



# Survey Report

<b>Report Title:</b>	<b>Public Views about NHS Wheelchair Services</b>
<b>Organisation:</b>	<b>Healthwatch Bolton</b>
<b>Dates:</b>	<b>Autumn- Winter 2016/2017</b>
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## Acknowledgements

Healthwatch Bolton would like to thank all respondents for sharing their views and experiences about NHS wheelchair services.

## Disclaimer

Please note the report relates to views and experiences shared during survey consultations with users of NHS wheelchair services.

## Background

This piece of work began in Bolton in 2016 and was sparked by Bolton Clinical Commissioning Group revising its wheelchair eligibility criteria. Healthwatch Bolton was asked to comment on this change in service and brought a number of members who use wheelchairs together to look at the various proposals. Following this process it was decided that some wider work on people's experiences of accessing wheelchair services was desirable in order to better inform commissioners about the impact of any changes in wheelchair availability.

On a national level wheelchair services has drawn much attention and debates. Since 2010, the Department of Health (DH) has put wheelchair services at the top of its 'transformation' agenda. The precise nature of such transformation, however, remains largely unclear. Part of this relates to perceived difficulties of accessing 'user' views not least on their lived experiences of NHS wheelchair services.

## Strategic drivers

- Encouraging and supporting local people to share their views and experiences of wheelchair services including eligibility assessment criteria
- Engaging with hard to reach and vulnerable individuals.
- Desire to inform commissioners about the impact of wheelchair availability on disabled people's lives.

## Methodology

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A short online questionnaire was devised, both Healthwatch Bolton and Healthwatch Wigan and Leigh publicised the survey and expert patients shared the questionnaire among their contacts. The questionnaire:

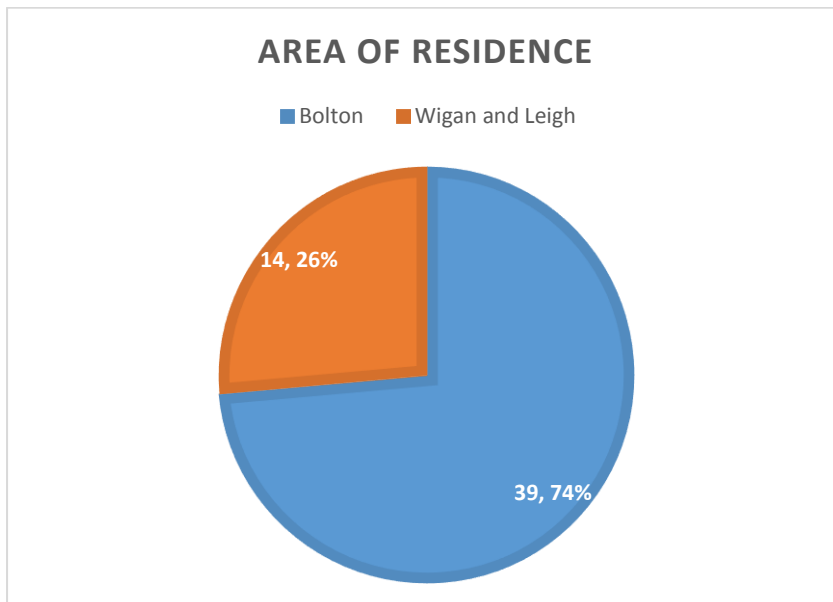
- Explored the views and experiences of wheelchair services in Greater Manchester
- Explained the role of our role of asking for general experiences of health and care services

