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Older People and Dissatisfaction with Wheelchair Services

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ABSTRACT *Britain has experienced an unprecedented increase in wheelchair use during the past two decades. The authors take a social model approach to disability and report on their study in the north-west of England into the social implications of this increase. Qualitative interviews and a large-scale social survey reveal the circumstances of users and their experiences. Building on their descriptive statistics, the authors use latent class analysis to identify from amongst their respondents the characteristics of dissatisfied users of UK National Health Service wheelchair provision: they were more likely to be older, frailer females; and to be living in residential and nursing care homes. Prescribing practices and policy guidelines are analysed to consider how a hierarchy of need is operating to determine wheelchair allocation.*

Introduction

Within western industrial societies the majority of disabled people are both older and female. In a study of wheelchair users in the UK, we found that those respondents who were most dissatisfied with the agencies responsible for providing wheelchairs were amongst the oldest and frailest of disabled people, and likely to be institutionalised. In this paper we discuss these issues in relation to hierarchies of disablement and health service policy and practice. We draw on the findings of a study into the social implications of the increases in wheelchair use, which was funded by the UK National Health Service (NHS) and carried out between 2001 and 2003 in the north-west of England (Sapey, Stewart & Donaldson 2004).

Background

Between 1986 and 1995 there appeared to be approximately a 100% increase in the numbers of wheelchair users in England and Wales. The evidence for the increase in wheelchair use lay primarily in two national studies. In 1986 the UK government disability surveys estimated there were 360,000 wheelchair

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users in England and Wales (Martin, White & Meltzer 1989). Ten years later Aldersea's (1996) investigation into the NHS Disablement Services showed that the number had risen to approximately 710,000 in England. The increase appears to be continuing and the Department of Health (2004) recently estimated there are now 1.2 million wheelchair users in England. This means that about 17% of *disabled people* in the UK are wheelchair users (extrapolated from Office of National Statistics and Disability Rights Commission data).

Little was understood about why the increase had taken place, or what the social implications were. Our research study, funded by the NHS Executive North West Research & Development Directorate, aimed to understand the extent to which the increases had affected the experiences and aspirations of disabled people. The study was in three phases. First we analysed the available data from a Disablement Services Centre (DSC) in north-west England that gave us some basic demographic information about the population of wheelchair users. Second, we carried out semi-structured, in-depth interviews with 33 wheelchair users in order to access the privileged knowledge they had gained from their experience of wheelchair use. We then used our analysis of these interviews to produce a postal questionnaire, sent to nearly 5000 people from the patient database of the DSC, stratified by location, age and sex. The survey, which sought to quantify attitudes towards a range of disability issues and gather some demographic data, resulted in a response of 1226 people. From our previous experience of using postal questionnaires, we had expected a responses rate of between 20–30%. We were unable to follow up those who had not responded due to the way we were ensuring the confidentiality of DSC patients. Follow-up is normally the most effective way of increasing response rate (see for example Parkera and Dewey 2000). However, we believe this to be one of the largest surveys of wheelchair users to have been carried out in the UK and that the respondents are a representative sample (see Sapey, Stewart & Donaldson 2004: chapter 4).

The DSC was a partner in the study and the main NHS stakeholder in our research. From the outset they were very co-operative partners, concerned to improve their services and to listen to what disabled people had to say about their experience of wheelchair use. This DSC is contracted by a number of health trusts to assess need and supply wheelchairs to over 20,000 patients in the north-west of England. It was this population from which our interviewees and social survey sample was drawn.

In addition to knowing more about the social circumstances and aspirations of wheelchair users, the DSC management were keen to know how their organisation was regarded: for example, whether their services were experienced as efficient and effective; and whether their staff were found to be knowledgeable and courteous. These questions led us to identify the group of people who were most dissatisfied with wheelchair provision. The initial results of the qualitative part of this study indicated that people were receiving different levels of provision, possibly associated with the nature of their impairment and professionals' attitudes affecting the assessment process. However, a descriptive statistical analysis of the survey data indicated a high level of satisfaction with the DSC. Only about 1 in 20 respondents reported being dissatisfied with the personnel at the DSC, though less than half felt they could get good advice through the centre (Sapey, Stewart & Donaldson 2004).

