

West Berkshire Neurological Alliance

West Berkshire Disability Alliance

West Berkshire Independent Living Network

Report for West Berkshire Wheelchair Service and Berkshire West Neuro Local Implementation Team

Shared experiences of wheelchair users: Funding and Using Wheelchairs

**Findings from a focus group held at West Berkshire Community Hospital
on 5th September 2011**

Executive Summary

The Wheelchair Service provides specialist assessment and professional advice on wheelchairs for clients but is limited by shortage of funding to providing a range of fairly basic wheelchairs. Those who opt for mobility vouchers towards the purchase of their own more specialised or expensive chairs are not supported whilst the vouchers are operable, usually 5 years. The Wheelchair Service listens to, indeed welcomes, views of service users and recently changed the service provision company after taking account of clients' views on the timeliness of completing repairs and availability of spare parts. Those present expressed the view that further improvements could be made if:

- a range of wheelchairs are available locally as back-ups
- more spares are held by visiting engineers
- more account is taken of some patients needing the help of carers to transfer from their chair
- information on the life-expectancy of the wheelchair is provided
- space could be provided on the wheelchair service webpage to report on the satisfaction of wheelchair service provided
- the assessment process at West Berkshire Community Hospital should include being able to view and try wheelchair stock samples.
- Resources should be increased so that calls incoming in the afternoon can be handled, rather than expecting everyone to be able to make contact in the mornings only.

Information - Clients should be aware that there is a wide range of seat cushions available. Different brands have very different characteristics, some being good for pressure relief others being good for posture, etc. Specialist assessment and advice is essential before selecting a model of cushion. There is no possibility that the Service can stock or duplicate the full range of cushions that are in use.

The Wheelchair Service is still considered a 'Cinderella service' and has recently suffered cuts in its support staff, so that telephone requests can only be dealt with in the mornings. The new Health Bill proposes that in addition to the NHS

Wheelchair Service, patients should be offered the names of two other approved services providers. Wheelchair users need to lobby the GP commissioners to ensure that their voice is heard and that minimum standards for wheelchair provision and service are laid down.

Limitations of this consultation

Wheelchair users are many and diverse and this consultation covered an incomplete cross section, with only 6 wheelchair users present representing 5 medical conditions, with a bias as regards age range. A carer and a family support worker represented two other conditions. The age range of those present spanned the spectrum of the 'adult' age range, including two users below the age of 30 who have been wheelchair users since birth, but not including any older people or children. Of the 4 people present and hosting the meeting, two were carers whose partners were long-standing wheelchair users and one was a voluntary family support worker.

The questions had been set before the meeting and set the general direction for the meeting, although those present were encouraged to raise any aspect of 'being a wheelchair user'. The purpose of the meeting was inform the local Head of the NHS Wheelchair Service about the day-to-day experience of wheelchair users and to provide suggestions for improving services in the long-term.

Either individually or collectively, those taking part should not be thought of as 'representative' or 'typical'. They were selected by local charities of which they are members because they are intelligent, good communicators, positive in outlook and interested in the way that services are provided. In addition to being able to describe their own experiences they all also have some understanding of how others cope with day-to-day living using a wheelchair.

Analysis of those present:

Total attendees 11

6 wheelchair users

9 health voluntary sector Trustees

8 wheelchair service users, including 2 carers

7 with mobility impairment

7 wheelchair service users with more than one wheelchair

5 wheelchair users with 2 or more wheelchairs (one with five chairs)

4 hosting or recording the event

4 in personal/family support roles reference others with wheelchairs

3 carers

2 carers of wheelchair users

1 service manager

Conditions covered specifically

Stroke,

MS (2 users, one carer)
Traumatic Spinal Injuries
Spinal Stroke
Cerebral Palsy
Motor Neurone Disease (support worker)
Traumatic Brain injuries (carer)
Multiple disabilities from birth

The Head of the local NHS Wheelchair Services was present (*see text in italics*)

The meeting followed the general agenda:

- How important are wheelchairs for you?
- Acquiring and paying for wheelchairs
- Maintenance and repair experiences
- What the local NHS wheelchair service does well and how the wheelchair service might improve
- Any other related matters
- Wheelchair users' recommendations for the future
- Anticipated developments in the local Wheelchair Service

How Important is your wheelchair to you?

The facilitator introduced the discussion, referring to his wife who has been a wheelchair user for 25 years. She has 3 wheelchairs, one of which is specially adapted for use as a front car seat and is invaluable so that he and his wife can talk to each on car journeys. His wife has two other manual wheelchairs for use at home and as a backup.

The first user has a spinal cord injury and is on his 7th power chair. 3 chairs were bought and maintained using his own funds but 4 had been obtained through the NHS wheelchair service.

An MS patient uses a manual wheelchair that is very useful and she 'loves it to bits'. It was like any another easy chair in her house. She had recently fallen out of it due to overenthusiastic pushing but was not seriously injured.

A user with MS and trigeminal neuralgia was on his 2nd wheel chair and wishes he could redesign it to make it lighter and more 'fit for purpose'.

