a level between a manual wheelchair and a powered one, if you're in a manual wheelchair people treat you as though you've got a brain more than if you're in a powered one. Again it's that step again ... I've a friend over in Ireland and her brother about three years ago was in a car accident and he's a paraplegic, but because he was very fit and healthy to start off with and he's been all over the world on basketball and he's really into his sport and that. I mean he's six foot four and he's only, now he must only be 25, but he's independent and I know it sounds silly, but I'm still dependent on people because I can't self-propel and the chair is, well it's not really, it's something I think that in a couple of years it might be of antique value.

A young man in his mid twenties who had sustained a spinal injury talks about his struggle to negotiate his manual wheelchair in his local environment but also his reluctance to use a powered wheelchair, as it would signify defeat.

Well it's hard to get around, just out and about in the streets, it looks flat when you are on foot, but you soon discover that it isn't flat when you are in your wheelchair. Even kerbs are an absolute nightmare and I suppose one answer to it would be to get an electric wheelchair, but that is something I want to avoid if I can ... I think that it is something about admitting defeat in some ways. Whereas if you are pushing about you're sort of using your body to get yourself around. Even if you are not using your legs you are using your arms, but as soon as you start using an electric wheelchair there is a stigma attached to it.

Another male interviewee linked being able to gain more physical independence with regaining a more positive image.

I'd feel more human if I were ambulant with sticks.

Some interviewees with acquired impairments were anxious to emphasise the difference that they felt between themselves and other wheelchair users who had congenital impairments, based on the biological differences that they perceived between them.

This sounds bad. I wouldn't look down on them, I'm not that sort of person, but there is something different about having an injury, an accident, you're different because I've known what it is like to walk and everything like that, whereas somebody who's been disabled from birth doesn't. So I probably do not consider myself in the same situation as them and in some ways it is easier for them, because they have never known, they've never had to put up with the shock of losing the ability to do everything. I'd rather go on holiday with

people who had spinal injuries, I suppose partly because I know what's wrong with them.

A female interviewee who was born with cerebral palsy takes a different perspective. She talks of her pride in being disabled and in doing so, celebrates her disabled identity.

I see it as a chair with four wheels and I think that's how it should be seen, but I do know that able-bodied people or more able people see it differently. And when I'm in my scooter I am treated differently. A large part of me thinks that I am disabled, so what! And I am actually proud to be disabled, but it is part of me and I have a really good life and it's the people that think that I don't, because they see restrictions that aren't necessarily there.

This woman, talking within an affirmation model of disability, first identifies that it may be either non-disabled people or differently disabled people who are likely to perceive her and her impairments as a barrier, rather than a disabling environment. The previous interviewee who had acquired his impairment, although not speaking from the lay model, was still located in an individual model of thinking that we would expect to find in non-disabled people.

Definition of need

Aldersea identifies the advantages of access to local wheelchair facilities as a vital part of the educational programme and its importance in the development of social skills.

The provision of such equipment enables the child and young adult to benefit from other services provided and, in particular, will enable the child to be educated or provided with independent mobility and help prevent deformity and enhance the quality of life which thereby facilitates the development of the individual's physical, psychological and social skills. (Aldersea 1996: part II p. 11)

This statement clearly endorses the provision of a mobility aid based on the following rationale: postural management of the physical impairment and independent mobility will result in access being facilitated to education, and to community based health and welfare services. It is assumed that these factors contribute to the social development of the individual. Whilst these aims may be of value, particularly to the developing child, it must be appreciated that there are other factors identified by wheelchair users that impact on social inclusion. Service providers need to be attuned to how individuals perceive their impairments and the extent to which they control social constraints. Failure to do so encourages the view that medical and rehabilitation agencies foster social oppression by embracing paternalistic notions of empowerment and by identifying individual rather than social problems. Contrast these three views on medical experimentation aimed at getting paralysed people to walk:

I think they're [people like Christopher Reeve] living in a fantasy world. I think being such a high profile person like he is, he could do more good for disabled people. I didn't

like the advert where it showed him walking because it made it like, well if you want to be normal ... you've got to be walking. ... I thought well what you're stating is it's not acceptable to be paralysed...

I've been asked to go down that route, but I would never go down that route simply because I think about life now and before I had my accident. One day I woke up and I had nothing, and I've coped with nothing, and I've learnt to deal with nothing, and I've got on with nothing and that helped. That nothing has brought everything. Now to be given a chance of having it back is scary. ... Just to be a guinea pig and to try out stuff and that, but they don't tell you the ins and outs, and you've got to bear in mind that it's so many, that so many months or years is going to be taken away from your life because you're going to be involved in occupational therapy, physiotherapy, back and forth to the hospital and I don't want that. I've got a life.

Well I'm 110% behind them, yes I'm very hopeful and very confident that something will happen. I don't suppose I'll ever play football again, but if I could just get out the chair for part of the day I'd be so much better off, and if just other things like bowels and bladder, if they were improved...

Wheelchair prescription has historically been based upon a medically defined service model of delivery premised upon the categorisation of the users for administrative purposes. The role of a wheelchair service has historically been to supply a mobility aid which best suited the need of the disabled person. This remit has also come to include the supply and funding of an appropriate seating insert which varies according to postural management required by the individual. The assessment of need of wheelchair users by health care professionals has been biased towards a medical assessment of clinical needs and although this has played an invaluable role in the lives of some of interviewees, the views of many are clearly at odds with medical definitions.

Contrast the experiences of two wheelchair users: a 30 year old man whose impairment has been caused by trauma; and a young girl whose impairment is congenital. The young girl's story is told by the identified male who works with the girl in an educational setting. The two characters also have links to the local wheelchair basketball team. Both parties wish to use the voucher system to purchase a wheelchair of their own choice for different reasons. The man, because he lacks faith in a professionally run service and the girl, because of the quality of the wheelchair supplied previously. The man describes his experience at the Disablement Services Centre.

The experience is very strange as well as the whole routine. You have to get assessed by going into this room and sitting in front of a panel. And I entered this room and sat in front of a panel and they said, "Why are you here?" I said that I was told I could maybe get a new wheelchair through the

voucher scheme and they looked at my chair and they looked at me and they said, "Oh you know what you want" and I said, "Yes" and that was it. And I went, and the next minute I got a voucher in the post for about £1200 that covered most of the cost of the chair.

The girl, accompanied by her parents had also been assessed at the DSC.

I found out that her mum and dad had already tried to apply for a voucher scheme, which they were offered £375 which I said was absolutely disgusting. How they can expect you to buy any sort of wheelchair for £375?

The money to buy the girl a more fitting wheelchair had to be raised through charity.

There are similarities between the two applicants based on the categorisation guidelines; both would fit into the full time user category and both *should* fit into the high activity category. One applicant has a substantial voucher award and the other does not. We suggest this can be explained in the following ways:

1. Breakdown in the communication process at assessment resulting in a failure of the assessors to appreciate the girl's needs. Or these needs may have been played down by the parents based on their own expectations for their daughter.
2. The categorisation of users based on a scientific discourse which constructs a hierarchy of disability based on impairment. Links are made by the assessors between the type of impairment and the assessors' expectations of the disabled person's lifestyle, which are informed by cultural discourses about disability, i.e. prejudice. This may have guided their decision making.

The latter highlights how therapists, who despite being provided with a categorisation system that is intended to be rigid in its application to wheelchair users, can still give rise to inequality and restricted social functioning. In the girl's case this results in a 'failure to thrive', to use a medical terminology. Thompson (1998) contends that powerlessness is linked with oppression. In this case the girl had little control over the choice of her wheelchair and this had implications for her lifestyle. An interviewee with an acquired impairment, speaking from the lay perspective, establishes 'the difference' on which that hierarchy is built:

I think, they [people with congenital impairments] haven't had to cope with it in so much as they haven't had, OK I was twenty when I had my accident so I'd had that independence. I had gone through the teenage years and done all the running and the jumping, and I think personally because they don't know about it they're not going to miss it. So what you don't know about you don't miss. I might be wrong.

Such episodes result in a lack of faith in medical services. It was not surprising therefore that many wheelchair users were in favour of using an advocate when dealing with services which involved professional interventions. Several wheelchair users did identify other wheelchair users as being their preferred advocate.

The social effects of stigma

There's still a huge stigma about being in a wheelchair like, 'Oh he must be retarded or whatever' and you know you get people talking to the person who's with you rather than you, but yes, some people definitely don't treat you as an equal.

The interviewees reported the oppression they experienced in their everyday lives, which seemed to them inextricably linked with the social stigma associated with wheelchair use, as this middle-aged man illustrates:

I never wanted to get to a stage where I had to use a wheelchair, it's not embarrassing, *it's just people.*

Stigma in this instance reflects the low social value that society assigns to wheelchair users, which can be extended into one's presentation as a professional in the health and social welfare services:

I said, "I don't want a wheelchair, what do I want a wheelchair for?" And the stupid thing was that I'd spent a lifetime working with older people and people with disabilities and that was for somebody else. You see I was the carer. It doesn't happen to me, absolutely no way. I don't need a wheelchair.

Interviewees talked about three influential sources of stigma:

- that provided by cultural representations of disabled people in popular television shows;
- fear of the infectious nature of disease;
- that gained by association with medical professionals.

This gave rise to relative isolation of the wheelchair user by the creation of difference between themselves and non-disabled people.

Cultural representation

One interviewee uses an example of how common conceptions about disabled people are gleaned from a popular television programme:

Well, it sums it all up in *The Office*. I know it's a television programme, but when David says, "The disabled" and he like belittles it, "And you can't tell the difference with the ones in the wheelchairs. It is very difficult to tell whether they actually have got a brain or not but give generously anyway", kind of thing. People assume that if you cannot walk that you have a mental impairment as well and I don't know where that has come from.

Explicit in this extract is the stereotypical image associated with physically impaired people as a social group; that is wheelchair users who are dependent on others for their care, charity for their well-being, and by implication are socially inept.

The majority of social interactions of wheelchair users are without doubt tainted by the effect of stereotypical imagery. An interviewee, who reflected on his

assumptions about wheelchair users before he became one himself, sums up the dilemma the public faces.

I'd like to think ... that I would not treat them any differently and I think once I'd got to know them I wouldn't have done, but perhaps the first time that I met them I maybe would have been not very sure how to act with them. That is it, just not knowing what is wrong, not knowing how they ended up in that situation; if they'd always been like that or if it was an accident or what. Not knowing how, what they can or can't really do.

This mix of lay and individual voice is basically inspired by the medical model: "not knowing what is wrong". The person in the wheelchair may locate the 'wrongness' elsewhere. However, this interviewee went on to suggest that more wheelchair users being around challenged lay attitudes:

The thing is there's another lad who's in a wheelchair who lives in the village so he's sort of broken them in to wheelchair users.

The individual/medical model discourse of 'what is wrong?' creates particular barriers for the social inclusion of disabled people. Slack (1999) describes the experience of being on the receiving end of that question:

Communication with new people can never be fresh and barrier free, because they draw on their visual sense first and take the cue from there. They have made some judgements already because they are privy to visual information about me which they then feel at liberty to comment on. The opening to a conversation will mostly be, 'how long have you been in that wheelchair?', or 'what happened to you?' Some people feel they have a natural right to hear my life story, whether I wish to tell it or not. This poses serious difficulties in new acquaintances because the agenda for the conversation has been pre-written by someone else. The effect is to block the possibility of opening the conversation with equal information sharing about each other. (Slack 1999:33)

Fear associated with wheelchair users

A young woman in her early thirties describes the attitudes and behaviour of others around her based on the nature of her illness.

I say I've got Earl Downs Syndrome, and they say, "What is that?" I say, "It was something that I was born with" and then it is like their whole demeanour changes and they look away suddenly ... and the children are clutched towards them. It is not contagious!

When an illness is seen as infectious, or perceived as a mark of dishonour or shame, people with those conditions may be rejected by the healthy population. Another fear which may exist for non-disabled people is the uncertainty about how to behave and communicate with a wheelchair user.

With an adult it's like all this political correctness and everything. I think they're so frightened of coming out and saying, "What have you done?" Or they're afraid to talk to

you, maybe they lose confidence when they see a disabled person.

Inferences made because of medical association

If it comes to social services or places, when it comes to organisations or professional bodies, then I do think that I suffer a kind of stigma as far as independence is concerned, because it is not an individual that I am depending on it is a service. I'm not entirely happy with it, but it is something that I have got to let go of because in the end I am looking at the quality of life for myself and my family.

Another interviewee talks about his perceived change in identity when he became involved with health and welfare professionals.

I think the most important thing that anybody has got to remember is that a quarter of a second before my accident, before I hit the bottom, I was as able as anybody else, more able than most people really. And I just want people to remember that I haven't changed personally, it is just physically and that is really hard for some people. I suppose that I have changed a bit because it is inevitable, people you come across in Social Services, yes most of them are fine. I suppose because you're their job now rather than somebody they might just meet.

Interviewees described a variety of strategies in which they attempted to 'negotiate' the social consequences of the stigma associated with being or becoming a wheelchair user. The first is by resistance, whereby all means are used to remain ambulant and hence maintain a normal appearance, and secondly by avoiding people who know them. The following extract given by a 24 year old woman, who is now a full time wheelchair user, describes how her resistance to becoming a wheelchair user was based on the friendships she wished to maintain with her non-disabled peers.

I should have been in a wheelchair before, but I did not want one. I would not give in. I'd lost all my mates at school, once they found out that I wasn't going to walk again and because I was a bit unsteady. I wouldn't go out and get drunk in case I fell. Every time I fell I got worse and they disowned me and didn't want anything to do with me. I thought that if I go in a wheelchair then I'll have no mates. I was embarrassed enough because the dystonia makes you twist. I just wanted to be what I call normal, and then I thought that it would be more normal to be on crutches.

Another interviewee emphasised the way he avoided such encounters.

I've never been up town, there's a new shopping centre in [name of town], and it's been built for five years and I've never seen the shops yet. I don't like to bump into people. I was always one fit lad and it's all the same questions, "What's wrong with you?" and "What have you done?"

Another interviewee cited the embarrassment of being in a wheelchair as the reason for his avoidance tactics.

I'm still embarrassed about it really. I'm a lot happier going out and about in places where people don't really know me; still partly because I see people out in town who I haven't seen for years and perhaps I would not have spoken to them anyway, but I see them looking and thinking, "Oh bloody hell there's [name] in a wheelchair, what's happened to him?" So I go out in other towns and I don't care because I don't know as many people.

A strategy for coping can be changing, or restricting one's circle of friends:

My friends now are friends that I've built up relationships with since I've been back home. Friends before my accident have nothing to do with me, are embarrassed to see me when I'm in town. Bearing in mind there was ten of us that went out on the night of my accident, couple of cars, and I even see them in town and they look at me, and I don't know if they're embarrassed or anything or whether they think I've changed. I don't know. Out of all my friends that I used to know before my accident, I've only got two that I keep in contact with.

Implications for wheelchair services.

Whilst interviewees acknowledged the potentially valuable role of the wheelchair services, some criticised professionals for tending to remove choice and control. As we have noted, Aldersea (1996) outlines how the escalating cost of the wheelchair service and the need for financial restraint is to be managed. Wheelchair prescription is defined by set criteria, whilst outcomes are measured in terms defined by cost-benefits, the amount of mobility gained, and how this impacts on social isolation. Instances have been quoted where the introduction of the voucher system, which at its inception was supposed to offer people more choice in accordance with their lifestyle, still favours those who are classified as being full-time, active wheelchair users with types of acquired impairments that are more socially accepted – injuries rather than illnesses. This reinforces the idealised hierarchical division which seems to exist between different categories of wheelchair users. In contrast to this division we have been told of instances where advocacy by a wheelchair user on behalf of another has led not only to an improved outcome, but served to unite wheelchair users in a collective identity.

This administrative system is rigid in its application and has failed to take into account the other causes of social isolation and the other inhibiting social factors about which wheelchair users talk. If success is defined in terms of increased mobility, other social factors that influence social participation must be taken in to account. For example, particular emphasis must be placed on the reaction of others as the basis of discrimination experienced by wheelchair users in their day to day interactions with non-disabled people. This is one of the negative influences wheelchair users have to negotiate everyday of their lives. Most of the interviewees talk about feeling vulnerable when they are out in their wheelchairs and would not contemplate going out unaccompanied.