## Who Responded

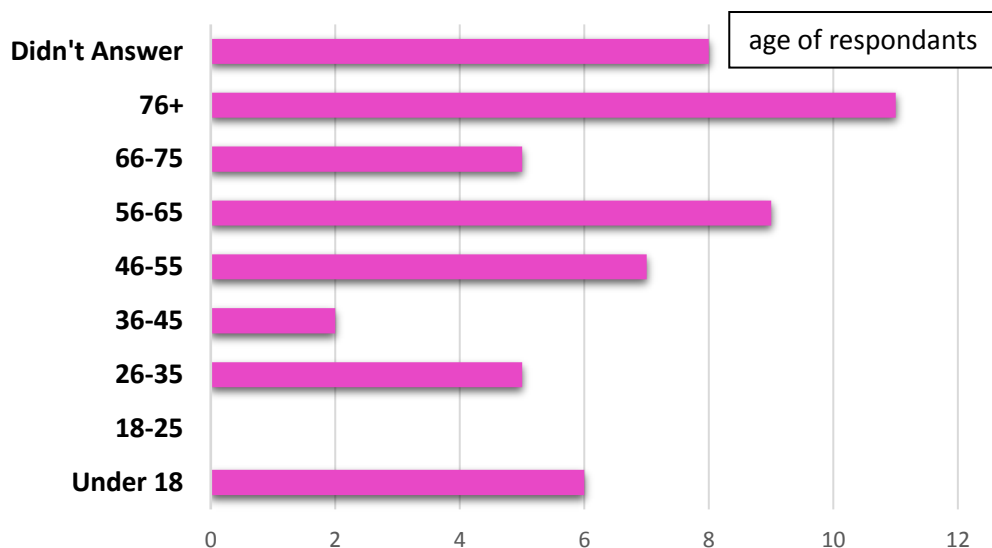
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We received 53 completed survey questionnaire. All respondents were from Greater Manchester.

### Place of Residence

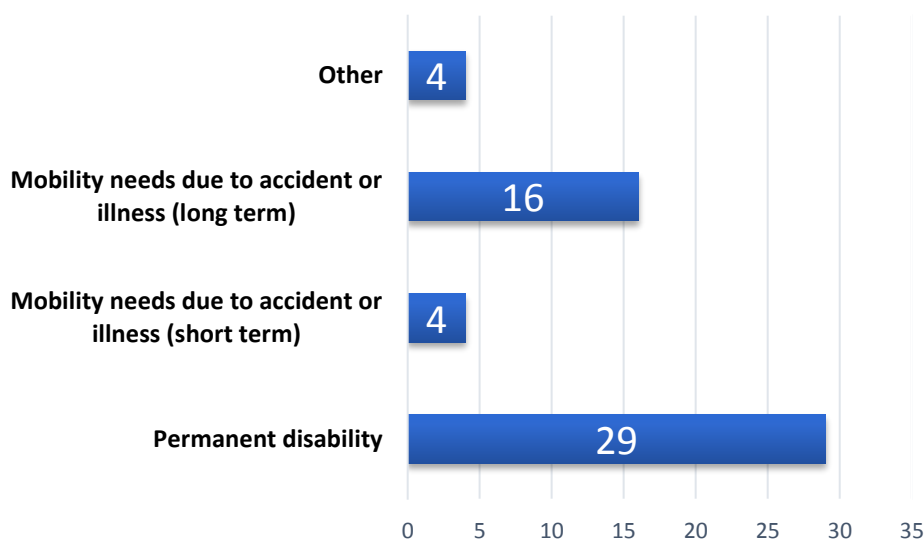


### Age



Nearly a third of wheelchair users (11) were 76+ of age. A total of 6 respondents were under 18. The oldest wheelchair user in the sample was 95 years old, the youngest was just 8 years old.

### Reason for needing a wheelchair



- Over half (29 people; 54%) of respondents stated they needed a wheelchair as a result of having a permanent disability.
- 16 (30%) respondents cited long term mobility due to accident or illness as the reason for needing a wheelchair.
- Only 4 (8%) of the respondents had a wheelchair as a short-term measure following an accident or illness.
- Half (4%) of the respondents in the 'other' category bought their own wheelchairs, and the remaining half acquired their wheelchairs through the NHS wheelchair service.