A user with cerebral palsy was on her 3rd specialist wheelchair obtained from the Wheelchair Clinic

The support worker representing MNDA patients had experienced lots of people using wheelchairs.

One user who had experienced a spinal stroke was on his 3rd wheelchair but was semi-ambulatory and his chairs received a lot of punishment due to transfers, being folded-up and put in the car, etc. He uses the Wheelchair Service.

Another user, with multiple needs since birth, had taken advice from physios who suggested funding his own wheelchair and obtaining it from Smile Rehab, Greenham Common. He had raised part of the money by himself.

A carer said his wife had used a wheelchair for 17 years. She has a fleet of 5 wheelchairs because they never get rid of old chairs but keep them for backup. She uses a specialist rise-and-fall chair indoors, which can turn in its own footprint.

Acquiring & Paying for Wheelchairs and Maintenance & repair experiences

The spinal injury user said repair of power chairs was a problem, as the chair needs to be taken away for maintenance. There is also difficulty in obtaining parts for repairs, which can take a long time. In the past spares were kept by the engineer but now wheelchairs tend to be taken away and often there is no spare chair available. He uses Shopmobility in Newbury which loans out wheelchairs but charges £10 per week for the service. There appears to be no protocol for obtaining a spare chair. With manual chairs spares are more readily available.

One user goes to SMILE at Greenham and said repairs are very quick and the company will loan out another chair. He has been given advice on how to help maintain a wheelchair.

Response - there is always a spare power chair available at repairers (Hewerdine) and also a spare chair at the Wheelchair Clinic but, with 5000 clients, holding one or two spares for every type and size of chair is not a feasible proposition.

One user said he goes straight to place where he knows he can borrow a chair. He needs special footplates, which must fit onto a replacement chair. Not every power chair is suitable for his requirements. If a special chair breaks down and needs to be taken away for repairs then the person should be informed on how to obtain a replacement chair.

Response – in the past more parts were available but the problem more recently is that only an approved repairer may be used. The service made a change to the approved repairer and based the decision on: clients' satisfaction, how long it takes to complete repairs and amount of parts available. Spare chairs should be available.

The question was raised about obtaining views on the performance and real experiences of the new approved repairer.

The support worker said a client had a special chair that allowed her to transfer to a commode. This was bought privately using a voucher with extra funding from MNDA. Hewerdine could not provide a loan replacement when the chair needed repair so the client had to borrow a chair from Shopmobility but this was not completely satisfactory.

Response - If you go for voucher to buy a chair privately, then you go outside of system so and cannot be helped with the loan of a chair.

The Wheelchair Service cannot provide specialist wheelchairs to meet the lifestyle aspirations of all clients. The service can only provide basic chairs that are approved by the NHS. A wheelchair that converts into the front seat of a car makes life more pleasant for a couple but has to be privately funded, so there is a mismatch between lifestyle choices and what is available from the service.

It was suggested that due to changes in NHS commissioning it is important that wheelchair-user patients engage with the new GP Commissioners as soon as possible. The question is how do you represent case to the new commissioners? The Wheelchair service has always been a 'Cinderella' service.

Seating and chairs for different purposes

One user said his Flotex cushion had become worn out and it took 4 - 6 weeks to have a replacement delivered. He suggested that there must be reasonable number of spare, standard cushions for quick replacements or repair situations. He recommended carrying a stock of cushions as replacements.

Response – there are a couple of hundred cushions in use and many different kinds so the Wheelchair Service cannot stock all that are being used.

One user had been to Stoke Mandeville hospital for seating assessment and they had recommended a new cushion and a flexible back for his chair that was a great improvement.

One user said little wheels on the front of the wheelchair got stuck so he had a specialized wheelchair with large front wheels to allow him to climb kerbs or go off-road. It was generally agreed that the built environment was much improved and dropped kerbs are now found in an increasing number of places.

Another user needed new footplates to deal with pressure sores on feet. There had been delays due to getting to clinic. 'The process takes forever.'

Another user required 2 wheelchairs as with only one chair it was found to be too heavy to carry up stairs.

Another user said he would love to have indoor and outdoor chairs.

There are differences between folding and fixed chairs. Some lightweight specialist chairs cannot be folded.

Cushions RoHo pressure-relief cushion tend to get punctured. Different specialists suggest different types.

Response - RoHo are best for pressure relief if the person is at high risk but are not good for posture. The Jay cushion is better for posture. Side transfers are also important for some patients and other cushions are better for this. There are hundreds of cushions available with different covers and different foam fillings. Specialist advice is needed.

Servicing

One patient asked if reminders could be sent out about servicing.

Another asked if during maintenance visits if the engineer could give a prognosis on the life of chair.

Response – all power chairs have an annual check.

Power packs

The support worker asked about power packs for manual wheelchairs.