Interviewees were realistic in arguing that the range of challenges and difficulties which they faced in their lives could not be reduced to a set of technical fixes by professionals. The limitations of the individualism and medicalisation inherent in

the training and practices of professionals, which tended to turn people with impairments into clinical cases, seemed to be clearly understood by interviewees, but this ultimately led some wheelchair users to under-play their needs and tolerate the social limitations that they experienced as a consequence. However, only those interviewees who had gained access to other sources of wheelchair provision (those who had sustained a spinal injury or those who had access to funding) were willing to criticise wheelchair provision from a statutory source.

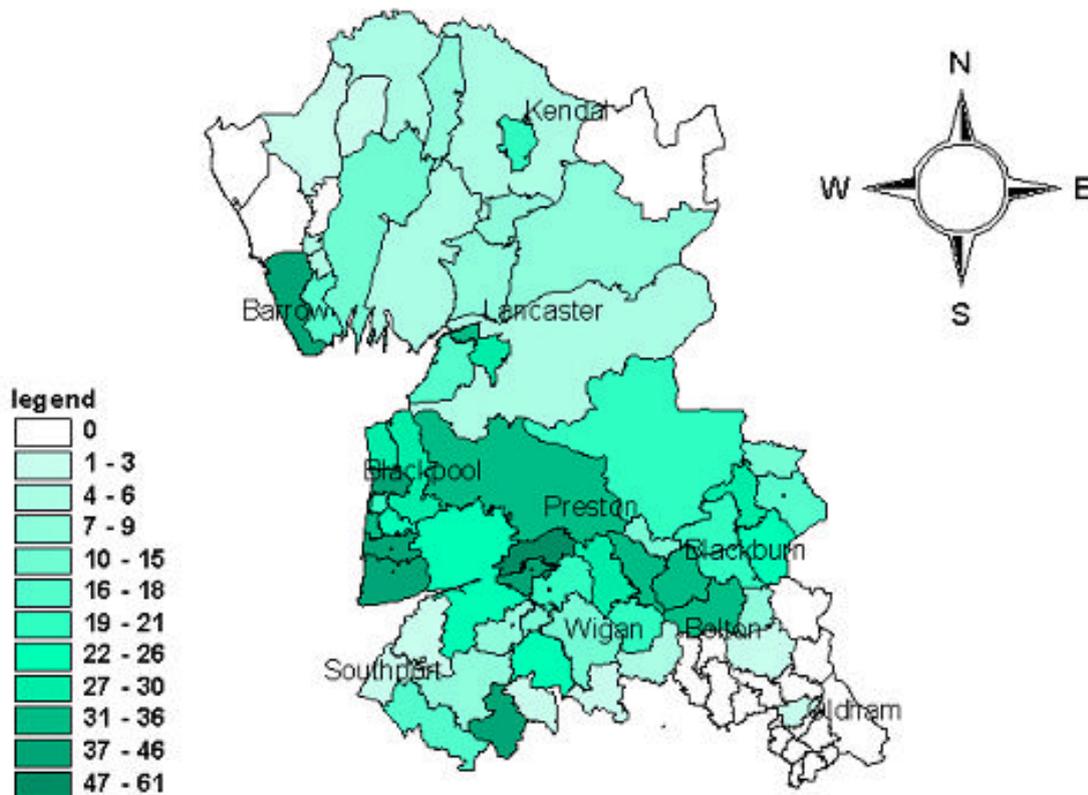
4: The survey

The sample

This chapter reports on the questionnaire survey of patients on the Preston DSC data base in early 2003. Some categories of patient were excluded from the mail-out as the DSC staff felt it would inappropriate and possibly distressing to those people: for example, those diagnosed as terminally ill. All the patients mailed were recorded as having a wheelchair from the DSC. Great care was taken in achieving anonymity, both of the sample mailed to, and the actual respondents. On the basis of our sample size and stratification terms, DSC data processing and administrative staff prepared the address list and mailed the questionnaires. The DSC was the return address for respondents. Only at this stage did research staff collect the questionnaires, which were completely anonymous.

We agreed that a 20% sample of the full patient data based should produce a sufficient response to be representative. The sample drawn was stratified by health areas of the region covered by Preston DSC. The postcode map below shows the achieved distribution of respondents.

Figure 1. Geographical Distribution of Respondents



It confirms our confidence in the representativeness of the survey: areas of high population show high returns; the more rural areas, lower; the whole region served by Preston DSC is represented. In order to preserve anonymity we did not ask respondents for their full postcode, hence we cannot refine our data to investigate the problem of a postcode lottery discussed in chapter 3. Despite this, it is rather clear that a disproportionate number of respondents live in the Fylde coast and Wyre, implying there is a higher incidence of immobility there. It is widely recognised that the Fylde coast is an area with a high retirement population of older people which would account for this disproportionate incidence of wheelchair use. This supposition seems to be supported by the higher ages of respondents giving Fylde coast postcodes, except that there is an unexpected concentration of teenage wheelchair users in Fleetwood, not matched by any other postcode area.

Our expectations of representativeness were realised as we achieved a 25% response rate to our mailed survey questionnaire of April 2003; the total number of questionnaires used in our analysis being 1226. The Preston DSC had provided us with selected data on all the 24,739 patients on their data base in June 2001. Hence we can say that 4.95% of the patient data base has responded to our survey. We will show that our sample matches the full data base on the key variables of age and sex.

Key demographics

Table 1. Respondent

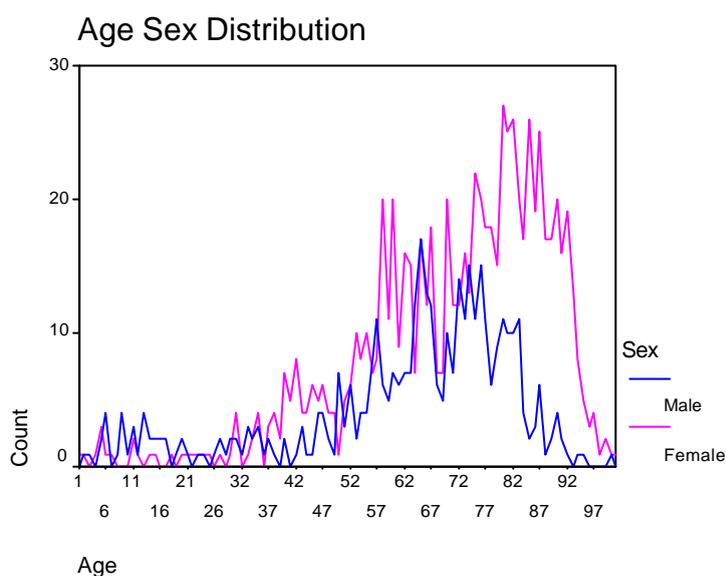
	Frequency	Percent	Valid Percent
self	603	49.2	58.4
other	429	35.0	41.6
Total	1032	84.2	100.0
Missing	194	15.8	
Total	1226	100.0	

Just over half of the questionnaires were filled-in by the wheelchair users themselves. Relative to other social surveys, there appears therefore to be a very high rate of completion by another person. That 'other person' will invariably be the carer/partner/parent of the wheelchair user, or it is likely to be care staff where the respondent is in a residential home. We might have hoped for a higher rate of self-reporting, but as the data will show, our population is old and it has many medical conditions. We have demonstrated in previous chapters that disabled people are excluded from control over many aspects of daily living, not least of which might be filling in one's own survey form! Hence we have some concern over whose view is being represented. However, many of the questionnaires have notes confirming that the views are those of the wheelchair user.

Table 2. Sex Distribution of Wheelchair Users in Survey

Sex	Number	Percentage
Male	403	33.9
Female	787	66.1
Total	1190	100

Graph 1. Age and sex of wheelchair users



Overall, there are nearly twice the number of women to men. Up to middle age the proportion of men to women is roughly the same. It is in the age range above 60 years that the proportion of women increases dramatically. Typically, the wheelchair user is an older woman. This distribution is consistent with that reported by Sapey (1995) in his study of Cornwall patients from the Plymouth DSC and is also consistent with data we received from Manchester DSC in 2000.

Table 3. Age Statistics for Respondents and Total Population

	Survey	Preston DSC July 2001 (Cornwall only)	Plymouth DSC April 1993
Valid cases	1192	23216	4728
Mean	67.92	67.61	67.9
Median	72.00	74.00	74
Mode	80	81	85
Std. Deviation	19.371	22.154	23.19

We should note the close correspondence on age between our survey respondents and the full Preston DSC patient data base, making our survey representative on a key variable.

Table 4. Distribution of medical conditions

Condition	Frequency	Valid Percent
Amputation	48	4.4
Arthritis	272	24.8
Cancer	8	.7
Cardio Vascular	61	5.6
Chest conditions	23	2.1
Cerebral Vascular Accident	205	18.7
Diabetes	15	1.4
Disease	40	3.6
Fracture	13	1.2
Genetic	4	.4
Hereditary	2	.2
Ischaemic	5	.5
Mental Health Problems	10	.9
Miscellaneous	41	3.7
Neurological Disorders	186	16.9
Old Age	46	4.2
Orthopaedic	66	6.0
Respiratory Failure	9	.8
Syndrome	43	3.9
Tumour	1	.1
Total	1098	100.0
Missing	128	

This list will not be representative of all wheelchair users as some, notably those with terminal illnesses, were excluded from the sample. Our categories of medical conditions were taken from a standard NHS listing used by the DSC staff. Where multiple conditions were given on the survey form, only the first one was recorded though we cannot be sure that this was the most significant in terms of ambulant immobility. These conditions are of course being self-reported. Three conditions account for 60% of respondents: arthritis, CVA and neurological disorders.

We had hoped this data could be compared with earlier findings to ascertain if conditions had any significant role in the increase in wheelchair use, but have not been able to find data that is comparable for wheelchair users, rather than all disabled people. However, Cooper (1998:10) reports on an undated survey by the 'British Ministry of Health' that categorised the 'disability etiology' of wheelchair users (see Table 5).

Table 5. Percent of wheelchair users by disability etiology, pre-1968

Condition	Percent
Arthritis	28
Organic nervous disease	14
Cerebral vascular disease	13
Other bone injuries and deformities	11
Lower limb amputations	9
Cerebral palsy	8
Traumatic paraplegia	7
Respiratory and cardiac disease	3

Whilst this list is undated, we feel safe in assuming that as it was produced by the 'British Ministry of Health' it predates 1968. The data confirms the obvious, that illnesses associated with ageing were and are still dominant, but given our caution about the accuracy of self-reported data and the way we have had to select from multiple conditions, there is little more that could be concluded from this.

Medical conditions form a central point of reference for those operating in the health services and as we have discussed in chapter 3, they may also form the basis of unequal and differentiated services. One aspect of wheelchair use that may justify differentiated services is whether people are full-time or part-time users. Nearly two-thirds of our sample were part-time users (Table 6) and this is consistent with Aldersea's (1996) findings.

Table 6. Full-time and part-time wheelchair users

	Frequency	Percent	Valid Percent
Full-time	429	35.0	36.8
Part-time	737	60.1	63.2
Total	1166	95.1	100.0
Missing	60	4.9	
Total	1226	100.0	

From the concerns we raised in chapter 3 about hierarchies of impairment, we decided to compare conditions with levels of use (Table 7). However, these categorisations are much broader than the specific conditions that formed the hierarchies. From our examination of this information with other data from our survey, we were not able to draw any specific conclusions about the way the differentiated service might be operating.

Table 7. Crosstabulation of Condition by Use.

Conditions (excl. <2% of sample)	Full time users
Amputation	54.2%
Arthritis	27.6%
Cardio Vascular	16.4%
Cerebral Vascular Accident	42.1%
Disease	50.0%
Miscellaneous	46.2%
Neurological Disorders	46.7%
Old Age	26.7%
Orthopaedic	31.7%
Syndrome	44.2%
All conditions	36.4%

A comparison of type of wheelchair with level of use does show a few differences which should be expected. Table 8 shows that part-time users are less frequently provided with a self-controlled electric wheelchair and more frequently provided with standard wheelchairs than are full-time users.

Table 8. Type of Wheelchairs Provided to Full and Part Time Users

	Full time user	Part time user	Total
Standard manual self propelled	165 42.3%	324 48.9%	489 46.5%
Standard manual attendant controlled	110 28.2%	245 37.0%	355 33.7%
Lightweight manual	26 6.7%	33 5.0%	59 5.6%
Buggy	4 1.0%	2 .3%	6 .6%
Powered self controlled	61 15.6%	35 5.3%	96 9.1%
Powered attendant controlled	7 1.8%	5 .8%	12 1.1%
Other	12 3.1%	14 2.1%	26 2.5%
Not known	5 1.3%	4 .6%	9 .9%
Total	390 100.0%	662 100.0%	1052 100.0%

Just over a half of our respondents were married or living with a partner. Almost 30% were widowed.

Table 9. Marital status

	Frequency	Percent	Valid Percent
Single	154	12.6	12.7
Married	593	48.4	48.8
Living with partner	23	1.9	1.9
Divorced/separated	82	6.7	6.8
Widowed	362	29.5	29.8
Total	1214	99.0	100.0
Missing	12	1.0	
Total	1226	100.0	

When examining the marital status of respondents we note that the high proportion who are widowed relates to the age and sex composition of wheelchair users. They are preponderantly older women who have survived their partners. Table 10 shows the dramatic rise in widowhood as age increases.

Table 10. Age by Marital status

Age Group	Marital status					Total
	Single	Married	Living with partner	Divorced separated	Widowed	
1-9	18					18
	100.0%					100.0%
10-19	22					22
	100.0%					100.0%
20-29	15		1			16
	93.8%		6.3%			100.0%
30-39	22	12	2	2		38
	57.9%	31.6%	5.3%	5.3%		100.0%
40-49	14	37	11	10		72
	19.4%	51.4%	15.3%	13.9%		100.0%
50-59	13	97	5	19	8	142
	9.2%	68.3%	3.5%	13.4%	5.6%	100.0%
60-69	16	156	1	26	21	220
	7.3%	70.9%	0.5%	11.8%	9.5%	100.0%
70-79	14	176	2	17	66	275
	5.1%	64.0%	0.7%	6.2%	24.0%	100.0%
80-89	11	96	1	6	166	280
	3.9%	34.3%	0.4%	2.1%	59.3%	100.0%
90+	3	8			93	104
	2.9%	7.7%			89.4%	100.0%
Total	148	582	23	80	354	1187
	12.5%	49.0%	1.9%	6.7%	29.8%	100.0%

Nearly a quarter of respondents live on their own (see Table 11). This compares with 30% of all disabled people, but only 11% of the total population (Oliver and Sapey 1999: 108). Whether married, or living with their partner or another close relative, three quarters of wheelchair users live with at least one other person.

Table 11. Living Arrangements of Respondent

	Frequency	Percent	Valid Percent
Living alone	286	23.3	23.7
Not living alone	920	75.0	76.3
Total	1206	98.4	100.0
Missing	20	1.6	
Total	1226	100.0	

Focusing on those who are living alone, it is valuable to know something about their network of support. We asked if the respondent could rely on a carer nearby to help them.

Table 12. Carer Nearby by Household Living Alone

Carer available nearby	Living alone	Not living alone	Total
Yes at any time	201 71.3%	432 50.5%	633 55.6%
Yes, sometimes	63 22.3%	247 28.9%	310 27.2%
No	18 6.4%	177 20.7%	195 17.1%
Total	282 100%	856 100%	1138 100%

Of the 282 respondents who live alone, just 18 (6.4%) have no carer nearby on whom they can rely for help. There is nothing demographically unusual about these 18 people. Of the 856 respondents who do *not* live alone, 177 (20.7%) have no carer nearby. Whilst 93.6% of wheelchair users who *do* live on their own can rely on a carer nearby, a much lower proportion (79.4%) of respondents who do *not* live on their own can also rely on a carer nearby. Overall, the availability of a caring network is high and although one might expect it to be the case, it is encouraging to confirm that living on one's own appears to be associated with a higher rate of carer availability.

Table 13. Marital Status by Household Living Alone

	Living alone	Not living alone	Total
Single	37 24.0%	117 76.0%	154 100.0%
Married	2 0.3% ⁴	586 99.7%	588 100.0%
Living with partner		23 100.0%	23 100.0%
Divorced/separated	51 63.8%	29 36.3%	80 100.0%
Widowed	192 54.1%	163 45.9%	355 100.0%
Total	282 23.5%	918 76.5%	1200 100.0%

Although widows are only marginally more likely to be living alone than not, they constitute nearly two thirds of all those who live alone. Being single or married is associated with living with someone else; divorce and separation are clearly not. However being separated or divorced, although associated with living alone, is not associated with the absence of a support network. Only 14% of divorced and separated respondents could not rely on a carer nearby – second only to widows of whom 10% had no carer nearby.