Using only descriptive statistics limited what we could say about these findings; hence we subjected the data to a latent class analysis comparing responses across many attitudinal statements rather than one at a time. More will be said about this method later, but first we need to say something about hierarchies of disability.

Hierarchies and Need

In an NHS guidance document *Wheelchairs: guidelines for purchasers and providers based on categories of users* published in November 1995, (reproduced in Aldersea 1996), need has been defined in terms of the categorisation of users' mobility status. There are three main categories, which can be described as non-walking, partial walking and short-term users, including those not likely to live very long. Such a generalised conceptualisation is constructed through an individual model of disability approach, whose discourse of categorisation also distinguishes levels of dependency. Liggett (1988:192) suggests that when practices "operate by producing and managing identities", the process binds both disabled and non-disabled people to their respective identities. The creation of sub-groups based on impairment within these administrative guidelines is such a practice. Given finite budgets and the differences between the contracts that the DSC has with the seven primary health trusts in the north-west of England, those therapists who are involved in the prescription of wheelchairs are charged with the task of rationing resources. This exercise results in an hierarchical provision. Therapists are bound to their identity as the expert assessors of need while wheelchair users are bound to an identity forged by their place within the hierarchy.

It was possible to identify within the interviews from our study that wheelchair users felt that people who have a spinal injury and have retained the use of their upper limbs and their ability to self-propel were at the apex of this hierarchy; lower down the hierarchy are those people who have a congenital impairment and who are more likely to use a powered wheelchair. Those at the top of this hierarchy may also amplify their own advantageous position. Both sexes tended to report instances of resistance to cultural stereotypes; in particular some 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. Conversely, those who needed to use an electric wheelchair would commonly report long periods of waiting for suitable chairs to be provided.

We shall return to this theme later in the paper, but first we wish to say more about the data analysis and our quantitative findings.

Social Survey – Methodology

In our social survey we posed 136 questions, including a series of 39 attitudinal statements to which respondents were asked to state their strength of agreement/disagreement or whether the statement did not apply to them. The topics of the survey questions were drawn from the themes that arose in the literature review and the qualitative data gathered from the 33 interviews we had undertaken. There were four main themes: *Identity as a wheelchair user; Control; Utilitarian issues*; and *Therapy*. It was the first two of these that informed the attitudinal statements and the sub-themes we identified within them were (Sapey, Stewart & Donaldson 2004:22):

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 – 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.

Our attitudinal statements were intended to help quantify the extent to which wheelchair users identified with a range of attitudes associated with these themes. We were concerned to ascertain attitudes towards key factors within the opposing social and individual models of disability; the extent and nature of people's everyday activities and the barriers to these; the way people viewed themselves and their perception of the ways others viewed them; and their attitudes towards the Disablement Services Centre from which they had acquired at least one wheelchair.

The statements can be viewed in the main report (Sapey, Stewart & Donaldson 2004), which is available online. In that report we undertook a descriptive analysis of the survey responses, seeking correlations to identify any trends in the data.

Study Findings

We have concluded elsewhere (Sapey, Stewart & Donaldson 2005) that the overwhelming majority of respondents viewed wheelchairs as potentially liberating, rather than negatively, as clinical equipment. Whilst they believed the environment was a major barrier, they also felt their impairments were limiting their lives. Furthermore, given that our respondents were predominantly older people (they had a mean age of 67.9 years) and, in the main, disability is an experience of old age, we argued that this demonstrated the significance of a social relational model of disability for explaining the way a majority of disabled people experience disability. In terms of professional attitudes we concluded:

> To 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. (Sapey *et al.* 2005, pp. 503–504)

This is not to argue that the social model is without its own problems, but we do claim that our study shows that many more disabled people identify with key components of the social model than professionals have been willing to accept.