Response– these are not available from the NHS service but they do try to help supply them by working with charities, which can provide power packs. In Oxford the NHS service has done work with MNDA who have provided 6 chairs. The criteria for needing a battery-powered wheelchair is; ‘the person is unable to self propel indoors’.

Regarding recycling of power packs, there was a case of man with his own wheelchair and who was given a power pack but it could not be taken back to fit onto an NHS wheelchair, due to what seemed like unnecessary bureaucracy.

Response - In principle you can take back power packs and fit them onto other chairs. The Service provides help if possible.

Voucher system and Prices

Information - If a client accepts a voucher to buy a chair then they have gone ‘outside the system’. The voucher is valid for 5 years. The voucher system was set up for manual and not for power chairs.

Cost of wheelchairs – companies make only small volumes, so costs are high. NHS gets a good deal with a contract price because they can buy in bulk.

Price can't be reduced on many chairs because they are not on NHS lists. All disability equipment has premium added. There is 50% mark-up on wheelchairs.

Response - asked for information on new approved wheelchair service that has a contract for 3 years, with option of rollover for a further 2 years.

Comments on servicing

It was suggested that there be a 'comments' space on the Wheelchair Service web pages, so that clients can give their views.

Response – The Service carries out monitoring by contacting user groups, inviting people in, looking at complaints and doing surveys of clients. The idea of a customer satisfaction survey on the website was welcomed.

What the Wheelchair Service does well?

One carer reported that his wife had been through a pressure relief assessment process some 18 months ago. The paperwork was 'lost' for 6 weeks and the outcome was a chair that seems OK, but does not meet the O/T's brief.

Response - the Service is trying to obtain state-of-the-art pressure monitoring kit but the cost is £22 – £24k for the kit. The Service is applying to The League of Hospital Friends. At present staff numbers are small but there has been much effort put into training.

One user suggested assessments should be done at home so chair and lifestyle can be assessed together.

Response – the majority of assessments are done at home. Clinics are held at several other centres such as West Berks Hospital and the MS Centre.

It was suggested keeping a core range of half dozen wheelchairs at West Berks Hospital for people to try out.

Response – often, only one in five people turn up to attend wheelchair clinic appointments. Wheelchair appointments are given out, followed by a phone call to confirm. If clients do not turn up, people are phoned to reschedule.

Several people considered this was unacceptable behaviour on the part of wheelchair users.

With spinal injuries a specialist unit such as Stoke Mandeville provides the prescription for wheelchairs.

Response – ‘Outdoor’ wheelchair users need to have instruction and to pass an examination. Insurance is recommended for such users.

Developments with the Wheelchair service

Information - At present because of cuts, the Wheelchair Service can only provide a phone answering service in the morning. As there are only 1.5 staff supporting the administration, afternoons are taken up with ordering and calls are only recorded.

The Paediatric Wheelchair Service is going to be outsourced to others qualified to be suppliers. In future GPs will provide the names of 3 different qualified wheelchair providers, one of which will be NHS Service.

The response time specified in Wheelchair Service contracts will be for a 3-day standard response.

The emergency response target will be ‘same day’, if contact is made before 3 o’clock, or ‘next day’ if contact is made after 3 pm.

For some people, who may need support from carers, it may be difficult to prepare for the visit of the engineer if for example help is needed to get out of the chair to make it available for servicing. It was suggested that the repairer should employ a checklist prior to making a repair visit. All engineers are supposed to have awareness training so they ask suitable questions.

Customer service really important but people have no clear expectations.

Response - Service can take phone calls in the morning. In the afternoons an answer-phone is available to receive calls. Emails are accepted and are more useful, as the client can keep a record of the communications.

GP commissioners and ‘Any Qualified Suppliers’.

It was suggested to hold focus groups around ‘what qualities are needed by a qualified provider?’. Minimum standards need to be set.

Response- if you use the wheelchair service then after an initial referral you can self refer at any time.

The facilitator thanked everyone for their contributions.

Recommendations

- The level of administrative cover in the Wheelchair Service should be increased such that calls can be monitored promptly throughout the full working week
- The appointments system should be reviewed in detail, to improve attendance rates
- The assessment system needs to be to a more consistent standard at all times
- The assessment centres should all carry stock samples for use during assessments
- The service should carry some additional seating stock
- The re-introduction of Herwerdine as the approved service operator requires monitoring
- Admin systems at Hewerdines should be reviewed to ensure they account more fully for clients' specific needs prior to, as well as during, maintenance visits
- Spare parts carried by service teams need to be kept to more appropriate levels than has been the case
- Maintenance engineers should routinely offer advice on life expectancy of equipment in use
- The efficacy of the 3-day standard service response time and its definition requires monitoring and possibly reviewing
- Space should be provided on the Wheelchair Service web page for clients to report on the satisfaction of seating services provided
- Consistency of advice on seating and cushions should be better ensured
- The proposed move to clients having to be offered a choice of three approved services providers warrants commissioners consulting with service users to ensure that contracts will be fit for purpose and that minimum standards for wheelchair provision and service are laid down and met.

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West Berkshire Neurological Alliance

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