Table 14. Receives any Disability Benefit

	Frequency	Percent	Valid Percent
Yes	963	78.5	84.8
No	173	14.1	15.2
Total	1136	92.7	100.0
Missing	90	7.3	
Total	1226	100.0	

The least reliable part of our data relates, we believe, to social security benefits. Although we asked questions about disability and means-tested benefits, the responses are such that we do not have high confidence in its reliability. Hence we are not presenting detailed tables here. The table above, showing a straight count of major disability benefits, produces a worrying 15.2% who do not appear to receive any social security.

⁴ Both these women had husbands living in residential care homes.

Table 15. Ethnic group

	Frequency	Percent	Valid Percent
White	1185	96.7	98.8
Black Asian	4	.3	.3
Other	11	.9	.9
Total	1200	97.9	100.0
Missing	26	2.1	
Total	1226	100.0	

The non-white groups seem extremely low to us, but we cannot offer a comparative test. As we have explained, although the Preston DSC collected data on ethnic origin, it was not recorded at the time we received a data set, hence we cannot compare our distribution with the full patient set. We can tentatively suggest that as wheelchair users are predominantly older, the incidence of use by people from ethnic minorities will take some time to work its way into the general population of wheelchair users. All four black Asians were between 40 and 69, whilst 'other' was evenly distributed across the age range proportionately. Given the very small numbers, it is probably advisable to be very cautious about using this data to make any inferences.

Housing demographics

Table 16. Type of Home

	Frequency	Percent	Valid Percent
House	579	47.2	48.1
Bungalow	326	26.6	27.1
Flat	137	11.2	11.4
Maisonette	7	.6	.6
Residential/nursing home	136	11.1	11.3
Other	18	1.5	1.5
Total	1203	98.1	100.0
Missing	23	1.9	
Total	1226	100.0	

It is worth noting here (Table 16) the high proportion of respondents who live in dwellings on one floor, 38%. We can presume that many wheelchair users will move to live on one floor with level access which would account for this particular phenomenon. There may be problems of internal accessibility even on one floor, but for nearly half the respondents who live in conventional houses, there is presumably the issue of accessing the first floor. The 11.3% of respondents in residential care/nursing homes is high in contrast with a national average of around 1%. Among this group, about a quarter of respondents filled in the questionnaire themselves compared with 58% of our total sample (Tables 1 and 17).

Table 17. Respondents Living in Residential Homes – Who Filled in the Questionnaire?

	Frequency	Percent	Valid Percent
self	30	22.1	24.8
other	91	66.9	75.2
Total	121	89.0	100.0
Missing	15	11.0	
Total	136	100.0	

Table 18. Type of Home by Satisfied with Access Within Home

Type of Dwelling	Satisfied with access	Dissatisfied with access
House	399	138
Maisonette	2	4
Bungalow	254	51
Flat	94	32
Residential/ nursing home	100	7
Other	14	2
Total	863	234

As would be predicted, table 18 indicates a higher level of satisfaction with the accessibility of bungalows (83.3%) than other dwelling types (76.9%), however there is a similar level of dissatisfaction with access within flats (25.4%) and houses (25.7%). Flats were more likely to have level access than houses and council tenants were somewhat less satisfied with internal access than those in other tenures. It is the tenants in social rented housing who are most likely to occupy flats, whereas houses are mainly in owner occupation. Council tenants are fairly evenly distributed across houses, flats and bungalows, whereas the tenants of housing associations tend to be in flats in our survey. Of course, it is houses (405) which predominate in the main tenure of owner occupation, with bungalows (211) next and just 19 flats or maisonettes. There is high satisfaction with access within residential care homes.

The proportion of people who are dissatisfied with access inside their homes (21.3%) is a significant group. In the study by Beresford and Oldman (2002: Tables 3.2 and 3.3) specifically about the housing needs of disabled children, 24% found the access into the house unsatisfactory, 11% found internal access impossible by wheelchair or walking frame and 10% had unsuitable width of access doors. Overall, Beresford and Oldman found that one-third of families reported difficulties of access in and around the home. Our data is not as sophisticated or detailed as this, however, our overall dissatisfaction level of 21.3% with access within the home is twice as high as comparable figures from Beresford and Oldman.

Table 19. Home Purpose Built by Home Adapted

	Home adapted	Home not adapted	Total
Home purpose built	118	12	130
Home not purpose built	188	786	974
Total	306	798	1104

Of those living in purpose built homes, 118 out 130 have also had adaptations, indicative of a high order of accommodating the dwelling to the specific needs of the wheelchair user even when the dwelling was purpose-built. This is consistent with the expectations of a Lifetime Homes policy (Cobbold 1997) where housing is purpose built to an adaptable standard. What is surprising is the lack of adaptation in non-wheelchair dwellings (under a quarter adapted).

Table 20. Home Purpose Built by Satisfied with Access Within Home

	Satisfied with access	Dissatisfied with access
Home purpose built	126 90.6%	13 9.4%
Home not purpose built	697 76.1%	219 23.9%
Total	823 78.0%	232 22.0%

Wheelchair users in purpose built dwellings are very satisfied with access within their homes, whilst in non-purpose built homes, satisfaction is slightly lower than the overall sample.

Table 21. Home Adapted by Satisfied with Access Within Home

	Satisfied with access	Dissatisfied with access
Home adapted	280 90.0%	31 10.0%
Home not adapted	543 73.6%	195 26.4%
Total	823 78.5%	226 21.5%

Those in adapted housing are similarly satisfied with access within their homes to those in purpose built housing. The levels of satisfaction of those in non-adapted properties is the lowest, with more than 1 in 4 respondents being dissatisfied. Our survey is not detailed enough to pick up any specific or special housing problem for wheelchair users, however there are clearly local and individual difficulties for a significant proportion of our respondents.

Education and employment

We asked questions on education and as expected the number of people for whom disablement was an issue in relation to this was very low as wheelchair use is predominantly a feature of later life. However, 60 people of whom 43.1% were still of school age had attended or were attending special schools (Table 22). A slightly higher number (78) said their education had been seriously disrupted due to their disability, fewer of whom were still of school age (24%).

Table 22. Attended or Attending Special School

	Frequency	Percent	Valid Percent
Yes	60	4.9	5.5
No	556	45.4	50.6
Not applicable	482	39.3	43.9
Total	1098	89.6	100.0
Missing	128	10.4	
Total	1226	100.0	

Table 23. Education Seriously Disrupted

	Frequency	Percent	Valid Percent
Yes	78	6.4	9.3
No	765	62.4	90.7
Total	843	68.8	100.0
Missing	383	31.2	
Total	1226	100.0	

Given the age profile of our sample, we expected the high proportion of retired respondents shown in table 24. We think it is significant that 6.7% declare themselves to be unemployed, more than three times those who are employed (1.9%). The only other groups in which that distribution would be comparable are amongst the most excluded and marginalised in society such as homeless people or asylum seekers. Whilst these numbers are small, table 25 shows that twice as many people have had to give up a job due to their impairment as currently are in employment.

Table 24. Employment Status

	Frequency	Percent	Valid Percent
Employed	21	1.7	1.9
Unemployed	74	6.0	6.7
Retired	795	64.8	72.0
Not applicable	214	17.5	19.4
Total	1104	90.0	100.0
Missing	122	10.0	
Total	1226	100.0	

Table 25. Had to Give up a Job

	Frequency	Percent	Valid Percent
Yes	41	3.3	10.5
No	350	28.5	89.5
Total	391	31.9	100.0
Missing	835	68.1	
Total	1226	100.0	

Wheelchair demographics

The main purpose of our survey was to ascertain the attitudes, aspirations and social circumstances of wheelchair users and those findings are presented later in this chapter. However we also asked a number of questions about the wheelchairs that people were using, including the level of satisfaction. We present these findings as demographic data about the equipment and its use.

Table 26. Use Wheelchair Indoors

	Frequency	Percent	Valid Percent
Yes	414	33.8	35.8
No	743	60.6	64.2
Total	1157	94.4	100.0
Missing	69	5.6	
Total	1226	100.0	

Table 27. Use Wheelchair Outdoors

	Frequency	Percent	Valid Percent
Yes	1147	93.6	96.5
No	42	3.4	3.5
Total	1189	97.0	100.0
Missing	37	3.0	
Total	1226	100.0	

The proportion of people using their wheelchairs indoors and out-of-doors is to be expected and reflects the levels of full-time and part-time use. This proportion has not significantly changed since Aldersea’s study in 1996.

Table 28. Satisfied with Access Within Home by Wheelchair Use

	Uses wheelchair indoors	Does not use wheelchair indoors
Satisfied with access within home	303 78.5%	531 78.9%
Dissatisfied with access within home	83 21.5%	142 21.1%
Total	386 100.0%	673 100.0%

Whether people use their wheelchairs indoors or not, equal proportions, approximately 1 in 5, experience difficulties of access within the home.

Table 29. Respondent has had Training to Use Wheelchair

	Frequency	Percent	Valid Percent
Yes	243	19.8	20.7
No	930	75.9	79.3
Total	1173	95.7	100.0
Missing	53	4.3	
Total	1226	100.0	

There are some variations in the circumstances of those who did or did not receive training. When we look at medical condition, the one group that stand out are amputees because they are twice as likely to have received training. This may be explained by their having received their wheelchair whilst in hospital and hence received training prior to discharge.

Other features of those who received training tend to reinforce the notion of a hierarchy within wheelchair services. Typically the person at the top of this hierarchy will be a male, full-time user, aged 20-50, and will have a light-weight or powered wheelchair. People with any of these characteristics are significantly more likely to receive training.

The highest proportion of untrained users live in residential care (82%) although the range is not great with the lowest proportion living in bungalows (77%).

We know from an analysis of the patient data provided by the Preston DSC in January 2003, that some 23% of wheelchairs are issued for less than one year. These will obviously be to people who are either terminally ill or very old, and the

former group were not included in our sample. It is therefore not surprising that amongst our respondents, 23.4% had been using their wheelchair for between 1 and 2 years.

Table 30. Length of wheelchair use

up to (years):	Frequency	Cumulative Percent
1	155	13.6
2	111	23.4
3	105	32.6
4	116	42.8
5	69	48.9
6	114	58.9
7	72	65.3
8	59	70.4
9	65	76.2
10	20	77.9
15	12	89.7
61	1	100.0
Total	1137	
Missing	89	
Total	1226	

The significance of this issue is that in the process of conducting this study, we had conversations with researchers at Edinburgh University where it was being suggested that up to 80% of wheelchairs were being issued for less than 6 months. Consequently, they were arguing that economics would justify the majority of wheelchairs being of a basic standard. The analysis undertaken by the Preston DSC shows this argument to be flawed and the figures in table 30 show that half of our respondents have been using a wheelchair for over 5 years. However, table 31 also shows that half of the respondents have acquired their current wheelchair within the last year, giving some sense of the limited lifespan of a wheelchair.

Table 31. When was the Main Wheelchair Acquired?

Had chair for (up to years)	Cumulative Percent
1	50.5
2	62.4
3	70.4
4	76.3
5	82.5
10	95.5
23	100.0

Most respondents have one manual wheelchair (Table 32). Relatively few (20.3% of respondents) have a powered wheelchair (Table 33), but as we shall note, having a powered vehicle is critical in how safe one feels using it on one's own.

Table 32. How Many Non-powered Wheelchairs Respondents Possess

Chairs	Frequency	Percent	Valid Percent
0	12	1.0	1.0
1	1123	91.6	93.7
2	53	4.3	4.4
3	4	.3	.3
4	6	.5	.5
6	1	.1	.1
Total	1199	97.8	100.0
Missing	27	2.2	
Total	1226	100.0	

Table 33. How Many Powered Wheelchairs Respondents Possess

Chairs	Frequency	Percent	Valid Percent
0	887	72.3	79.8
1	189	15.4	17.0
2	33	2.7	3.0
3	1	.1	.1
4	1	.1	.1
5	1	.1	.1
Total	1112	90.7	100.0
Missing	114	9.3	
Total	1226	100.0	

Table 34 shows that the majority of respondents (76%) had one manual wheelchair. Almost all the people with powered wheelchairs had more than one, and only 11 had no non-powered wheelchair. While 221 respondents have powered wheelchairs, table 35 shows that only 112 consider this to be their main wheelchair. Possible explanations include transportability and image.

Table 34 How Many Non-powered Wheelchairs by How Many Powered Wheelchairs?

	How many powered wheelchairs					Total
	0	1	2	3	4	
How many non-powered Wheelchairs?	0	7	3		1	11
	1	848	164	27	1	1041
	2	32	13	2		47
	3	2	1			3
	4	4		1		5
Total	886	185	33	1	1	1107

Table 35. Type of Main Wheelchair

	Frequency	Percent	Valid Percent
Standard manual user propelled	505	41.2	46.1
Standard manual attendant controlled	374	30.5	34.2
Lightweight manual	59	4.8	5.4
Buggy	6	.5	.5
Powered self controlled	100	8.2	9.1
Powered attendant controlled	12	1.0	1.1
Other	29	2.4	2.6
Not known	10	.8	.9
Total	1095	89.3	100.0
Missing	131	10.7	
Total	1226	100.0	

Unfortunately during the drafting and re-drafting of the questionnaire, the question on vouchers was deleted. Respondents who had vouchers may be under any of the values in table 36 except PACT and Charity. The vast majority of wheelchairs were supplied by the DSC and the fact that respondents report their wheelchairs to be in good working order (Table 37) indicates the efficiency and effectiveness of the DSC.

Table 36. Source of Main Wheelchair

	Frequency	Percent	Valid Percent
DSC	1057	86.2	88.7
PACT	7	.6	.6
Private purchase	67	5.5	5.6
Charity	8	.7	.7
Other	52	4.2	4.4
Total	1191	97.1	100.0
Missing	35	2.9	
Total	1226	100.0	

Table 37. Whether Wheelchair is in Good Working Order

	Frequency	Percent	Valid Percent
Yes	1153	94.0	97.7
No	27	2.2	2.3
Total	1180	96.2	100.0
Missing	46	3.8	
Total	1226	100.0	

Table 38 shows the responses to our question as to whether people felt safe using their main wheelchair alone. Some respondents expressed a difficulty in answering this question because they did not know whether they would feel unsafe using their wheelchair alone, as they never in fact did so. These people have been coded into 'feel unsafe' on the grounds that they probably do not use

it alone, either because there is some concern or risk over safety, or because they have not been issued with a self-propelling wheelchair. This is justifiable, we feel, as many people using attendant controlled wheelchairs indicate that they have attempted to use them on their own.

Table 38. Whether Respondent Feels Safe Using the Wheelchair Alone

	Frequency	Percent	Valid Percent
Yes	520	42.4	52.9
No	463	37.8	47.1
Total	983	80.2	100.0
Missing	243	19.8	
Total	1226	100.0	

That said, less than half of users felt unsafe using their chair alone and this relates to the qualitative finding outlined in chapter 3 in which several wheelchair users expressed apprehension, fear and misgivings whenever they had to go out on their own. The type of vehicle appears to be significant as three quarters of respondents with an attendant controlled wheelchair as the main vehicle felt unsafe when attempting to use the chair alone, whereas 90% of respondents with self-controlled powered wheelchairs and 70% of respondents with attendant controlled powered wheelchairs felt safe. With self-propelled wheelchairs, the proportion who felt safe was 59% of standard wheelchair users and only 50% of light-weight wheelchair users.

There is clearly a relationship between the design of the wheelchair and the lack of feeling of safety when using it alone in relation to attendant controlled wheelchairs. However, there are other explanations for the lack of feeling of safety of people using self-propelled wheelchairs. These may include type of use, and medical condition. What is clear from this data is that self-controlled powered wheelchairs appear to offer wheelchair users the greatest feelings of safety.