## Wheelchair Usage

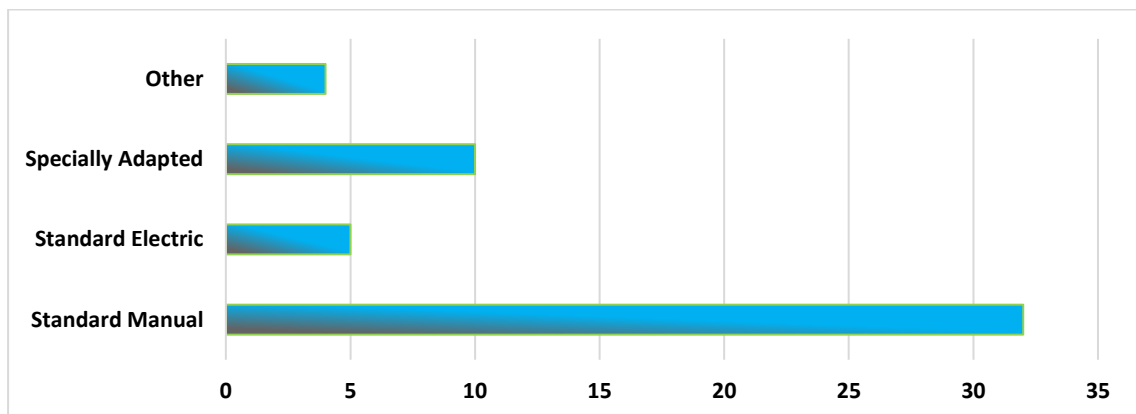
Reflecting some of the common exclusion criteria used in wheelchair assessment processes we asked people about what types of wheelchairs they used and asked about their patterns of usage.

Unsurprisingly considering the various different reasons for needing a wheelchair we found considerable variation in the types of wheelchairs people are using and the patterns of usage.

Again unsurprisingly we found that many people either are able to , or have to - (due to their accommodation being un wheelchair friendly, for example) manage without their wheelchair indoors. They use their wheelchair outdoors in order to be able to access the community, for work and social reasons thus allowing them to maintain a quality of life and participate in society.

We also found considerable variation in the regularity of people's usage this reflected a number of issues including, fluctuations in people's conditions and the type of regularity of activities that people participate in.

### What type of wheelchairs are people using?



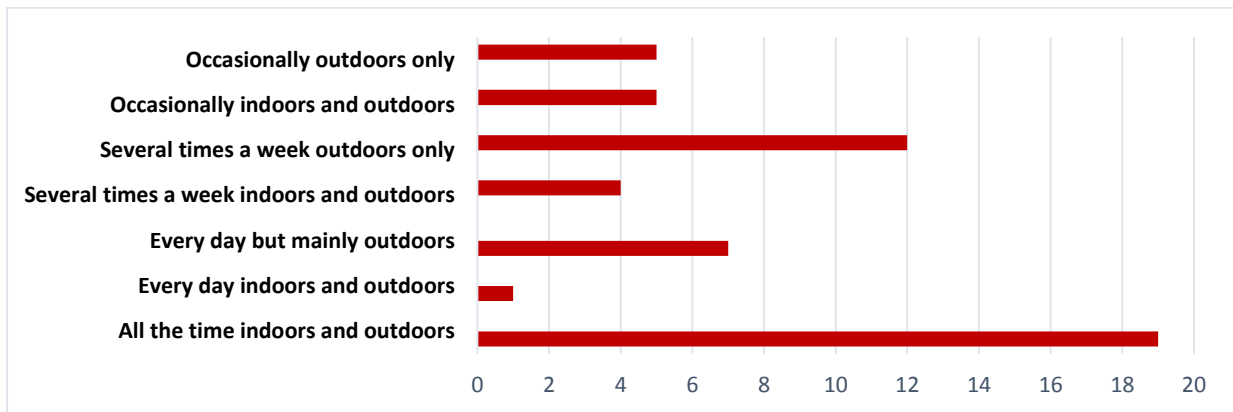
Over two-thirds of respondents (63%) said they use 'standard manual' wheelchair, only 5 (10%) respondents said they use 'standard electronic'. Two respondents stated using mobility scooter alongside their standard manual wheelchairs.

*"...I have a learning disability and now unable to walk longer distances which restricts the family when we go out. The Wheelchair has given us more freedom." - respondent in 'other' category*