In relation to the main topic of this paper – the attitudes of older wheelchair users towards professional services – our descriptive statistical analysis showed that although many of our respondents were able to get good advice about wheelchairs through the private sector (34.7%), a higher proportion thought that they received good advice from the DSC (43%). A large majority (71.8%) of respondents knew nothing about wheelchairs prior to becoming a user themselves, indicating the importance of finding good advice and of the role of the DSC in this. The responses to the last three, attitudinal statements, which concerned the DSC's services and staff, indicated a high level of satisfaction. Almost three quarters of respondents (72.9%) thought that they could rely on the DSC and just under two thirds (63.3%) had experienced the DSC staff as efficient. Only one in 20 (4.7%) found the DSC staff unapproachable, which is a very low level of expressed dissatisfaction. Wilson (1993) argues that satisfaction surveys will report low levels of dissatisfaction with welfare services, due to the unequal power relationships between service providers and service users. We endeavoured to provide assurances to respondents that they would and could not be identified, so we do have reasonable confidence in these results. In contrast with other issues that have affected our respondents, their dealings with the DSC appear to be very positive. In this descriptive analysis of the data we did not find any strong correlations that might indicate reasons for dissatisfaction, but as we have argued elsewhere:

> There are several issues like this one where a significant minority of wheelchair users appear to be dissatisfied or experience oppression. We are carrying out further investigations into the hypothesis that certain groups of wheelchair users are pushing the boundaries of social expectations and as such they tend to experience a greater level of oppression. 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, whilst simultaneously establishing themselves at the top of the DSC hierarchy. (Sapey, Stewart & Donaldson 2005:501–502)

Latent Class Analysis of Data

Using descriptive statistical analysis we have been able to identify levels of satisfaction with wheelchair services and have formed the basis of a hypothesis as to why a significant minority of wheelchair users are not satisfied. In order to examine this further we needed a more sophisticated approach. The method chosen was the technique known as latent class analysis. Some background to this approach will help in understanding and interpreting the results.

It is not always possible to directly observe social phenomena. For example, Francis, Peelo and Soothill (1992) argue that a commitment to a career cannot be directly observed, however there are many other indicators of career commitment that can be measured. They distinguish between latent variables, which cannot be observed, and manifest, or measured variables, which can be observed and are thought to measure part of the latent variable. Various attitudinal variables, such as beliefs about the likelihood of promotion after pregnancy, or adequacy of pay, can be measured. If it were believed that commitment to a career causes these indicators then co-variation among the measured variables would be expected. However, it would be inaccurate to say that latent variables necessarily cause observed variables; a strong commitment to a career does not cause a positive attitude toward pay structure. It makes more sense to say that the latent variable, for example the level of commitment to a career, explains the relationship between the observed variables. If a latent variable did exist, then controlling for it would "result in diminishing the co-variation between all of the observed variables to the level of chance co-variation. Consequently, the latent variable is said to be the 'true' source of the originally observed co-variations" (McCutcheon 1987:5–6).

There are a number of statistical modelling techniques available for studying the relationships between observed variables believed to be caused by an unobserved latent variable, in order to characterise that latent variable. Mathematical models that allow characterisation of latent/unobserved variables based on manifest/observed variables come under the umbrella of latent structure analysis (Henry 1983). The various models differ according to whether the variables (manifest and latent) are discrete or continuous. Factor analysis is a technique for developing continuous latent variables derived from continuous observed variables. However, factor analysis is not appropriate for developing typologies, which, as a rule and not a law, attempt to develop discretely scored categorical (either nominal or ordinal) classes.

Latent class analysis on the other hand, is a technique for analysing relationships between any types of observed variables that it is believed are explained by discrete latent variables.

Latent class analysis is most commonly used for examining symmetrical relationships among categorical variables (McCutcheon 1987). A symmetrical relationship between variables is one in which the variables under observation are statistically proven not to be independent of each other, but at the same time are not believed to be causally related.

With our survey data, the latent class analysis was used for two main purposes: first to explore what typologies might exist within responses to our attitudinal statements; and second to provide further data which would help us test the hypothesis that dissatisfaction with wheelchair services is related to hierarchies that therapists operationalise. In this way, the hierarchy becomes our latent variable that we seek to identify by the manifest variables of satisfaction with various aspects of the DSC.