Attitudes

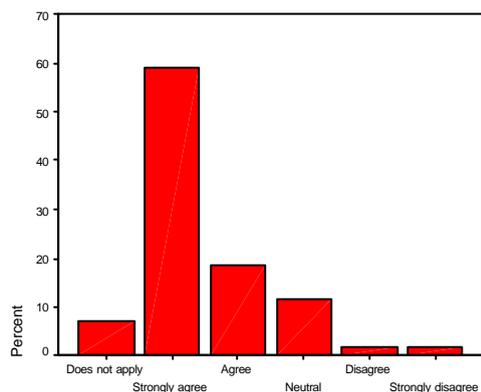
A significant criticism of the social model of disability is that whilst it may be relevant to disabled activists and academics, it does not equate to the experiences of the majority of disabled people. While a similar criticism has been made by feminist scholars of the original materialist theorising by people such as Michael Oliver and Vic Finkelstein (Morris 1991, Thomas 1999), their objective was to expand and strengthen a social analysis of disablement. The criticism we refer to is that put by people working with disabled people, usually from an individual model perspective, who wish to maintain that the problems people experience arise from their impairments. This approach is reinforced by medical, rehabilitation, and social welfare professionals and as a result disabled people are coerced into viewing their situation in terms of an individual model.

We posed a series of statements which were designed to elicit the orientation of respondents to models of disability, the first two of which were deliberately

provocative. Respondents were invited to express their attitude to the statements on a 5 point scale from *strongly agreeing* to *strongly disagreeing* or to indicate that the statement did not apply to them. These statements in their original wording, along with the number of respondents, head the bar charts below which give the percentage distribution of responses. The statements were grouped and each group was followed by space for comments. The results are presented in the order in which they appeared on the questionnaire. We have not included any comments here as we have only had time to sample them rather than engage in a full analysis of this data.

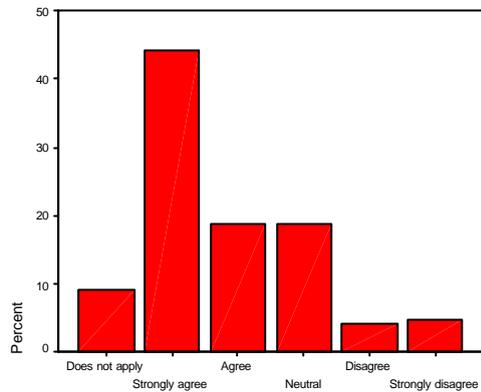
As we noted in chapter 1, Ann Begg MP refers to her wheelchair as ‘the liberator’. This very positive view of wheelchairs formed the basis of our first two statements. Given the criticism that wheelchairs are clinical equipment associated with the failure to walk, we expected that respondents who see themselves as disabled people in a negative light, would also view their wheelchair negatively and would hence disagree with this statement. As Oliver (1993) has argued, the rehabilitation industry contributes to this negative view of not-walking or nearly-walking.

Chart 1. Wheelchairs can be liberating for disabled people. (N=1093)



However, respondents to our survey showed such a strength of agreement with the proposition that only 3.5% demurred. On the face of it, this can be seen as a rejection of the wheelchair as symbolic of the failure to treat and cure. It also suggests that a significant majority of wheelchair users, those who actively agreed with the statement (77.9%), may have developed a positive identity of themselves as wheelchair users. This statement came first in the attitudinal section of the questionnaire, following 2 pages of demographic and technical questions and hence respondents were not primed to answer this in any particular way. The high level of agreement adds significantly to the social model analysis of disablement by showing graphically the extent to which it identifies issues that are in accordance with the experience and attitudes of wheelchair users.

Chart 2. My wheelchair has liberated me. (N=1057)

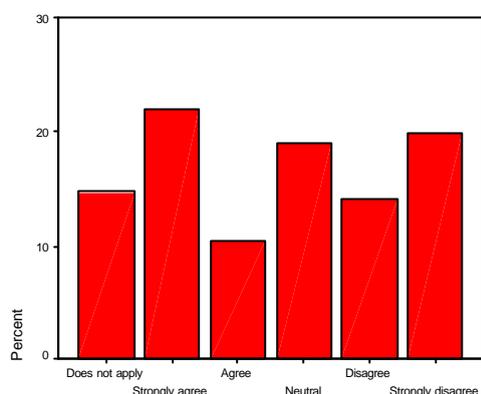


When applied to oneself, the situation becomes more complex. The proportion of respondents agreeing that they have personally experienced liberation falls to 62.9%, whilst those who actively disagree, which means that they have not found their wheelchair liberating, rises to 9.1%. We examined variables which could be associated with this distribution and there is a strong association here to being in residential care and lack of independent living. Only a half of respondents in residential care agreed that their wheelchair had liberated themselves, whereas nearly two thirds of wheelchair users living independently agreed with this statement. Living alone was not a significant variable for this attitude, however, age is significant. The youngest respondents (or their carers filling in the questionnaire for them) do not support this statement strongly, but support increases through middle age and then declines again in extreme old age, with which there is clearly a connection to being in residential care.

Despite the fall in agreement with the second statement, this first group confirms the validity of the social model of disability as a means of understanding and explaining how wheelchair users experience the world. However, it is also clear that in practice many people are experiencing some form of barrier to gaining advantage from this equipment. The next group of statements attempts to explore the nature of these barriers.

The first of this next group required respondents to consider if it was their wheelchair that prevented them from doing things that they would like to do.

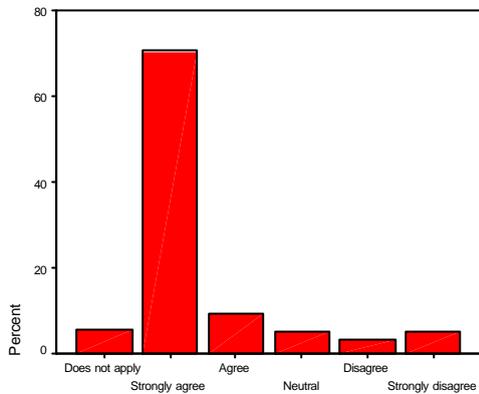
Chart 3. My wheelchair stops me from doing many things I want to do. (N=1015)



The distribution here shows the least variation of any of our attitudinal statements with 32.3% in agreement and 34% in disagreement. We could presume that this relates to factors such as the range of activities that people wish to undertake, their location, medical condition, age and so forth. In examining this distribution we found that the sex of respondent was irrelevant. However, age did appear to have an influence with the youngest respondents (under 10 year olds) disagreeing, or regarding the statement as not applying to themselves, as was also the case for the oldest respondents. The middle aged and older respondents up to 70 years were more evenly distributed. We think it is fair to conclude that the very young and very old are making lifestyle decisions which do not include aspirations beyond what can be achieved using a wheelchair and that the equipment they are using is appropriate to their need.

Tenure did seem to have some significance with higher proportions of respondents in owner occupation agreeing with the statement. This was rather surprising given that social rented tenants were more likely to be dissatisfied with access within their home. We might have expected them to be more likely to agree with this statement as they would presumably encounter more environmental barriers in using their wheelchairs. This adds some weight to concluding that the responses to this statement are referring to the wheelchair itself, rather than to its utility in a particular environment.

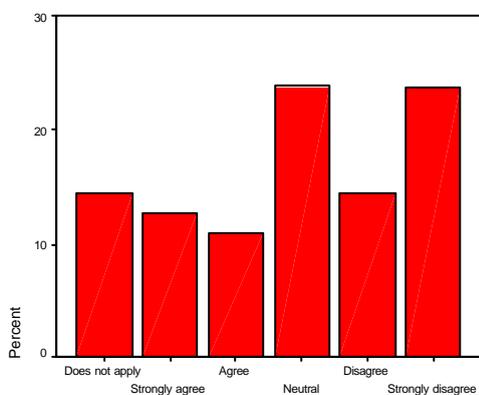
Chart 4. My illness/condition stops me from doing many things I want to do. (N=1140)



In contrast with the last statement, where responses were the most evenly distributed, agreement with this one (chart 4) was the strongest of the attitude statements. The level of agreement with the statements on the liberating potential of the wheelchair, which we associate with acceptance of the social model, has to be balanced with this clear statement about the illness or conditions which a respondent has. It is that condition or illness which is seen as unequivocally limiting. The level of agreement with this statement could be claimed to show adherence to an individual model of disability and yet as we will note later, respondents are aware of the social construction of barriers to their independence. This finding provides an indication of the need to include impairment effects in the social model of disability, as argued by feminist theorists (Morris 1991, Thomas, 1999).

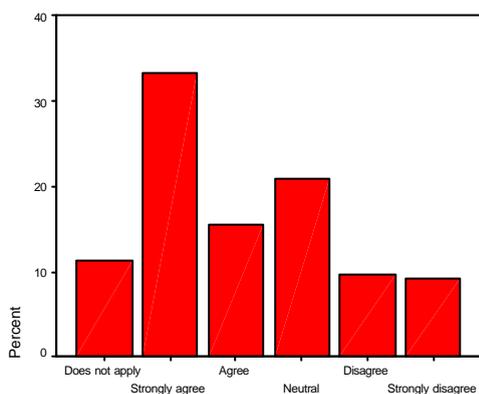
The only key variables of social division showing a slight positive correlation with those respondents who disagreed with this statement were sex (males), tenure (council tenants) and age (respondents in their 30s); though given the relatively small numbers involved, this could be entirely idiosyncratic.

Chart 5. Other people's attitudes towards me using a wheelchair stop me from doing many things I want to do. (N=1041)



Nearly two-thirds more people disagreed (38.1%) with this statement than agreed (23.6%). However, this still means that one in four wheelchair users are experiencing limitations caused by other people's attitudes. Sex and whether someone is a full-time wheelchair user shows a small but significant correlation with agreement to this statement: 25.4% of males agreed compared with 22.7% of females; 25.5% of full-time users compared with 21.1% of part-time users. However, when we looked at age there were some very much stronger correlations: age group 10-19 years – 54.2%; 40-49 years – 38.6% and 50-59 years – 43.3%. Interestingly, this fits the profile of the person at the top of the hierarchy of wheelchair users discussed above (see discussion following Table 29). It may be, therefore, that those disabled people who are most actively attempting to participate in mainstream society are more likely to experience negative attitudes from other people.

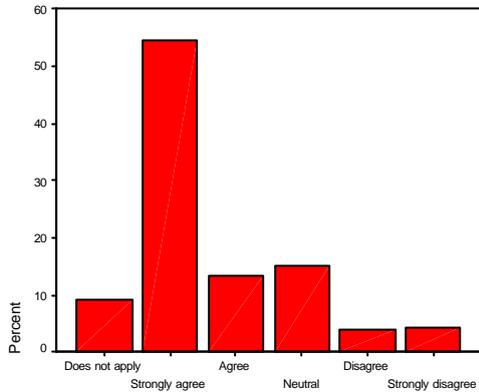
Chart 6. The environment around me makes it hard for me to do many of the things I want to do in my wheelchair. (N=1065)



Our respondents viewed the environment around them as the second most significant barrier in this group of statements. While not as strong a limiting factor as impairment, their environment was significantly more problematic than either the attitudes of others or their wheelchair. Environment in this statement could mean many things to each respondent; doorsteps, kerbs, busy roads or hilly area. So, one might expect respondents on the Fylde coast to disagree and those in the foothills of the Pennines and Cumbria to agree more strongly. Equally, those living in towns might fare better than those in rural areas. However, an analysis of this statement by postcode proved inconclusive.

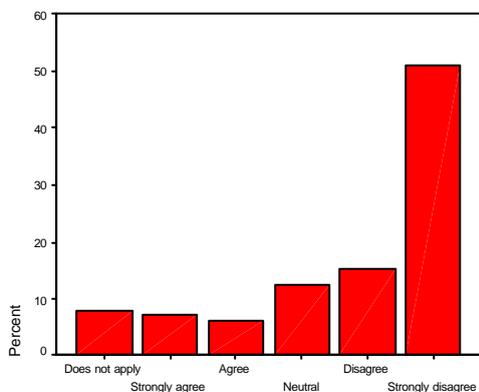
From these first two groups of statements we can conclude that wheelchair users do not feel that using a wheelchair is necessarily negative, indeed it can be liberating, and that while they clearly relate their own limitations to their impairment, they also strongly identify with environmental, design and attitudinal barriers around them. We would argue therefore that the individual, medical and lay models of disability are not adequate to explain the experience of disablement. What we look at now is the attitudes people may have towards approaches to resolving some of these problems.

Chart 7. Discrimination against wheelchair users should be dealt with strongly under the law. (N=1097)



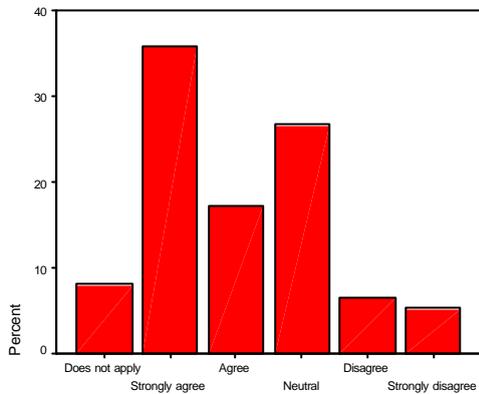
There is a strong identification with the need for anti-discrimination legislation, which is probably much greater than in the population as a whole, with just over two thirds of respondents (67.7%) agreeing with this statement and only 7.9% disagreeing. The affiliation respondents have to the social model is affirmed again, though here in the context of a rights based approach to reducing the exclusion of wheelchair users.

Chart 8. Wheelchair users should take responsibility for solving their own access problems. (N=1063)



This strong rejection (66.1%) of individualising the access problems which wheelchair users face is probably an indication of respondents' understanding that the causes of these barriers lie elsewhere. Expecting the individual to adjust to an inaccessible environment is costly, whereas designing access into the built environment at the outset brings general benefits to all and is cheaper (Stewart *et al.* 1999). This has implications for rehabilitation professionals who will not be understood by their patients when they make them try to adjust to an environment which itself is not to be changed.

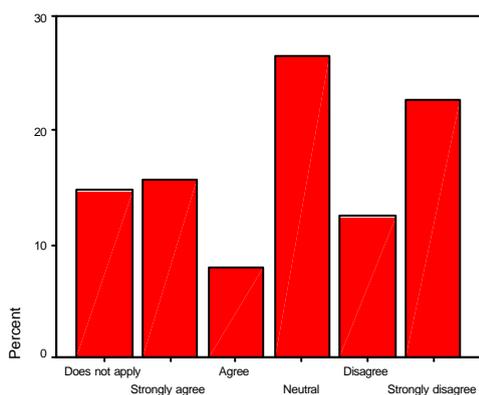
Chart 9. The Disability Discrimination Act will help to change attitudes towards wheelchair users. (N=1079)



Despite many criticisms of the Disability Discrimination Act, 1995, that it is either too weak or inappropriate, just over half of our respondents did have faith in this legislation. However, compared with the belief in the value of legislation exhibited in chart 7, this result suggests a drop in confidence in the power of our present UK law to change attitudes, but perhaps a belief in its potential.

The responses to the issues raised by the attitude statements so far certainly suggest that the majority of wheelchair users would not identify with the 'sick-role' and that there is an underlying desire for most respondents to lead more active lives. The next group of statements, which concern the aesthetics of wheelchairs, were intended to explore the issue of identity further. We included them because wheelchairs are often symbolic of dependence, yet as we have illustrated in chapter 1, design may vary considerably and good design can promote a positive image.

Chart 10. I would enjoy using my wheelchair more if it looked better. (N=1048)

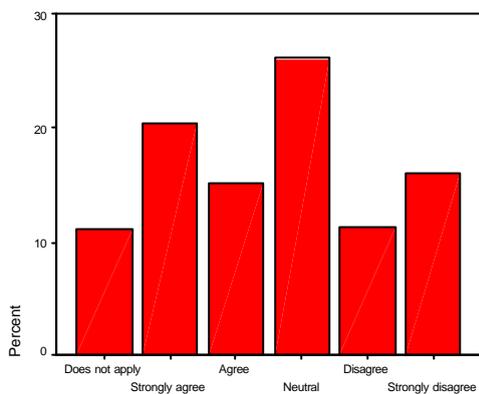


A majority of respondents either disagreed with (35.1%) or were neutral about (26.5%) this statement. Unlike many of the other statements in the questionnaire, the wording of this one means that answering that one was neutral is significant as it implies having an opinion akin to those who disagreed. Whilst there may be

many differences in the reasons people either disagreed or were neutral, both responses imply that respondents are not dissatisfied with their wheelchair due to its appearance. The important group to look at are the 23.6% who agreed with this statement.