### Wheelchair usage patterns

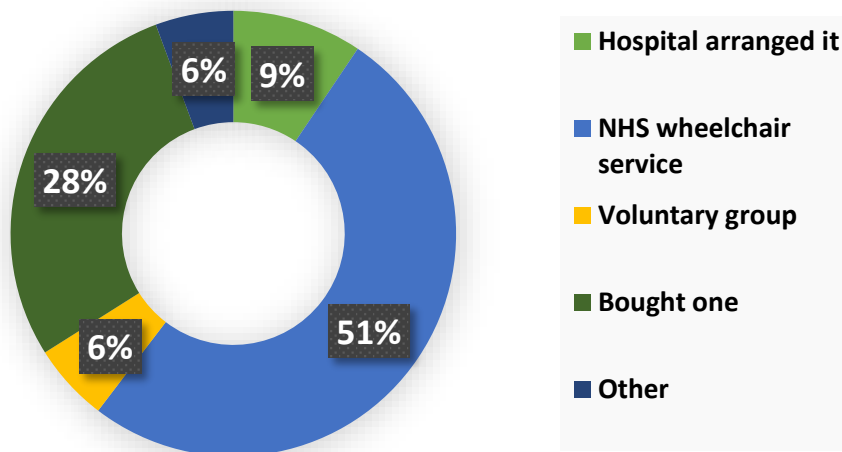
- More than a third (36%) of respondents stated they use their wheelchairs 'all the time' indoors and outdoors.

- 8 people (15%) stated they used their wheelchair everyday, with the majority of this group using them mainly for outdoor mobility with 7 (13%) respondents stating using them ‘everyday’.
- 12 people (23%) stated using their wheelchairs ‘several times a week’ again outdoor mobility was the main reason for wheelchair use in this category.
- 10 people (19%) stated they used their wheelchair occasionally, interestingly in this category ‘indoor and outdoor’ and ‘outdoor only’ use were evenly split.



## Experiences of Wheelchair Services

### Where are people getting their wheelchairs?



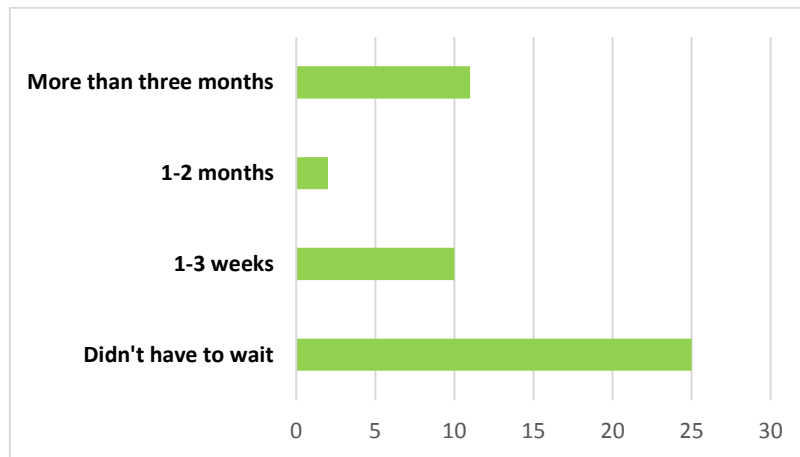
- Over half of the respondents stated they acquired their wheelchairs through the NHS wheelchair service.
- Nearly a third (28%) of respondents stated they bought their own wheelchairs through disability grants and out of frustrations relating to NHS wheelchair waiting times.

- Only 3 (6%) respondents stated they acquired their wheelchairs through ‘other’ ways such as ‘shop mobility’, ‘stroke team’ and ‘grants’.

Some respondents who described themselves as having a permanent disability stated they were refused an adapted wheelchair by local providers due to ‘technical’ eligibility criteria. One respondent shared what it takes to get an adapted wheelchair:

*“I was technically refused a wheelchair from the local wheelchair services because I can stand. My present wheelchair was a fight to get and eventually the CCG arranged for my wheelchair to be provided by Manchester Wheelchair services. There needs to be an overhaul of Bolton wheelchair services recommendations as to who is eligible for a wheelchair and all situations should be addressed in the assessment not just because someone can stand”*

### Waiting Times



- The majority of respondents (25; 52%) said they did not have to wait for a wheelchair.
- However 11 (23%) respondents experienced more than three months wait for wheelchairs.
- 10 people (19%) experienced a wait of between one and three weeks before obtaining their wheelchair.

The delays experienced related to:

- Inconsistent wheelchair eligibility assessment criteria
- Accessibility (e.g. need to fit ramps at home )
- Areas of residence
- Procedural issues caused by an unwieldy system

*“They [wheelchair services] wouldn't let me have it [the wheelchair] for 2 months (May to July) because they said I needed a safety officer, who*

*when he came I could tell him more about the wheelchair than he knew!  
They treated me with total dis-respect or any consideration to the  
safety of my un-born child..."*

### **Waiting for a Wheelchair; Effects and Coping Strategies**

Delays experienced by people waiting for a wheelchair affected people's mobility and their general wellbeing, increased their stress and sometimes worsened their condition. People described situations where the wait had caused them significant problems in continuing with their daily activities causing stress and social isolation. A number of people had come up with alternative arrangements, including buying their own chair as an alternative to struggling on through an in-determinant period of waiting.