The data consisted of 1226 respondents on 39 Likert-type attitudinal questions. Each attitudinal question was converted to a binary response, coding positive responses (responses 1 and 2) to 1 and the rest to zero. Missing responses in our study were judged to be high, with 576 respondents not responding on one or more of the items. Detailed investigation of these missing responses showed that the majority of them related to statements about access to the facilities in local shops, pubs and restaurants. There was a large group of respondents who responded to all the other questions, but not to these "external facilities" questions. For this part of our study, we decided to exclude these "external facilities" non-respondents, leaving 650 respondents who answered all the rest of the attitudinal questions.

Models were fitted using Latent Gold (Vermunt & Magidson 2000). One question of interest is the number of groups in the data. We can have any number of groups from one (indicating that all respondents are responding similarly) to 650 (with each respondent forming their own group). We used the BIC criterion to determine the optimal number of groups. The Bayesian Information Criterion (BIC) statistic (Kass & Raffery 1995) is based on the log-likelihood, and the minimum value of BIC is used to determine the optimal number of clusters. This analysis produced four clusters.

Latent Gold places respondents into clusters based on the probability of them responding in similar ways to a number of the attitudinal statements. The actual number of attitudinal statements that this might apply to within each cluster varies according to the data being examined. There were several issues on which these clusters differed, and cluster 4, which contains 5.4% of the new sample, is the one differing most in that the respondents believe many of the attitudinal statements do not apply to themselves. However, given our interest in hierarchies within the wheelchair services, it is cluster 3, which consisted of 12.9% (84 people) of this sample that stood out as being dissatisfied with the DSC.

Although the latent class analysis produces clusters, we are wary of allowing these to be treated as static typologies as that might tend to stereotype wheelchair users. People may change their views over time and in response to different experiences that would result in them moving from one cluster to another. Therefore we have chosen not to give Cluster 3 a popular name.

The Attitudes of Cluster 3 Respondents

We chose to set high levels of probability to identify important tendencies within the manifest variables. The level we set was 70:30 – that is to say, the probability of agreement or disagreement is greater than 70% or lower than 30%.

Regarding attitudes towards the DSC (Table 1), Cluster 3 respondents showed a low tendency to agree that they could rely on the DSC to give them good advice (Q86). Unlike Clusters 1 and 2, which agreed that the DSC was helpful, Cluster 3 respondents were divided. However when it comes to the approachability and efficiency of DSC staff (Qs87 and 88), whilst Clusters 1 and 2 are satisfied, Cluster 3 is not satisfied.

Apart from their dissatisfaction with the DSC, the other attitudes that are important in characterising Cluster 3 did not distinguish it greatly from Clusters 1 and 2. Cluster 3 respondents are highly likely to agree that wheelchairs can be liberating, but that illness or impairment may prevent them from doing what they want; they report not being affected by other people's attitudes; they are likely to believe that they are not responsible for solving their own access problems. There is little disagreement within Cluster 3 that the aesthetics, cost and choice of wheelchairs matter. They do not tend to view themselves negatively.

Table 1. Latent class analysis of results for statements about the DSC (significant responses highlighted)

Clusters	1	2	3	4
Q86 If I have a problem with my wheelchair, I know I can rely on the Disablement Services Centre to help				
Does not apply	0.0891	0.0833	0.0027	0.4889
Agree	0.8189	0.8180	0.2912	0.5051
Neutral	0.0846	0.0903	0.3500	0.0059
Disagree	0.0074	0.0084	0.3561	0.0001
Q87 I find the staff at the Disablement Services Centre approachable				
Does not apply	0.1327	0.2051	0.0003	0.4174
Agree	0.8012	0.7568	0.1159	0.5719
Neutral	0.0658	0.0380	0.6323	0.0107
Disagree	0.0004	0.0001	0.2515	0.0000
Q88 I find the staff at the Disablement Services Centre efficient				
Does not apply	0.1321	0.1844	0.0000	0.4209
Agree	0.7800	0.7565	0.0250	0.5647
Neutral	0.0877	0.0591	0.6888	0.0144
Disagree	0.0001	0.0001	0.2862	0.0000

The Social Circumstances of Cluster 3 Respondents

In Cluster 3 we have identified a group who are less satisfied with the services they receive. In terms of other attitudes there are no significant differences with the majority of other wheelchair users, but in terms of social circumstances there are several differences between Cluster 3 and other clusters that shed light on the nature of this hierarchy.