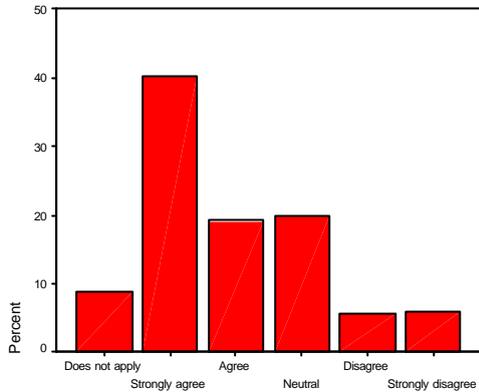
In some respects this group is similar to, but not the same people, as those who felt that other people's attitudes restricted them. They are slightly more likely to be full-time users; they are younger, although the age range is greater (10-69 years); however, they are slightly more likely in this case to be women.

Chart 11. The appearance of a wheelchair affects the way non-disabled people view wheelchair users. (N=1054)



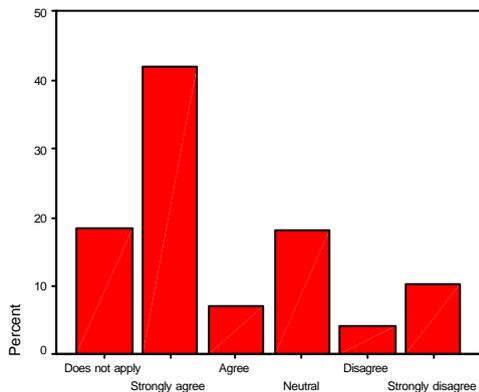
Although most wheelchair users tend to think that a better looking wheelchair would not alter the way they behaved, they do, marginally (35.6% agree while 27.3% disagreed with statement 11) seem to think that a better looking wheelchair would affect the behaviour of non-disabled people. Given that about 1 in 4 wheelchair users feel that they are limited by the attitudes of others, and hence seem to place high store on how they are negatively perceived and treated as being part of the excluding barriers they have to face, addressing the appearance of wheelchairs would seem worthwhile. However, it is not straight forwardly clear what it is that needs improving. Our respondents felt unsafe when on their own, especially so in an attendant controlled vehicle. However they felt more safe with powered vehicles, but we have noted from the qualitative analysis in chapter 3 that some wheelchair users believe the public have an especially negative attitude towards disabled people in powered wheelchairs. There is no doubt from the imagery we presented in chapter 1 that the style of a wheelchair affects the way someone is seen. In today's consumerist society it would seem likely that clinical, as opposed to aesthetic, design will increase stigma.

Chart 12. Wheelchair users have too little choice in the design of the chair they use. (N=1062)



There is clear and definite agreement (59.5%) on the lack of choice. This contrasts sharply with attitudes towards the two preceding statements. Our respondents may be disunited over what matters, appearance or attitudes, but they know they want more choice.

Chart 13. The wheelchair I would like is too expensive for me to buy. (N=1056)

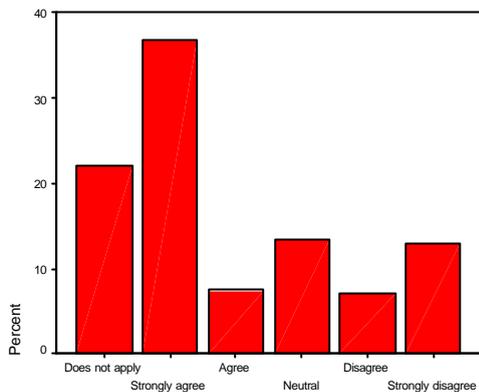


Half of our respondents (49.1%) know what they want and it is too expensive. There is a clear understanding of cost and its limiting character. We can presume that the further 14.4% who disagreed with this statement also know what they want and can afford it. Our respondents appear to be informed about the type of wheelchairs which are available, however we investigate more about where this knowledge comes from in later statements.

It is clear that half the respondents want a better wheelchair than the one they are currently using. A majority of these people did feel that they would enjoy using the wheelchair if it looked better, but they were far more likely to believe that the appearance of their wheelchair caused other people to view them negatively. As we have noted above aesthetics are important in today's

consumerist society and this is a point that the NHS needs to consider in terms of future wheelchair provision policy.

Chart 14. The roads where I live are too steep for me to get out of my home in my wheelchair **without** help. (N=1076)



As one might expect, the responses to this statement and the next one (Charts 14 and 15) have a strong correlation to the geography of the area in which the respondents live. There was some correlation between those answering that statement 14 did not apply to them or that they were neutral, with areas which are popular for retirement. This may be due to older people not attempting to go out on their own.

Chart 15. The roads where I live are too steep for me to get out of my home in my wheelchair **with** help. (N=1024)

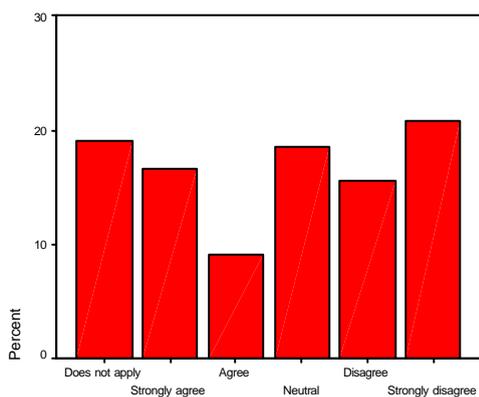
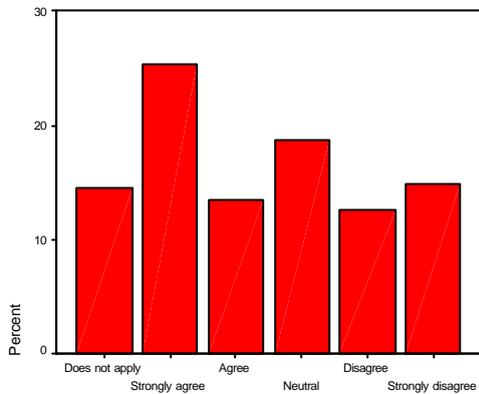
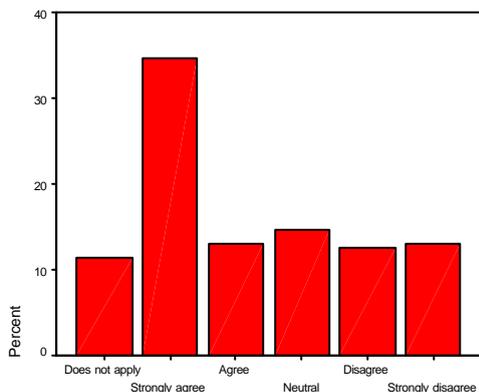


Chart 16. Pavements near my home are inaccessible because they are obstructed. (N=1044)



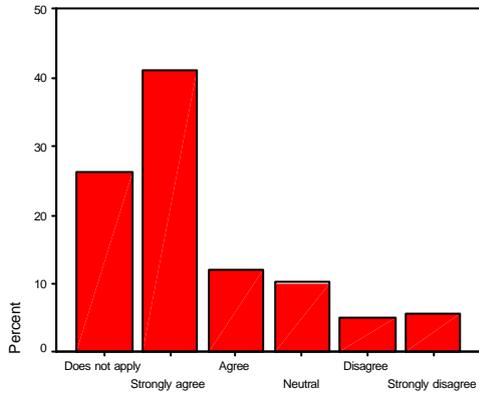
About 2 in 5 (39%) of respondents agreed with this statement while 27.5% did not, the remainder either being neutral or stating this did not apply to them, presumably as they do not attempt to use their wheelchairs on the pavement. The main causes of obstructions appeared to be cars and vans, and as we are all very well aware the parking of cars on pavements or across dropped kerbs is now common practice. With vehicle ownership on the increase combined with a increasing selfishness amongst car drivers, this problem is only likely to become worse.

Chart 17. It's very difficult to use a wheelchair near my home because there are too few dropped kerbs. (N=1074)



In addition to the comments that led us to appreciate that drivers cause obstruction, here 47.9% of respondents also cite the lack of dropped kerbs as making it difficult to use the pavements near their own homes. There must still be a phenomenally high proportion of pavements which have not yet been modified by local authorities to ensure the inclusion of wheelchair users.

Chart 18. I need help to go to *local shops* as they are difficult to access in my wheelchair. (N=1031)



Whilst we cannot say if it is the shops themselves or the access to the shops that cause difficulty, this next set of statements (Charts 18 – 21) demonstrates that wheelchair users find it easier to go shopping in town centres than either locally or to out-of-town shopping centres.

Chart 19. The *town centre* is easier to access than local shops. (N=1042)

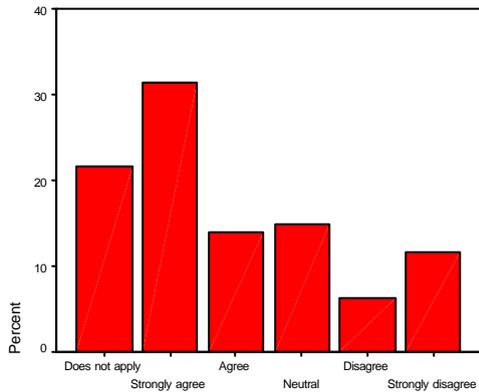


Chart 20. The *town centre* is difficult to access. (N=997)

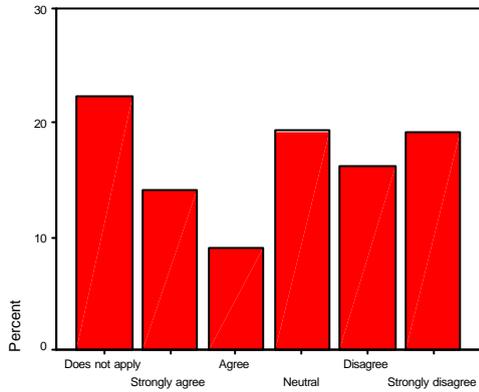
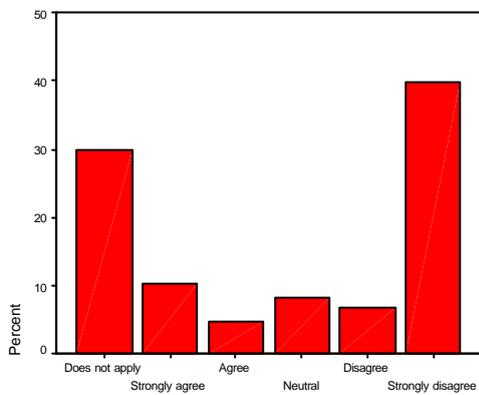


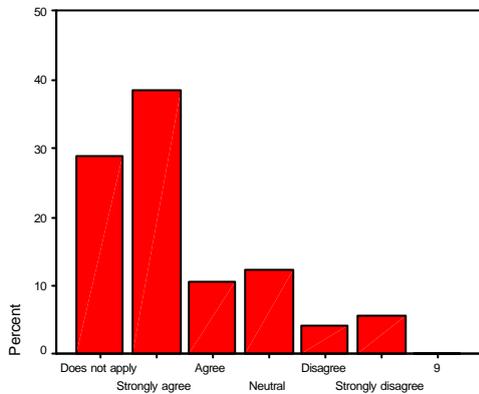
Chart 21. I can access *out-of-town* shopping centres on my own. (N=1009)



Only 15.2% of respondents agreed that they could access out-of-town shopping centres on their own. Given the trend towards this type of development, it would be helpful for planning authorities to take note of this high level of inaccessibility compared with more traditional town centre and local shops. As we have already stated, we cannot say whether these shopping centres are inaccessible because of their scale, parking arrangements or their geographical locations, so this does require further investigation.

As well as being interested in the necessity of shopping, we also wished to explore barriers to people's pursuit of leisure in pubs and restaurants.

Chart 22. There are *restaurants* I would like to go to, but do not as the *toilets* are inaccessible. (N=1063)



Nearly half of our respondents are prevented from going to a restaurant of their choice due to inaccessible toilets (Chart 22). Clearly toilets are a bigger problem than parking although one-third of respondents cited this in relation to restaurants (Chart 23) and one-quarter in relation to pubs (Chart 25). Pubs were also not as inaccessible in terms of toilets, though still a staggering 36.4% of respondents are unable to visit the pub of their choice. This survey was conducted at about the same time as the provisions of the Disability Discrimination Act, 1995 came into force with regards to goods and services, and if proprietors conform to these legal requirements, we should be able to expect this situation to improve.

Chart 23. There are *restaurants* I would like to go to, but do not because of lack of *parking*. (N=1019)

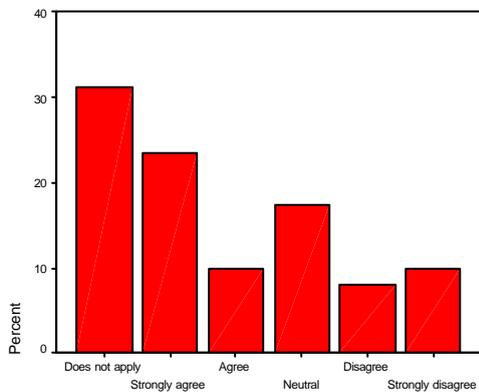


Chart 24. There are *pubs* I would like to go to, but do not as the **toilets** are inaccessible. (N=1022)

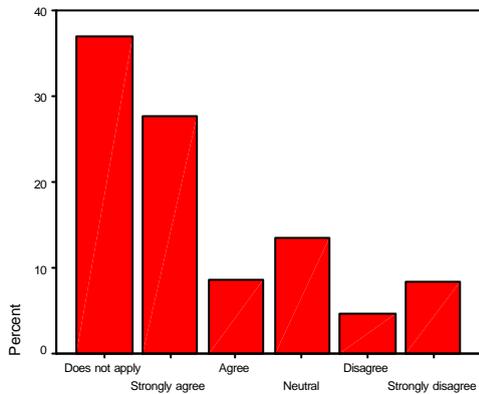
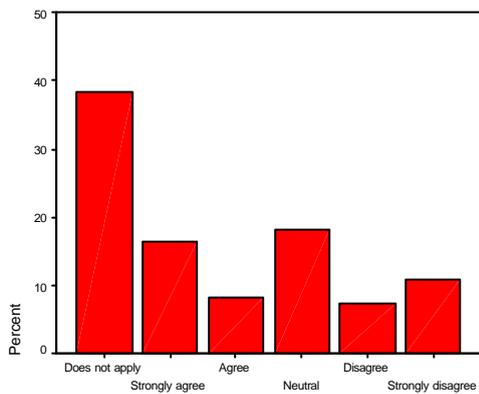


Chart 25. There are *pubs* I would like to go to, but do not because of lack of **parking**. (N=997)



A notable feature of this group of statements is the very large proportion of respondents for whom these leisure activities do not apply. This rises from 28.9% in Chart 22 to 38.2% in Chart 25. We might interpret this as a form of social withdrawal whilst the barrier of inaccessible toilets is a cause of social exclusion.

Social withdrawal is even more prominent in the responses to the next two statements about the use of sports and leisure centres.

Chart 26. I have difficulty travelling to my local leisure centre. (N=974)

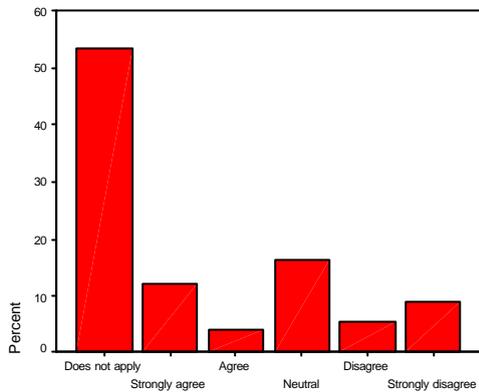
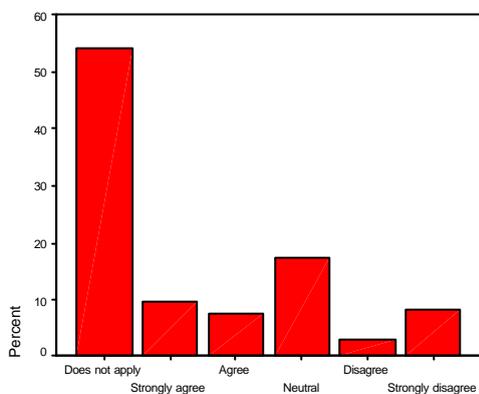


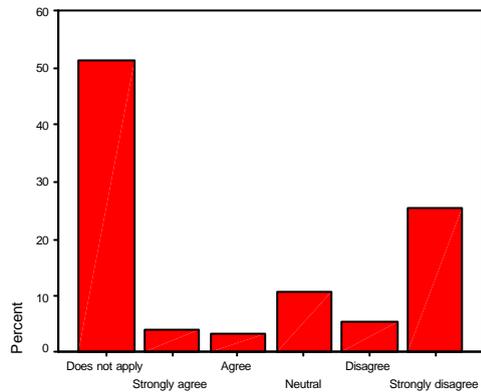
Chart 27. I find it quite easy to get in and out of the leisure centre. (N=946)



More than half of the respondents felt that these statements (Charts 26 and 27) did not apply to them. There is a clear correlation to age here with younger respondents having an opinion, whilst older people were not likely to participate. This reflects the pattern of activities in the rest of the population where a steeply declining curve of participation correlates to rising age, ending with only 30.4% of over 65 year olds taking part in sport activities outside the home (UK 2000 Time Use Survey, Office for National Statistics).