*"I got pregnant and needed a powered wheelchair (indoors only available at the time) I was in severe pain, housebound, and struggled to get about around the house. I had to wait 6 months for the chair to be assessed, ordered and delivered"*

*"Severe discomfort and pain leading to destabilisation and hospitalisation. Unsafe in travel. Demoralisation, self-esteem. Difficulties socialising and accessing the community"*

*"...waited a very long time - nearly two years. It impacted me in terms of using trains to get to meetings/conference from work and socially. At work, I used a mobility scooter, but it was too big to take up to my department floor so I would end up having to use lift and then walk to up to my entrance door using crutches; try and open doors whilst holding sticks and swipe cards etc. then I would swap my sticks for a walker - it was a faff"*

*"...I used walking sticks whilst waiting for a wheelchair"*

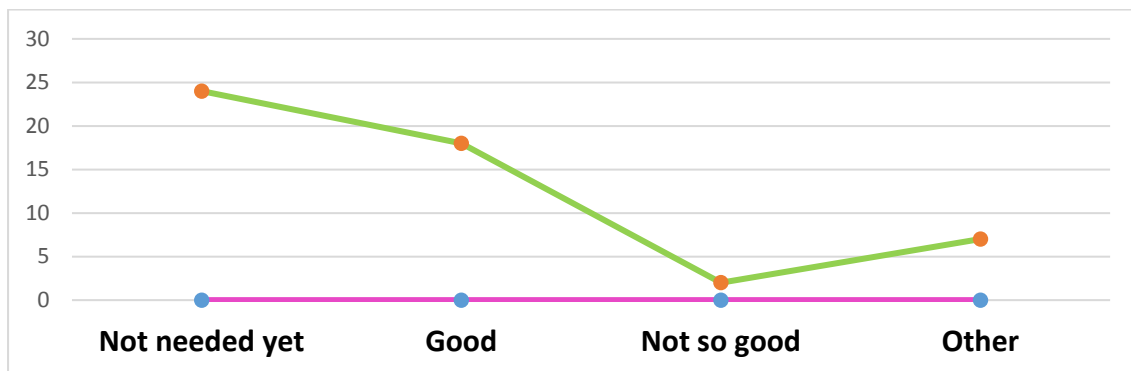
*"Had to hire one from Shopmobility or else I would not have been able to get out"*

*"We ended up buying one as our daughter could not get around"*

Respondents coped with delays in obtaining their wheelchair in a variety of unsatisfactory ways:

- Hiring (e.g. shop mobility)
- Borrowing (e.g. friends)
- Adapting old wheelchairs
- Walking sticks, walkers and mobility scooters
- Buying new wheelchairs (through money raised by family members)

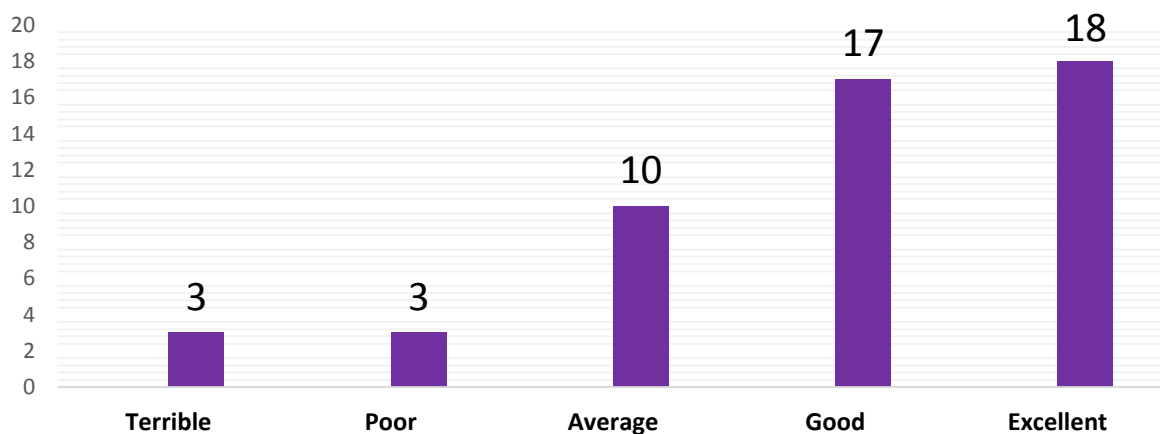
## Experience of wheelchair maintenance/repairs services