The first difference to note is that the average mean age of Cluster 3 at 73.1 years is higher than for all the respondents in this sample (650), at 63.9 years. While age is clearly a factor in dissatisfaction, it is important to bear in mind that more than half of DSC patients are over 70 years of age and Cluster 3 respondents only make up 12.9% of the sample. Therefore the vast majority of older wheelchair users are not expressing dissatisfaction, but age is an important factor in that group who are dissatisfied. The sex distribution of respondents in Cluster 3 was the same as the whole population of wheelchair users: one third male and two thirds female.

As can been seen in more detail in Table 2, as well as being older, Cluster 3 respondents were more likely to be full-time wheelchair users and to be living in institutional care. Those Cluster 3 respondents who were living at home were more likely to be in purpose-built or adapted dwellings: they were more likely to have ramped access and stairlifts; and they were also more likely to be satisfied with access within their homes. The higher prevalence of these factors tends to suggest that Cluster 3 respondents are sufficiently impaired to qualify for a wide range of housing and care services, and that their impairment is of sufficient longevity to allow for housing adaptations to be made.

In terms of the medical cause of their immobility, Cluster 3 were less likely than others to be diagnosed in the categories of either orthopaedic or neurological disorders, but more likely to have had a stroke (CVA) or for their

Table 2. Social circumstances of Cluster 3 respondents as compared to all respondents

Social circumstance	Cluster 3 (%)	All clusters (%)
Living in residential care	31.0	12.2
Home purpose built	20.0	14.2
Home adapted	34.2	31.9
Ramped access to home	50.6	43.3
Stairlift	43.9	37.1
Satisfied with access within home	86.4	78.1
Diagnosis – orthopaedic	1.3	7.0
Diagnosis – neurological	15.2	19.3
Diagnosis – old age	11.4	4.2
Diagnosis – CVA	22.8	15.4
Full-time wheelchair user	42.9	36.1
Attendant controlled manual wheelchair	41.5	30.2
Electric wheelchair	6.1	11.0

condition to be ascribed to old age (respondents self-assessed and allocated to one diagnostic category only).

Cluster 3 respondents were more likely than members of other clusters to be prescribed with an attendant controlled, manually propelled wheelchair and despite the apparent severity of their impairment, they were less likely to have an electric wheelchair. There are possible clinical reasons for this, for example, people who have had strokes may have peripheral vision or coordination problems which would cause them to be unable to control an electric wheelchair. A result of this prescription practice is that as the wheelchair user cannot propel an attendant-controlled chair herself, there is no need to instruct her in its use. This means that Cluster 3 respondents may have had less direct contact with DSC staff, which may be a contributory factor in their dissatisfaction with DSC services.

Thus, the respondents who are most likely to be dissatisfied with wheelchair services are older, frailer and more dependent than other wheelchair users. They are more likely to have had a stroke or be immobile due to old age, and rather than being prescribed an electric wheelchair that might seem appropriate in such circumstances, their dependency is potentially reinforced by the provision of an attendant-controlled, manually-propelled wheelchair.

Given the fiscal and contractual constraints on the NHS, service providers become the gatekeepers of scarce resources. To supply an equitable service within the limited resources provided, the disablement services work within administrative guidelines from the Department of Health. Relevant health professionals place service users into one of the three categories: (1) long-term full-time users, those with no walking ability; (2) long-term occasional users, those with limited walking ability; and (3) short-term temporary users. The categorisation of the person is intended to determine the type of equipment provided.

What we see in Cluster 3 is a group of people who appear to have been provided with equipment appropriate for ‘short-term and temporary’ users, whereas our evidence suggests that their impairments may have been long-term. It seems reasonable to question whether professionals may have been making clinical decisions based on a shorter anticipated lifespan for these people. An occupational therapist, nurse or other health professional will have undertaken these clinical assessments. We can begin to explain the disparity between the assessment and what the analysis of our data reveals, by returning to the notion of a hierarchy of disability and considering the basis on which that hierarchy operates.

When we hypothesised (Sapey, Stewart & Donaldson 2005) that the discontent of wheelchair users might be linked to people pushing at the boundaries of roles that were deemed appropriate for disabled people, we had particularly in mind the idea that younger, more active wheelchair users would be rejecting the traditional “sick role” (Parsons 1951). That view was supported by our interview data, yet what we have found through the latent class analysis of the survey data is that the most discontent group in relation to wheelchair services are older and frailer. These respondents were also less likely to have completed our survey questionnaire themselves (37.2% as opposed to 58.4% of all respondents), which suggests that they are more dependent on someone else to mediate their felt needs; they may lack a 'voice' when it comes to their own affairs. The sick role ascribed to them appears to be one of dependency, inactivity and lack of voice, and it is this that we suspect they reject. While this group are more dissatisfied with their own provision they are very positive about the potential for wheelchairs to be liberating.

In order to understand what might be going on here we think it is helpful to consider the differences between normative and expressed need (Bradshaw 1972). We have noted that wheelchair provision is based on a normative assessment of need. That is to say, the assessor has been trained to work to some form of objective, clinical and administrative criteria. These criteria are reflected in the NHS guidelines detailing the three levels of categorisation mentioned above. Yet what we believe is happening in practice is that respondents in Cluster 3 are not benefiting from such an assessment. Due to their lack of voice, their needs are not being expressed as strongly as are those of other people at the top of the hierarchy, hence health professionals are under less direct pressure to place them in a higher category of need – therapists are assessing expressed, not normative needs. In discussing this data with DSC professionals, they suggest that another determinant may be that carers of wheelchair users in this situation, that is without 'voice', may favour models of wheelchairs which enforce dependency.

Conclusions

Since this survey was completed, the Department of Health (2004) have published a good practice guide for the improvement of wheelchair services for both users and carers. The four strategies in this guide develop the existing approach of professional assessment and provision of equipment, whilst emphasising the overall experience of wheelchair users and their carers. The first strategy focuses on the need to develop and agree eligibility criteria with wheelchair user groups, an approach which is potentially in accord with developing respect for the views of service users. Strategies 2 and 3 are concerned with minimising delays and using resources efficiently, while the fourth is concerned with outcomes which should be enabling and promote independence. While this approach should be familiar to those versed in the modernisation project of the current British government, the problem from our perspective is that it may fail to recognise the causes of the greatest discontent with wheelchair services.

Prescribing by health professionals has always been based on assumptions about the relationship between impairment and need, which creates a hierarchy. However, our study shows that this hierarchy may be based on dependency and disempowerment caused by health professionals being influenced by expressed needs, whilst ignoring felt needs. These new strategies which seek to reassert the role of the normative assessment of need by professionals may simply recreate the circumstances in which those professionals not only devalue the felt needs of wheelchair users, but continue to be influenced only by those with a sufficiently strong voice. However, the

Department of Health are keen to ensure that the wheelchair users' views of their own needs are included in the process and as we have already noted, for those at the apex of the hierarchy this is already happening. The reasons for this may be twofold: first these people may be better able to express their own needs; and second, as they are fewer in number, they cause less demand on finite budgets even if they are prescribed more expensive equipment. What is needed is an additional strategy to ensure that those currently at the foot of the hierarchy can be heard.

Such a strategy would confront the causes of the discontent, found particularly amongst older users of wheelchair services – the creation and maintenance of a hierarchy based on weakness. Health professionals need to recognise that their expert approach, informed as it is by an individual model of disability, is as inadequate with the least vocal of wheelchair users as it is with the most vociferous. With the latter professional decision-making is influenced by expressed need, while with the former, the result can be dissatisfaction. This suggests that the Department of Health may be correct in emphasising the importance of the wheelchair user's experience. It is they who hold the expertise in relation to their own functional needs and their aspirations for social participation.

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