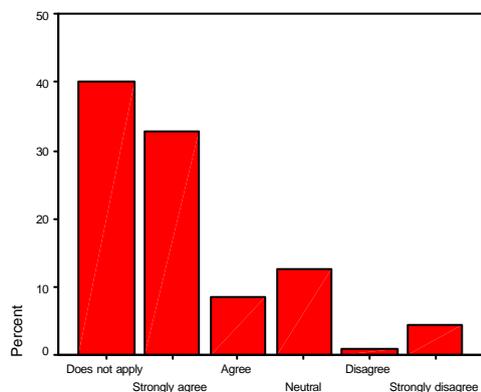
Those respondents who were participating in sport were fairly evenly distributed in terms of finding leisure centres accessible.

Chart 28. I am able to participate in sporting activities. (N=951)



We have to be a bit cautious about the responses to this statement (Chart 28) as it does invite a yes/no answer. However, 62% either said it did not apply or were neutral suggesting a high level of disinterest in participating in sport. This may be because sport has been interpreted in a particular way, implying some form of competition rather than simply having a swim for personal pleasure.

Chart 29. It is necessary to provide special leisure activities for wheelchair users. (N=964)



We posed this statement (Chart 29) as a way of trying to find out if wheelchair users wanted the kind of special provisions that have traditionally been provided and it is clear that many do (41.9%). There is considerable debate within disability studies over whether separate provision of services enhances participation or perpetuates exclusionary barriers. However, half of those commenting on this group of questions about sports and leisure gave very personal explanations for the way they had responded, while the rest were either related to their impairment or the environment. This, in conjunction with the strong identification with a social model of disability that we found in responses to earlier statements, suggests that our respondents are seeking appropriate provisions rather than segregated services.

The next group of statements returns to an earlier theme of identity and wheelchair use.

Chart 30. People tend not to talk to me when someone else is pushing my wheelchair. (N=1067)

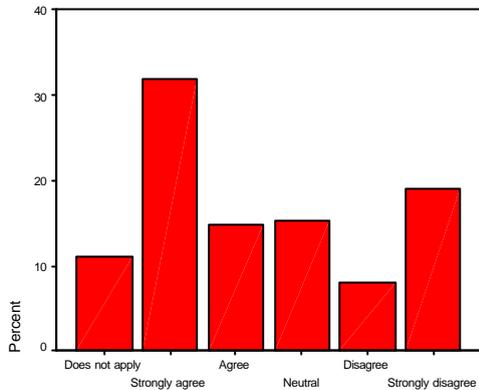
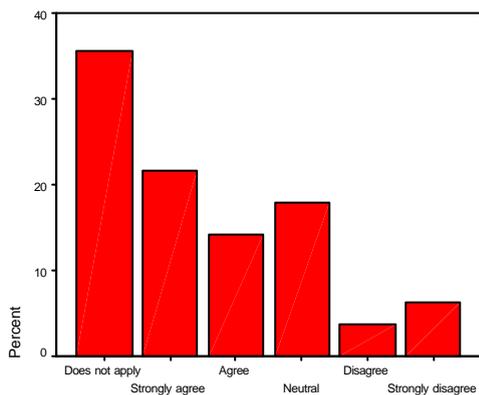


Chart 31. People do talk to me when I am controlling my wheelchair. (N=1005)

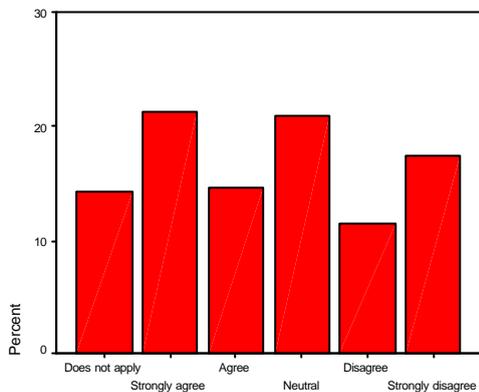


Taking together charts 30 and 31, it appears to us that there is truth in the cliché ‘does he take sugar?’ We included these statements on the advice of a wheelchair using member of our steering group who had experienced behaviour of this sort. Clearly, she is not alone as 46.8% of respondents agreed that people don’t talk to the wheelchair user when someone else is pushing it, whereas 36.1% agreed that people do talk to the user when they are in control. Crosstabulation reveals that the core of these two groups of respondents are the same people. One must note the high percentage of respondents to whom the statement in chart 31 does not apply (35.7%), presumably because they never do control the wheelchair themselves.

There is a complex issue here. We know that many users of manually propelled wheelchair users experience a stigma when using an electric wheelchair. However, if someone is able to propel themselves by using an electric wheelchair they are less likely to be over-looked by non-disabled people. Furthermore, we also know that they are likely to feel safer in an electric wheelchair. The

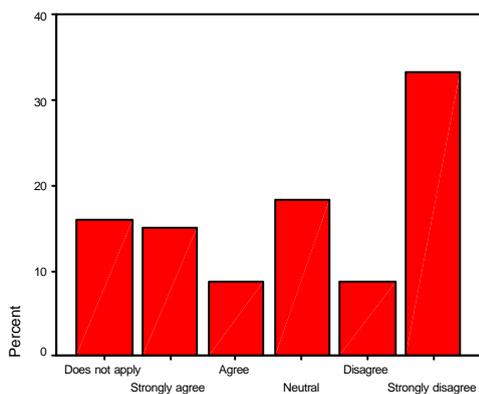
implication of this scenario is to do with the design of the wheelchair. Manufacturers and wheelchair purchasers (NHS) should take note of this.

Chart 32. Other people view me negatively because I use a wheelchair. (N=1031)



Of the respondents who agreed that other people viewed them negatively, 41.7% also agreed that other people's attitudes towards them using a wheelchair stopped them from doing many things they wanted to do (Chart 5). The correlation was even stronger with those who disagreed with the statement for chart 32, where 65.6% also disagreed with the statement for chart 5. These correlations are very strong and statistically significant.

Chart 33. I view myself negatively because I use a wheelchair. (N=1026)



Wheelchair users are far less likely to view themselves negatively than they think other people do. However, about a quarter of respondents do view themselves negatively because they use a wheelchair. This is a significant group of people who are being affected by a dominant social attitude towards wheelchair use and reflects the idea of internalised oppression which Reeve (2002) argues can lead to disabled people feeling worthless and accepting being abused. Reeve (2003) has further argued that many disabled people have to undertake additional

emotional labour in order not to feel negative about themselves. Responses to this group of statements (Charts 30 to 33) suggests that there is a link between the attitudes of others and the internalised oppression of disabled people. Improving the position of disabled people requires an end to the 'does he take sugar?' attitude.

The next group of statements concern how and where people obtain information about wheelchairs.

Chart 34. I know a shop where I can get good advice on wheelchairs. (N=1015)

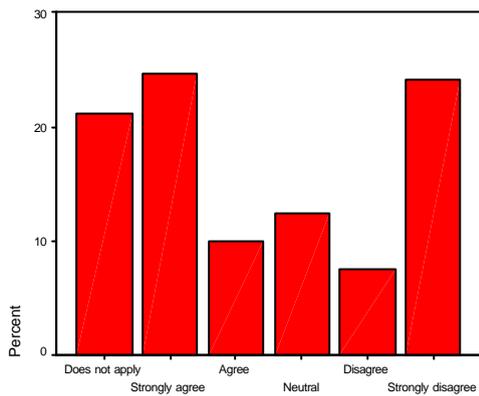


Chart 35. I have had good advice on wheelchairs from the Disablement Services Centre. (N=1040)

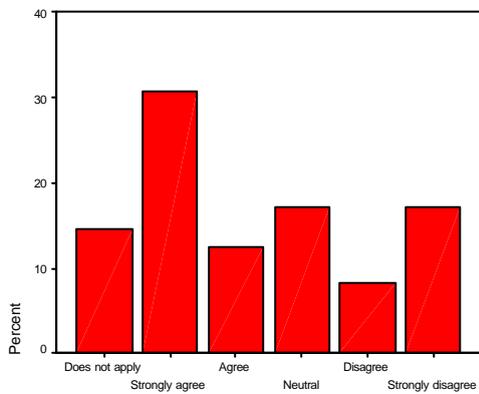
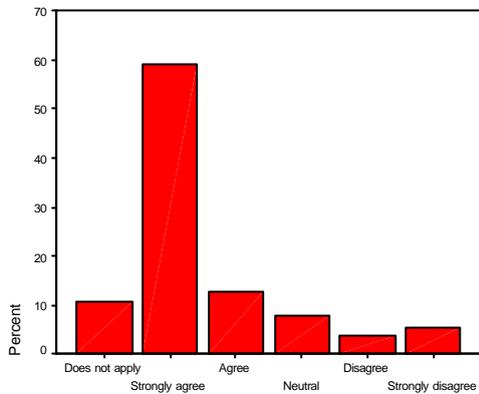


Chart 36. I knew almost nothing about wheelchairs before I got one for myself. (N=1092)



Although many of our respondents are able to get good advice about wheelchairs through the private sector (34.7%), a higher proportion agree that they have had good advice from the DSC (43%). A large majority (71.8%) of respondents knew nothing about wheelchairs prior to becoming a user, indicating the importance of getting such advice and of the role of the DSC in this.

Chart 37. If I have a problem with my wheelchair, I know I can rely on the Disablement Services Centre to help. (N=1096)

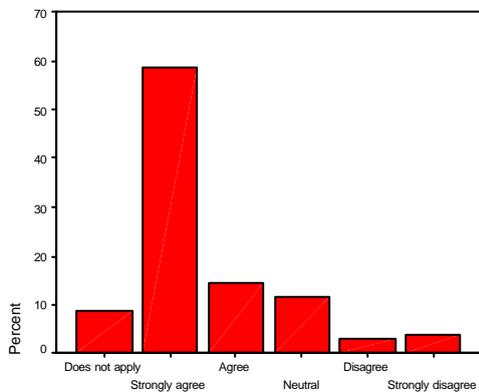


Chart 38. I find the staff at the Disablement Services Centre approachable. (N=1033)

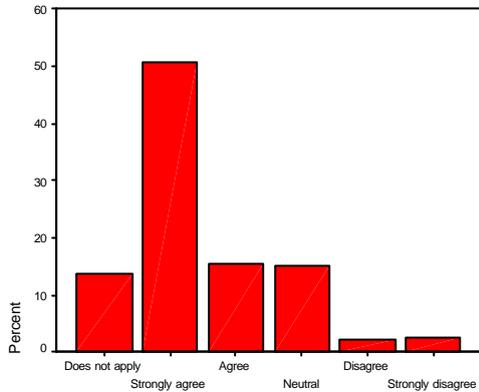
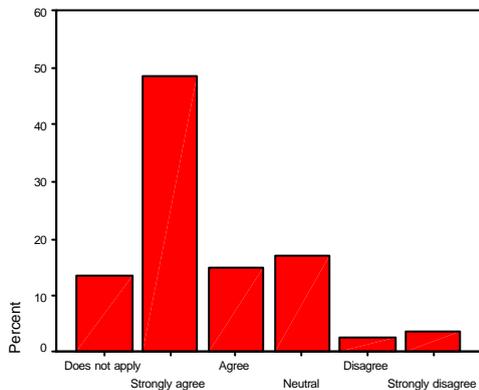


Chart 39. I find the staff at the Disablement Services Centre efficient. (N=1042)



The responses to these last three statements indicate a high level of satisfaction with the DSC, ranging from 72.9% agreeing that they can rely on the DSC to 63.3% who find DSC staff efficient. However as few as 4.7% actually disagreed that they found the DSC staff approachable which is a very low level of expressed dissatisfaction. In contrast with other issues that have affected our respondents, their dealings with the DSC appear to be very positive.

Transport

There are clearly two major causes of access difficulties for wheelchair users, the attitudes of others and the built environment. This section on transport concentrates on the latter as many of the social facilities that people may wish to use first requires that they are able to actually travel there.

Although transport is extremely important to wheelchair users, it is often inaccessible due to most vehicles having been designed to carry ambulant passengers. Accessible public transport has become an important campaign issue within the disability movement. Barnes (1991) details many of the barriers disabled people face and importantly argues that inaccessible transport prevents participation in other areas of social life.

We asked in our survey about different forms of transport and how easily people were able to use them with their wheelchair, with and without assistance. We present the findings in paired charts below.

Using Car

Chart 40. (N=1033)

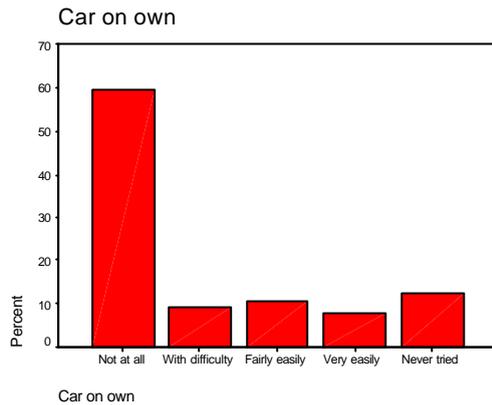
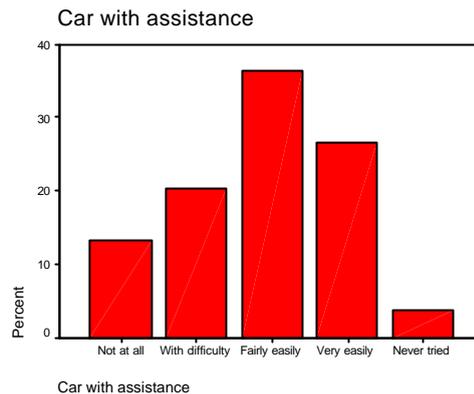


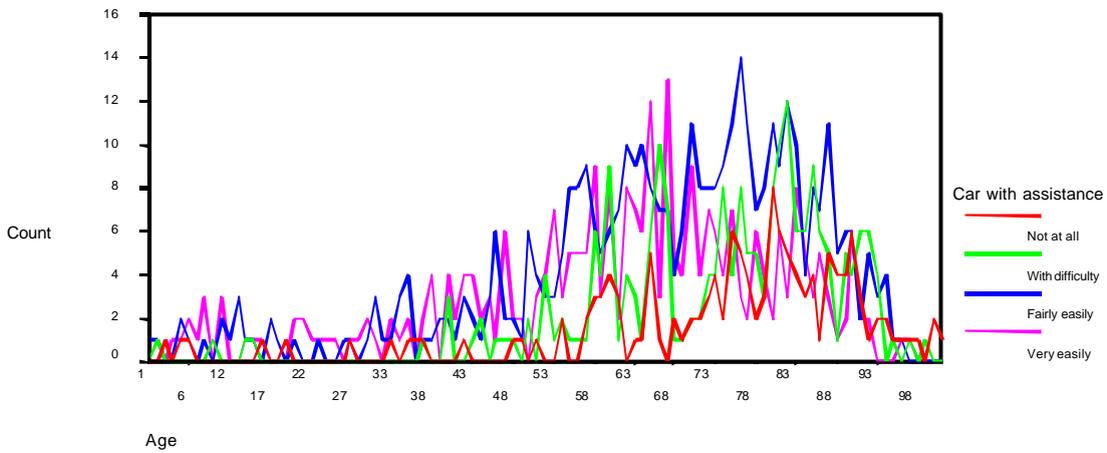
Chart 41. (N=1092)



Of all the forms of transport we asked people to tell us about, the private motor car appeared to be the most frequently used, probably due to its flexibility and greater accessibility than other modes of travel. However, in common with other forms of transport, the ease of use was greater when people had assistance; 62.9% managing without difficulty as opposed to 18.6% when using a car on their own. Those who actually manage to use motor cars either with ease or with difficulty rises from 27.5% alone to 83.2% with assistance. However, this still leaves 16.8% of respondents who have either never tried or are unable to use this form of transport. We might presume that this group are going to be older, perhaps living in institutions or maybe using a less portable powered wheelchair. However, our analysis of the demographics and attitudes for this group show no significant differences from the total sample. About a quarter of this group are using taxis and a further ten percent use buses. With regard to the remainder, we simply need to accept that a small, but significant group of respondents do not use, or need to use, motorised transport.