27 respondents (53%) had had their wheelchairs maintained or repaired. Of those,

- 18 (35%) rated the repair experience as 'good',
- 2 (4%) as 'not so good'.
- 7 (14%) respondents rated the experience in the 'other' category

## Overall how would you rate your experience of wheelchair services?



- More two-thirds of respondents rated their wheelchair experience as either 'good' or 'excellent'.

*"I feel wheelchair services have really looked after my son and considered his needs carefully. We'd have really struggled without the chair and the service. It has been invaluable to him"*

*"I'm very pleased with the outcome as the wheelchair has changed the quality of my life"*

- 10 respondents
- 6 respondents (12%) rated their experience as 'poor' or 'terrible'.



Respondents who were less than happy shared a number of experiences and perspectives describing their perspective.

One respondent shared an experience relating to how professionals often miss the 'human' story behind the disability. This person was concerned that wheelchair eligibility assessment criteria disadvantage people without an easily categorisable physical disability (i.e. people with some forms of learning difficulties or with dementia).

*"The process/paperwork took too long right the way from the referral via the GP's surgery (they were using out of date forms which protracted my application) to finally, getting the chair to meet my needs - it took over two years"*

*"Lack of knowledge of wheelchairs, lack of proper assessment of need and use of the chair, lack of understanding of the child and their life, lack of flexibility, obstructive and difficult service. One therapist did acknowledge that in over 7 years my need had not been met appropriately. Appalling"*

*"...any criticism or complaint of the service is poorly handled and results in therapists becoming defensive and obstructive rather than seeking to address the issues concerned"*

*"They [wheelchair repair services] don't give you a day or time - just turn up randomly, and then are surprised when the disabled person isn't there - how is this a good use of resources?"*

*"...the repair service has recently changed and they insist on taking my wheelchair away, leaving me stranded. This is not acceptable. We also need an emergency service which is not available"*

*"I have found with regards to obtaining maintenance and repairs depends on where the work is carried out. I have had appalling experiences from some companies and excellent experiences from others. Unfortunately, wheelchair users are tied into the contract that has been set up by their NHS provider. However if you have your own wheelchair, the market out there is extremely limited and the companies know that their services are unique and can control the prices which are exorbitant in many cases"*

## **Conclusions**

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The survey shows extremely mixed experiences of wheelchair services, some people have had smooth service provision and are happy with the process others have experienced combinations of long delays, processes rather than people orientated service provision and unhelpful or defensive staff.

There are some concerns in relation to eligibility and assessment which people do not feel take account of their individual unique circumstances and penalise those who are not entirely dependent on a wheelchair but who need one in certain circumstances; for certain activities, to access certain places or as a result of the individual vagaries of their illness or disability.

Where there are issues with regards to assessment, delay or repairs respondents evidenced that this has caused them myriad problems including;

- lack of general mobility
- inability to access family and community life
- difficulty accessing their work place
- social isolation
- pain
- negative effects on mental health and wellbeing
- worsening of physical conditions
- hospitalisation
- being unsafe
- being financially disadvantaged

## **Recommendations**

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### **To Commissioners**

The mixed experiences presented in this report suggest that a review of all Greater Manchester Wheelchair services is required. Wide variations in service need to be ironed out so that all wheelchair service users receive the good or excellent standard of service that some describe.

There is a case to be made for a Greater Manchester solution to wheelchair services. Such an approach would support consistency and no doubt be more economic as a result of superior buying power.

### **To Providers of Wheelchair Services**

Wheelchair eligibility criteria and wheelchair services need to take a person centred approach reflecting the many variations in people's conditions and lives. A truly asset based approach is required by all people working in these services in order to support disabled people's rights and aspirations fully.