The ease of use of a motor car is related to age. Chart 42 shows that at around the age of 75 years, those having some difficulty, even with assistance, or not managing at all increases, whilst those managing without difficulty decreases. This may be due to increased impairment problems or due to the likelihood that those giving assistance are also older and hence less able to provide the same level of support.

Chart. 42 Using car with assistance by age, excluding missing and never tried.



Using Taxi

Chart 43. (N=998)

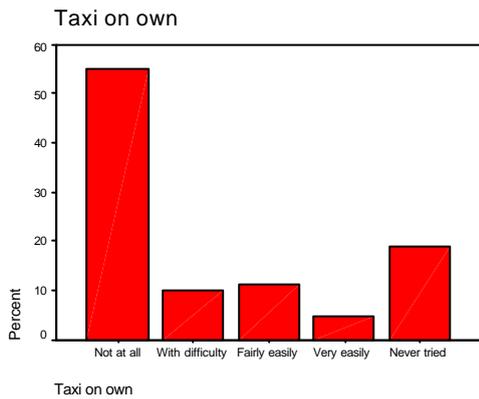
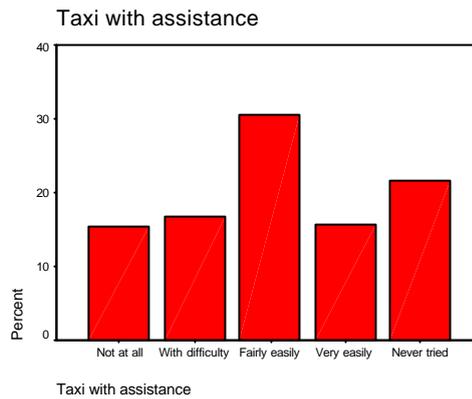


Chart 44. (N=993)



Taxis are the second most preferred form of transport and as with cars it is more likely that people will find them easy to use if they have assistance. Although no one is ever alone when they use a taxi as there will always be the taxi driver to assist to some extent, we would conclude from the large differences between charts 43 and 44 that many of our respondents are unable to rely on the taxi drivers alone. While 63% of respondents could manage with assistance, only 26.3 could manage without.

When designing the questionnaire we pondered for some time over how we might distinguish between the use of different types of taxis as the modern 'black London cab' style of taxi is built to an accessible standard. We concluded that this would be too difficult and hence cannot really say whether the differences here represent an unwillingness to assist or a design difficulty.

Using Bus

Chart 45. (N=982)

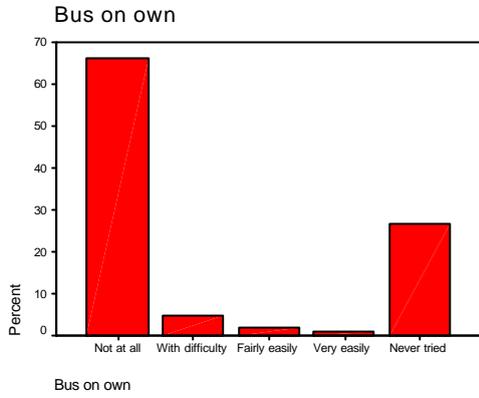
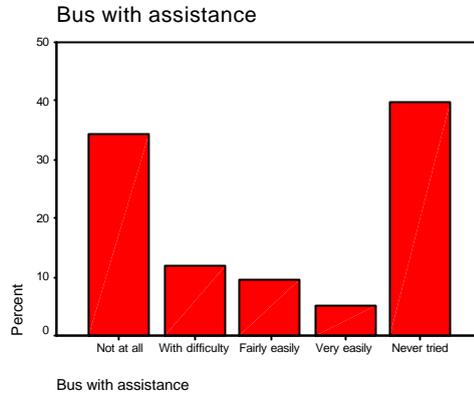


Chart 46. (N=941)



Using Train

Chart 47. (N=979)

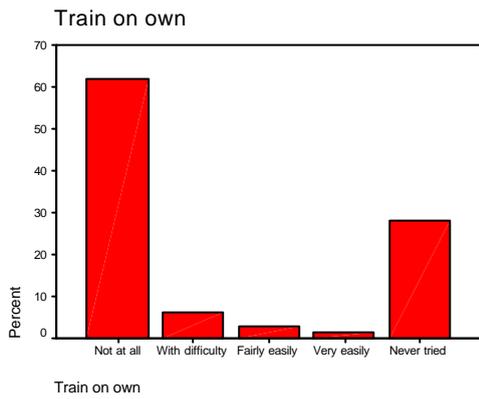
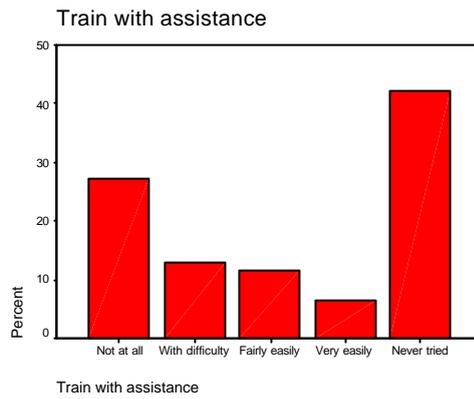


Chart 48. (N=941)



Using Plane

Chart 49. (N=970)

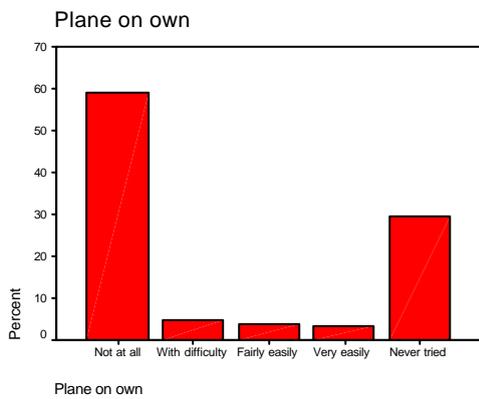
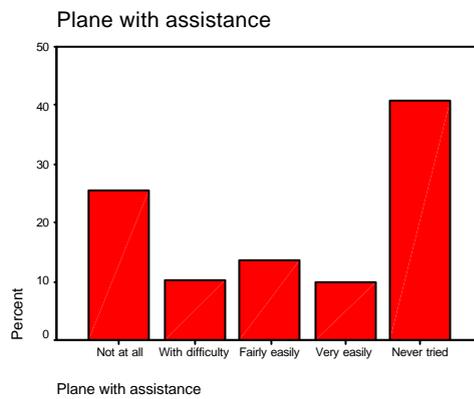


Chart 50. (N=946)



Whilst a similar picture emerges in terms of the importance of assistance, it is notable that 73.6% of respondents either cannot make use of buses or have

never tried; 69.3% similarly cannot make use of trains and 66.3% cannot travel by plane. Whilst the proportion of respondents who have never tried to use these forms of transport are similar at about two-fifths, there are differences in those who say they would be unable to do so; just over a third felt they could not use a bus whereas only a quarter felt the same about either trains or planes.

The focus of many protests by disabled people through the Direct Action Network has been the inaccessibility of buses and trains. Whilst we recognise that public transport is essential to many disabled people, our responses do tend to indicate that a large majority of wheelchair users would not actually wish to use buses and trains. Once again though, there is a significant minority who have tried, but who have difficulty.

5: Conclusions and recommendations

The objectives of this study were originally to:

1. To clarify the trends in wheelchair use and establish if the perceived increase since 1986 is continuing.
2. To establish the relative importance of different explanations for this increase.
3. To ascertain if the personal care, housing and other social needs of wheelchair users have changed during this period of increase.
4. To determine the resource implications of changing needs for service providers and purchasers.
5. To highlight aspects of service provision which are problematic for wheelchair users or other service providers.
6. To develop the research capability of NHS staff within disablement services.

Capability Building

Taking the last one first, there were two aspects of capability building with which this project engaged: within the Preston DSC; with the research assistant to the project. Several Preston DSC staff took part in the project through providing and explaining patient data base information, supporting the researchers through our advisory panel, and attendance of research awareness courses. We recruited a research assistant from within the NHS who is a physiotherapist. It is with the research assistant that more systematic capability building has, and is, being undertaken. The research assistant undertook the qualitative interviews and is currently studying for an MPhil at Lancaster University with the supervisory support of the researchers.

The data from the interviews which provided the topics for the construction of the questionnaire, also provided the fieldwork material for the research assistant's MPhil. An early finding from the interviews was that many wheelchair users were socially isolated despite having received considerable input from a range of rehabilitation therapists, in particular occupational therapy and physiotherapy. There appeared to be a gap between the expectations of rehabilitation therapists and the real lives of the interviewees. Whilst the former had high expectations that individuals would be dedicated to continuing therapy on their own, our interviewees found it impracticable to fit such activities into their every day lives. This gap appeared to be the result of therapists working strictly to an individual model of disability. The thesis of the MPhil. is about analysing the role of rehabilitation professionals with wheelchair users from a social model of disability perspective. That investigation remains part of the ongoing work of the funded project.

Trends in increases of wheelchair use

To establish periodicity of change we would need comparative snapshots of Preston DSC patient data at different points in time. As noted earlier, the integrity

of and range of data in the Preston DSC data base would not permit us to analyse trends over any period of time. During any chosen period we would also have had to take into account the changing health areas – authorities to trusts – and the changes in contracts. At the time of writing this report, June 2004, there are 19,797 people on the Preston DSC wheelchair patient database which is nearly 4,000 less than in June 2001. However, with the loss of certain contracts this actually appears to suggest the population of wheelchair users is stable. This confirms the intuitive knowledge of those in the DSC who thought that the increases during the 1990s were in fact slowing down at the end of that decade.

Our survey has provided information about the age of wheelchair users and the length of time they have been using a wheelchair as well as information about the types of wheelchairs supplied and time since acquisition. Our data provides a bench mark against which future studies could examine longitudinal trends. The final stage of this study will involve redesigning our questionnaire in a simplified form that could be used for this purpose.

Explanations for increase

At the outset of this study we noted that there were several explanations for the increase in wheelchair use. First, it has been suggested that the rising numbers were linked to the increasing population of older people, but our examination of different DSC datasets shows no significant change in the distribution of wheelchair users by age between 1993 and 2001 (see Table 3). Certainly the older population of wheelchair users has been increasing, but so too have the numbers of younger wheelchair users. During this period the overall increase in the population of over 65 year olds in the UK was 202,000 (2.2%) while there was a decrease in those under 16 year olds of 51,000 (0.4%) (Social Trends 2004: Fig. 1.3). The overall population change between 1991 and 2002 was a net increase of 163,000 (Social Trends 2004: Fig. 1.7). Thus any change in wheelchair use that could be accounted for solely by the increase in the ageing population, should increase the average ages of wheelchair users, yet the two datasets show a slight decrease in both the mean and median. This may be accounted for by the different sizes of the data sets, but what is clear is that there is no significant increase in the average age of wheelchair users during a period when their total numbers did increase.

Second, it is suggested that changing attitudes towards disablement may contribute towards the increased numbers of people counting themselves as such. Certainly we found a level of assertiveness amongst both our interviewees and survey respondents which would support this hypothesis, but it is not possible to say if this accounts for the increase. The overwhelming majority of wheelchair users view wheelchairs as potentially liberating (see Chart 1) and despite criticisms of the lack of choice and certain design failings, respondents were generally positive about wheelchair use.

Third, the increase may be as a result of changing prescription and allocation procedures within the NHS. As our survey was of the wheelchair users rather than of NHS personnel, it was not possible to find out very much about this. We

considered a question about who had 'prescribed' their first wheelchair and when, but this proved impossible to make reliable.

Fourth, changes in medical practice and health behaviours may have resulted in delayed mortality and hence a larger population was surviving to be disabled. Although some data was gathered about medical causes of people's impairment, the accuracy of this is far from that which would be required to make any firm claim to this cause. Our only evidence here is anecdotal from those involved in the provision of wheelchairs and that is clearly supportive of this explanation of the increase in relation to younger people, especially children.

Finally, the changing figures may have been methodological. As we have noted above in chapter 1, currently there are two competing figures for the number of wheelchair users, Aldersea's (1996) figure of 710,170 wheelchair users in England and the Audit Commission's (2000) figure of 640,000 for the UK. While these differ quite widely, they are both considerably larger than the 1986 OPCS figure of 360,000 and as we noted in the background to our study, local health trusts were themselves reporting increases of around 15% per year in the late 1990s. Artefact of measurement may well be an issue, but not to the extent of explaining the increase.

Our studies of the various explanations put forward for the increase in wheelchair users suggests therefore that the more probable causes lie in improving medical treatment, changing prescription practice and in changing attitudes of disabled people toward wheelchair use. The ageing of the population does not account for the change and while measurement reliability is an issue, it only affects the recorded volume of the increase, not the fact that there is one.

Changes in the social needs of wheelchair users

At the outset of this study, we had intended to undertake some form of estimation of need. What became apparent during the qualitative stage was that the nature of social need was of more relevance than its quantification. Taking action to accommodate that development was entirely in line with our proposed methodology whereby we conducted the in-depth interviews in order to be better informed about the type of questions we should put in the survey. Hence, our conclusions here relate more to the way in which people would wish to receive social support than the actual amounts and types of support they require. The latter is the task of caseworkers in the various health and social welfare fields to determine.

In our study, attitudes were investigated through a series of statements with which respondents were asked to state their strength of agreement or disagreement. The details have been discussed in the previous chapter and we will now draw out the main themes.

Theme 1: Models of disability.

The first theme which we have discussed extensively in chapters 1, 3 and 4 concerns the extent to which wheelchair users identify with particular models of disability. It is very clear from our survey that a majority of respondents identify

both positive and negative aspects of social life that are consistent with the analysis provided by the social model of disability. We think there are four major implications that we might draw from this strength of identification with the social model. The first implication is that the social model is more than a tool for a minority of disabled people, activists and academics, rather it provides an analysis of disablement that is relevant to the lived experience of wheelchair users.

Second, for many health and welfare professionals the social model of disability has become synonymous with a simplistic and inaccurate analysis of the limitations disabled people face. Such opposition is often based on a partial understanding of the social circumstances of disabled people. On the one hand it is argued that the material basis of the social model excludes explanations involving impairment and on the other, that an appropriate regime of rehabilitation can overcome barriers. The first of those positions fails to appreciate the complexity and sophistication of the social model of disability, whilst the second fails to accord with the experience and aspirations of disabled people.

Thomas (forthcoming) makes the case that since the original discussions of the Union of Physically Impaired Against Segregation in the early 1960s, the reformulation of disability was based upon a social-relational approach, meaning that disability results from a relationship between people with impairments and the social world. This does not deny the effects of impairment, rather it reconstructs disability as a form of social oppression that is additional to the limitations arising from impairments.

Third, as Oliver argues (see Chapter 1), disabled people become the subjects of rehabilitation professionals who, in devaluing the status of non-walking, also devalue the lives of their patients. It is necessary for all professionals involved with wheelchair users to recognise that impairment and wellness can and do co-exist. If disabled people are treated as unwell, they are then expected to occupy a particular role as a patient, one that is usually associated with being cured, despite there being no cure on offer.

The last implication of the identification with the social model of disability concerns the extent to which our respondents believed that their disadvantages could be overcome with the help of anti-discrimination laws. The requirements of the Disability Discrimination Act, 1995 are currently affecting many areas of social life, including health and welfare services. The Department of Health and the Disability Rights Commission have recently drawn up a *Framework For Partnership Action On Disability*, which amongst other things recommends disability equality and disability awareness training for NHS staff. We recommend that a shared commitment to a rights-based approach would assist disabled people to lead independent and meaningful lives.

Theme 2: Emerging barriers.

Another theme we can draw from our study concerns emerging barriers to access. These barriers generate exclusions and have developed as a result of forces beyond the ordinary control of health and welfare professionals. The

changes are part of late urban capitalism at its most mundane. When wheelchair users engage with the world of independent living they encounter new barriers to access: out-of-town shopping and the domination of the motor vehicle. Our respondents found out-of-town shopping centres to be inaccessible. This seems to be counter-intuitive as there is plenty of reserved parking, wide aisles for trolleys and lots of helpful assistants. This commercial retail world which is entirely orientated around car-access and walking long distances to find what you want when not in a car, appears to have produced an environment that is as inaccessible as the narrow doorways and steps of traditional local shops. Wheelchair users indicate that for most of them the town centre provides the easiest access to shops. Planners and retailers should take into consideration this finding when proposing re-development. We did not expect this finding, nor for it to be as clear and strong a message as we found, however we are unable to provide further explanations for this and recommend that additional investigations be undertaken.

The car itself is clearly a core issue for wheelchair users. On the one hand wheelchair users can use cars more easily than any other form of transport, including taxis, but on the other hand, cars have created barriers for wheelchair users when parked across paths, curbs, lay-bys and junctions. There appears to have been an increase in such obstructive parking. Motorists seem to think that it is more important to keep the carriage-way clear than it is to allow free passage for pedestrians. The mind-set which focuses on allowing other motorists to continue to travel at unimpeded speed fails to acknowledge the existence of pavement-users, often forcing them to use the very carriageway they have made more dangerous by their manner of parking.

It would appear to us that only the extension of anti-discriminatory legislation is likely to be effective in countering this cult of the car. If children, parents pushing prams, older people and wheelchair users are to be able to use pavements in the future action needs to be taken soon.

Theme 3: Consulting wheelchair users.

Interviewees expressed a clear preference for inclusion within the decision making process that led to the allocation of services for themselves. Their views were not receiving the attention which the experience of being a wheelchair user merited. As there is a fashion amongst health and welfare professionals and managers for empowering patients or service users and claiming to include them in each and every process to which they are party, one might suppose the expressed demand for inclusion from our interviewees was being met, and that here we are just reporting the anachronism of those who were not consulted in the olden days. Far from it. To make such a conclusion would be to miss the point expressed throughout the responses to our attitudinal statements, that wheelchair users know what they want, may be prevented from accessing it at a point when it actually matters, and believe that regulatory force is needed in order to remedy discrimination and injustice. In other words, wheelchair users embrace a rights approach to independent living which operationalises the social model. If health and welfare professionals and their managers fail to heed these

indications they will continue to be out-of-step with wheelchair users who are asserting a more inclusive approach to life as a disabled person, rather than simply conforming to the low expectations of a clinical model.

Theme 4: Extent of barriers to participation.

For many of the issues we investigated, there was a significant minority of respondents (usually between a fifth and a third) for whom there were important barriers. While many people said that issues such as other people's attitudes or the appearance of their wheelchair did not matter, in each case this significant minority of respondents were reporting their experience of oppression. Statistical interrogation of each of these minorities revealed that they were not necessarily the same people, but in each case they did appear to be the group that were most likely to be attempting to participate actively in those particular areas of life. For example, it was young adults who experienced most negatively the exclusion and oppression around lack of access to education, sports and leisure while it was older people living in institutions who were least able to experience liberation through their wheelchairs.

This raises an important question about the levels of expressed satisfaction in many of the areas under investigation. If those who are clearly dissatisfied are also those we would most expect to be actively participating, then could the levels of satisfaction be due to a high degree of social withdrawal? At the outset of this study we had wondered whether the increased numbers of wheelchair users had reached a point where there was a 'critical mass' that might be affecting the attitudes of non-disabled people and the organisation of social life. The oppressed minority we identified tends to suggest to us that a significant number of people are pushing the boundaries of accepted behaviour, in other words people are moving out of the 'sick roles' that have been assigned to them.

Implications for providers and purchasers

We have explored a number of areas such as education, housing and leisure which provide some information for a range of non-NHS service providers, both in the private and public sectors. As we reported in the previous chapter, there were significant numbers of people whose education was disrupted due to disablement and there were staggeringly few wheelchair users of working age who were actually in employment. If we only consider those people who declared themselves employed or unemployed, that is to discount those who are retired or stated the question of employment status was not applicable, then only 28% of those declaring themselves as economically active were in employment. This contrasts with 49% of all disabled people and is comparable only with the employment rates of people with learning difficulties (29%) and those with mental health problems (21%) (Office for National Statistics [neighbourhood.statistics.gov.uk]). Employment is not just a means to a greater income, but provides many people with important social contacts. Unemployment is a major contributing factor to social withdrawal.

The lesson of this study for many providers is to take note of the significant minority of people who experience oppression as a result of their exclusion, but

to also recognise that as barriers are removed, enabling more people to participate in their chosen activities, so it is likely that the aspirations of others will increase. We have noted in the example of out-of-town shopping centres that solutions are not necessarily as simple as providing an environment that conforms to certain notional criteria, but involves having a more in-depth understanding of the relationship between people with impairments and those places. One of the contributing factors and something we covered in more depth, is the provision of wheelchairs themselves.

Certain factors stand out about the way people view their wheelchairs and the Preston DSC as the major provider in the north-west. As we have noted above, people feel safest with electric self-controlled wheelchairs and although a large majority of our respondents report being satisfied with the support and service they receive from the staff at the DSC, we know from issues raised with us by local disability information and advice centres and from our interviewees that the waiting time for outdoor electric wheelchairs is far too long. This is a funding issue and is one of two things that could be considerably improved by increasing the budgets available for wheelchair provision. The other is to increase the range of wheelchairs available so that people have more choice, something that is currently only available to those wheelchair users at the top of the hierarchy discussed earlier.

The picture we obtain from this survey therefore is of a service that has a skilled, competent and willing workforce, but who are limited in what they can actually do by the policy of purchasing standard issue equipment. This is not a new problem, rather it is a service approach that has developed since the immediate post-war period when the Ministry Model 8 was produced, 'a wheelchair designed for the service, rather than the wheelchair user' (Woods and Watson 2002a). Vic Finkelstein, a founder of the disability movement, has argued that in the UK we have two competing policies between wheelchair users. On the one hand there is a group for whom we build suitable highways, resting places with accessible toilets and refreshments and offer an increasing array of sophisticated and comfortable wheelchairs. These are of course car drivers. On the other hand, we expect disabled people to use vehicles that can often only be controlled or propelled by another person, that are of identical design, and that they should have to negotiate raised kerbs, street furniture and speeding traffic. Whilst many of these issues are beyond the control of the NHS, the range, suitability and availability of wheelchairs is their responsibility.

Inter-relationships between different services

Joined-up services for joined-up problems has become a cliché of the new Labour regime, however it has a resonance for wheelchair users because no one service provider actually meets their needs. The basic problem with the joined-up thinking approach is whether the objective about which professionals are jointly thinking actually corresponds to people's understanding of how they want to live. Wheelchair users know a lot about the different services they receive and they are proportionately appreciative and understanding of organisational and resource difficulties.

One of the ways forward for ensuring that joined-up services are effective is to give the service user more control over their provision. This has been developed to some extent with direct payments in the social care field and of course with the use of the voucher scheme for wheelchairs. However, if wheelchair services are ever to become as effective as opticians in combining choice with prescription, then some further resources are required.

Final Comment

We would like to finish by thanking the 33 people who agreed to be interviewed for this study, the 1,226 people who returned their questionnaires and the members of the steering group who contributed their time and energy. While much of what we have found in this study may appear to be common knowledge, we believe that by quantifying some of these issues we have added some weight to the arguments that might be made for improving the lot of wheelchair users in the UK. The sample we have in this survey is unusual in that it covers the full age range of wheelchair users including children and older people. While many people were not able to complete the questionnaire themselves, their answers as mediated by a parent, carer or friend do not appear to be out of step with those who completed the survey themselves.

Whilst this report represents the main findings of the survey, we shall be undertaking further analysis of the data set and are able to make it available to others who may wish to use it, subject to agreement over that use. The interviews are also being studied in greater depth as part of Glenis Donaldson's MPhil thesis and when this is published it will be available from the Lancaster University library in the normal way.

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Appendix – Questionnaire

Code No.

The Social Implications of the Increase in Wheelchair Use

Postal Questionnaire



**A study by Lancaster University in collaboration with
Preston Disablement Services Centre.**

Funded by the North West NHS Executive.

We would like to invite you to participate in this research project by completing this questionnaire. Your views are important to us, please be frank when answering the questions.

Important!

This questionnaire is about people who use wheelchairs. If you are filling it in on behalf of someone else, please ensure the questions are answered about them and give their views.

Before you complete this questionnaire, we would like to tell you a bit about it

About this study

During the period 1986 to 1995 there is evidence of a 100% increase in the number of wheelchair users in England and Wales. The aims of this study are:

- To examine the trends in wheelchair use in the north west;
- To ascertain whether the increase is likely to be sustained;
- To establish the reasons for the increase; and
- To evaluate the health and social needs which arise as a result.

We started by looking at the information held on the database of the Preston Disablement Services Centre in order to gain the basic information needed for the study. Following this we carried out in-depth interviews with many wheelchair users. These people were randomly selected and this questionnaire has been designed on the basis of what they told us and other information we have gathered from various sources.

We now want to use the questionnaire to try and quantify the range of needs people have in the health, social care and housing fields. The questionnaire has now been sent to 5,000 people who are patients of the Preston Disablement Services Centre Wheelchair Service.

Throughout the development and progress of this study, we have tried to ensure that we consulted with wheelchair users in the region. This primarily involved having representatives of the Preston Access Group on our steering group. Although that group has subsequently disbanded, their representatives continue to advise us. This has helped us ensure that the types of need we are interested in finding out about are relevant to wheelchair users.

Following the study, we will be presenting reports and recommendations to local agencies providing services. We will be inviting representatives of disability groups to a presentation of the research and shall provide them with additional evidence for their campaigns for improved services. We shall also be writing about the study in magazines and journals that are read by therapists and social workers in order to try and influence the ways in which they practise and are trained.

Researchers at Lancaster University:
Bob Sapey and John Stewart

Your attitudes and views:

These are attitudinal questions. We want to know what you think about some aspects of wheelchair use and about disability. Please circle the number that best reflects your views and/or feelings about each statement.

If you think you cannot answer a statement, please tick the 'does not apply to me' box. If you are neutral, please circle number 3.

Neither agree or disagree

Example	Does not apply to me	Strongly agree				Strongly disagree
		←	→	←	→	
		1	2	3	4	5
1. I would like to win the lottery.	0	1	2	3	4	5

There is room for you to make additional comments after each group of statements. You could explain why you have answered in the way you have. We are particularly interested in knowing if your views have changed from when you first used a wheelchair and how you feel about the issues raised.

	Does not apply to me	Strongly agree				Strongly disagree
		←	→	←	→	
		1	2	3	4	5
40. Wheelchairs can be liberating for disabled people.	0	1	2	3	4	5
41. My wheelchair has liberated me.	0	1	2	3	4	5
42. Comments:						
43. My wheelchair stops me from doing many things I want to do.	0	1	2	3	4	5
44. My illness/condition stops me from doing many things I want to do.	0	1	2	3	4	5
45. Other people's attitudes towards me using a wheelchair stop me from doing many things I want to do.	0	1	2	3	4	5
46. The environment around me makes it hard for me to do many of the things I want to do in my wheelchair.	0	1	2	3	4	5
47. Comments:						

	Does not apply to me	Strongly agree ← Strongly disagree →				
		1	2	3	4	5
48. Discrimination against wheelchair users should be dealt with strongly under the law.	0	1	2	3	4	5
49. Wheelchair users should take responsibility for solving their own access problems.	0	1	2	3	4	5
50. The Disability Discrimination Act will help to change attitudes towards wheelchair users.	0	1	2	3	4	5
<i>51. Comments:</i>						
52. I would enjoy using my wheelchair more if it looked better.	0	1	2	3	4	5
53. The appearance of a wheelchair affects the way non-disabled people view wheelchair users.	0	1	2	3	4	5
54. Wheelchair users have too little choice in the design of the chair they use.	0	1	2	3	4	5
55. The wheelchair I would like is too expensive for me to buy.	0	1	2	3	4	5
<i>56. Comments:</i>						
57. The roads where I live are too steep for me to get out of my home in my wheelchair without help.	0	1	2	3	4	5
58. The roads where I live are too steep for me to get out of my home in my wheelchair with help.	0	1	2	3	4	5
59. Pavements near my home are inaccessible because they are obstructed.	0	1	2	3	4	5
60. It's very difficult to use a wheelchair near my home because there are too few dropped kerbs.	0	1	2	3	4	5
<i>61. Comments:</i>						

	Does not apply to me	Strongly agree				Strongly disagree
		← 1	2	3	4	5 →
62. I need help to go to local shops as they are difficult to access in my wheelchair.	0	1	2	3	4	5
63. The town centre is easier to access than local shops.	0	1	2	3	4	5
64. The town centre is difficult to access.	0	1	2	3	4	5
65. I can access out-of-town shopping centres on my own.	0	1	2	3	4	5
66. <i>Comments:</i>						
67. There are restaurants I would like to go to, but do not as the toilets are inaccessible.	0	1	2	3	4	5
68. There are restaurants I would like to go to, but do not because of lack of parking .	0	1	2	3	4	5
69. There are pubs I would like to go to, but do not as the toilets are inaccessible.	0	1	2	3	4	5
70. There are pubs I would like to go to, but do not because of lack of parking .	0	1	2	3	4	5
71. <i>Comments:</i>						
72. I have difficulty travelling to my local leisure centre.	0	1	2	3	4	5
73. I find it quite easy to get in and out of the leisure centre.	0	1	2	3	4	5
74. I am able to participate in sporting activities.	0	1	2	3	4	5
75. It is necessary to provide special leisure activities for wheelchair users.	0	1	2	3	4	5
76. <i>Comments:</i>						

	Does not apply to me	Strongly agree				Strongly disagree	
		←	1	2	3	4	5 →
77. People tend not to talk to me when someone else is pushing my wheelchair.	0	1	2	3	4	5	
78. People do talk to me when I am controlling my wheelchair.	0	1	2	3	4	5	
79. Other people view me negatively because I use a wheelchair.	0	1	2	3	4	5	
80. I view myself negatively because I use a wheelchair.	0	1	2	3	4	5	
<i>81. Comments:</i>							
82. I know a shop where I can get good advice on wheelchairs.	0	1	2	3	4	5	
83. I have had good advice on wheelchairs from the Disablement Services Centre.	0	1	2	3	4	5	
84. I knew almost nothing about wheelchairs before I got one for myself.	0	1	2	3	4	5	
<i>85. Comments:</i>							
86. If I have a problem with my wheelchair, I know I can rely on the Disablement Services Centre to help.	0	1	2	3	4	5	
87. I find the staff at the Disablement Services Centre approachable.	0	1	2	3	4	5	
88. I find the staff at the Disablement Services Centre efficient.	0	1	2	3	4	5	
<i>89. Comments:</i>							

110. Which of the following best describes you and your housing?

- I am an owner occupier • 1
- I rent from the council • 2
- I rent from a housing association • 3
- I rent from a private landlord • 4
- I live in someone else's house • 5
- other • 6
- (please state)

111. Are you satisfied with the access **within** your home? yes • 1 no • 2

112. Comments:.....
.....

About your education:

113. Have you ever attended a special school for disabled children? yes • 1 no • 2 not applicable • 3

114. Has your education ever been seriously disrupted due to your disability?
yes • 1 no • 2

115. If yes, please explain how:

.....
.....

116. Are you currently a pupil in **primary or secondary school**? yes • 1 no • 2

117. Are you currently a student in **further or higher education**? yes • 1 no • 2

118. Are you currently on a **training scheme** either full or part-time? yes • 1 no • 2

About your employment:

119. Are you? employed • 1 unemployed • 2 retired • 3 not applicable • 4

If **employed**,

120. How many hours on average do you work each week? hours

121. What business are you in?
.....

122. What is your job?
.....

123. Have you ever had to give up a job because you use a wheelchair? yes • 1 no • 2

124. Are you doing any voluntary work? yes • 1 no • 2

If **YES**,

125. How many hours on average do you work each week? hours

126. Comments on employment:

