

**Report for Berkshire West Neuro Local Implementation Team  
and the Berkshire Shared Equipment Service**

**Funding and Using Disability Equipment**

**Findings from a focus group held at Padworth on 18<sup>th</sup> April 2011**

**Executive Summary**

Although those present were grateful for the improvements in service that are being provided, there is still a minefield of problems that patients face when seeking suitably-adapted equipment to allow them to lead as normal and independent lives as they are able. At this Focus Group eight different long-term neurological conditions were represented and a number of issues came to light.

Large expensive equipment servicing is costly to maintain. Some patients feel pressured by company sales staff promoting expensive maintenance agreements. Local authorities, which fund the initial purchase of such equipment, need to investigate leasing-out arrangements to limit the ongoing costs.

Patients were concerned at the long lead-in time in provision of specialist equipment and lack of urgency in carrying out repairs. In addition, those carrying out specialist measurements and individual assessments for equipment need proper training. The provision of ill-fitting equipment leads to much unnecessary pain and suffering and still further delays in rectifying the problem. The patient needs to be forceful, determined and an expert in obtaining the most suitable equipment.

Unnecessary red-tape with the Disabled Facilities Grant can mean expensive additional adaptations being required to meet the requirements of the scheme. Assistive technology needs to be given greater prominence as it offers new opportunities to improve memory, communication and sensory awareness as well as improved responsiveness. It allows people suffering invisible impairments, such as mild dementia, to maintain better control and live more independent lives.

Disabled access in some public buildings - Reading Library being one example - is still a major problem for wheelchair users who need to go and ask for a key and then find facilities too small to accommodate their wheelchair.

### **Limitations of this consultation**

Neurology conditions are many and diverse and this consultation covered an incomplete cross section, with only a small number of participants (7 conditions), a bias as regards age range, (all above 40 yrs) and a slight feminine bias, (5M, 4F). There was only one carer present. Two participants were wheelchair-bound. There was one family support worker present. Neurological Alliance volunteers led and took notes of the proceedings. Care was taken to avoid use of leading questions, but these may have occurred. The purpose of the meeting was circulated in advance and attendees were asked to prepare, which most had done. The intention was that attendees would not be current committee members of any neurological representative group, but three participants were serving in such a capacity. No individual affected by a very rare condition was present.

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 with the same condition may be affected differently.

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#### Analysis of those present:

Total attendees	16 of which:
Patients/service users/clients	5
Carers	6
Equipment users (self/carers)	11
Equipment specifiers	15
Health/Social Care front line (inc retired)	2
Local Authority observers	4
Commissioners	3
General disability service providers	8
Disability equipment providers	10
Voluntary sector	9
Hosts and scribes	3

#### Conditions covered specifically

Stroke,  
Motor Neurone Disease  
Dementia  
MS  
Parkinson's  
Spinal Injuries  
Polio

### **Transcription.**

The host gave some examples of the range of equipment that the focus group might wish to discuss, including a grabber for 'lazy' hands, a spouted drinking cup, wheelchairs, specially adapted kitchens, wet rooms, adapted cars, etc, then invited an open discussion on equipment that those present actually use.

**The Parkinson's carer's** wife has seen health decline over 15 years. Initially she used handrails to get upstairs. Now she has morning and night home care, involving 'strangers' in the house. This introduced problems with Health and Safety, due to the need to be hoisted rather than 'assisted and encouraged'. Some carers are not always trained sufficiently in use of common sense.

Now they have a hoist in the bedroom with a harness for lifting. This is not the preferred solution. It is much better to get in and out of bed using slider sheet or support from a person. A mobile hoist was also supplied to get his wife off the stair lift. This takes up 2/3 of the bedroom. The hoist is a fall back rather than something they want to use and it may be needed if wife becomes worse.

The stair lift is most useful but initially there was a problem to overcome with 2 steps to the lower landing. Now has a stair lift that will turn a corner to go from ground to first floor.

Lazy hands extender useful but wife unable to move fingers and hands. Incontinence protection – NHS and local council provide excellent service. RBH specialist advice very welcome.

**Spinal Injuries survivor.** Uses the Disability Facility Grant to obtain larger items of equipment such as a hoist, which came with a 5-year warranty. The hoist must be maintained and inspected 6 monthly and serviced each year. It is expensive to call out engineers on a one-off basis and funds are limited. Some equipment recently suffered a breakdown at a cost of £300 and he had to use money from a Direct Payment intended for paying taxis. There is often the need to juggle funds to pay for equipment and maintenance. After 5 years what happens to equipment?

**Polio survivor.** Stair lifts can be a problem. Some people don't use them because they have to twist to get off at the top. One disappointment is the persistence of companies to sell expensive maintenance agreements for equipment. Most companies are just there to make profit

**O/T observer.** The DoH and Trading Standards are looking into people who have been harassed by companies.

**Stroke Carer.** He was concerned that the controls on a disability scooter were effectively unusable for a stroke survivor then eventually discovered the option of a joystick control, which works well. Maintenance agreements are an issue. Why

don't councils lease equipment? When away from home he reported problems finding places to recharge chair batteries.

**The Host.** He stimulated further discussion that his wife now has 3 wheelchairs because her new NHS wheelchair does not collapse so cannot be taken on an aeroplane, so she renovated her old NHS chair for that. The third wheelchair is part of her car.

**MND patient.** She has an electric wheel chair. She needs to access her place of work and has a wheelchair there, needing two wheelchairs at present. To rationalize things she just needs a motorized wheelchair from the Wheelchair Service. She would prefer one wheelchair and a funding system that would allow her to choose the one she needs. A wheelchair was ordered in March but will not be available until October. One wheelchair came without a head support. Something was wrong with another wheelchair delivered. The Engineer said the backrest was too narrow. The Company made a mistake in the assessment, took a long time and it was expensive to get the problem sorted. The Wheelchair Service will supply a new manual wheelchair, but there is no sense of urgency or taking into account the discomfort of the patient.

She has been given a profiling bed but can feel the bars under the mattress, which is not suitable for that bed. It is difficult to get in touch with right person to get things done.

No one sees urgency

She is buying an adapted car. The process started in January but is taking a long time. So she needs to use the Readibus, which means getting taxis. A 7-minute journey costs £12. She has problems traveling along sloping pavements and still cannot use her motorized wheelchair at work.

**RBC observer.** She commented these examples made a useful contribution towards informing Social Services Directors and heads of Adult Care looking at the provision of equipment from commercial providers. She stressed the need always to have an assessment for individual requirements. Some providers may have assessors but their primary aim is to ensure a sale rather than supply the best equipment.

Readibus has limited ability to cope with large numbers of requests for transport.

**O/T observer.** She commented that if someone cannot see a statutory sector OT then they should be able to see a private OT for £40.

**Spinal Injuries survivor.** He commented that it beggars belief that there are delays in service for people with MND and that help with access to work is not efficient. These issues have been well known for at least 20 years. Delays in getting parts for wheelchairs is unacceptable, in his case a part ordered in

November was not fitted until mid January. Some 'front' staff on reception desks do not understand the importance. Thankfully, Shopmobility in Newbury were able to loan him a wheelchair during his crisis but at a cost to him of £180. The thing to do is complain. In his case this led to the Contracts Manager from Millbrooks sending a letter of apology from Millbrook offering in future the system would be to loan a temporary wheelchair if it breaks down. Throughout this saga, the Manager at the wheelchair clinic did not know. Staff have no appreciation of urgency.

**O/T observer.** She agreed that if anyone has problems it is important to tell the manager at the wheelchair clinic.

**MND patient.** She agreed, there is no sense of urgency.

A comment was made regarding difficulty accessing the disabled toilet in Reading Central Library. You have to ask for a key but there is no room to take in a wheelchair.

**The host.** The host gave a contrasting example of very quick service. His wife has had a series of pressure relieving mattresses, supplied by the NHS, and in one instance a faulty mattress was replaced within one hour of reporting the problem.

**Stroke survivor.** Leasing wheelchairs would be preferable. Each person knows what equipment works for them. The equipment provided does not always work. Her wheelchair from the RBH wheelchair service is fantastic. One bought by herself was unusable. You need to be persuasive, forceful and articulate as a disabled person to get what you want yourself. You can't always expect members of your family to fight your case.

**Polio survivor.** The biggest thing that has helped is the hoist in the back of her car to lift her scooter inside. Many people come up and ask about it.

**The host.** The host made a partial summing up of the problems raised in the meeting so far, giving an example of where advice from an OT resulted in two showers being unnecessarily installed in a wet-room under the threat that if only one was installed a Disabled Facilities Grant would not be awarded. In consequence when an adapted kitchen was required in the same property, O/Ts were not consulted. OT help had been much appreciated with installing a ramp to the back door of the property, but only allowed one ramp per property is allowed, so the main ramped entrance to the property had to be self-funded.

On the subject of adapted vehicles a specialist assessment helped him to realise that an in-car hoist was not the right answer, and a much superior alternative was readily identified. It is all about getting what you need.

**Alzheimer's Society.** The problem of having an invisible impairment such as brain problems was raised.

**Alzheimer's interest.** There is a need for money to help pay for software licenses to acquire more software for purposes of brain stimulation and therapy. He cited an example of an 80-year old man who improved incredibly due to computer-based therapy.

**Stroke carer.** Rotary Club and Freemasons will provide money to help people buy equipment.

**Spinal injury survivor.** Assistive technology is available but the NHS much more focused on dispensing drugs and curing people.

**Alzheimer's Society.** Software for ordinary people to help hearing and help people to improve memory is on the rapid increase. To re-program brains therapists have to work hard and self-help is a better way forward. She commended a specific course for those with a form of dementia, 75 hours long, incorporating some physical exercise and social time. This needs good tutors but costs £750 to £1000 per course to improve mind-body control. This course has helped 2000 people with dementia to stay in work. The Dementia interest delegate still runs his own business and is still in work, having shown a vast improvement in following the course. On the same course, with 8 participants, all have shown improvement. Called 'Insight', other benefits have included improved stopping distance when car driving, due to restoration of wider peripheral vision.

**Stroke survivor.** Some speech and language therapy equipment has been effective.

**Alzheimer's Society.** Improving hearing allows people to improve their speed of processing information from speech. Some equipment is being evaluated at present by service evaluation.

One problem more generally is that Alzheimer's Disease is considered by some to be a psychiatric illness rather than mental disability.

**Stroke carer.** When using Internet Banking the one he cares for cannot read the screen but can use figures. Some equipment that costs £40 can read fingerprint for identification. Also facial recognition software is available from web cam technology. The banks are being slow to respond on behalf of those who can benefit from such technology.

**O/T specialist.** There is a range of symbols that can be used.

Parkinson's carer. The Wii system has been shown to be helpful for Parkinson's. Patients stand in front of a screen and simulate ball games rather like Hawkeye technology for cricket/tennis. Parkinson's UK have funded a research project to

study Wii system. He gave a general warning to be skeptical when a precise scientific study has not been carried out.

**Alzheimer's Society.** Robust studies have been carried out on the 'Insight' equipment.

**Slough BC.** Work is in hand to transform the commissioning of the community equipment service. The referral route is generally from O/Ts and district nurses. South Central Ambulance service has been managing the service, but tendering for a new service will be going out in July. Anyone in Europe can bid for service. The new contract will require a better service for patients and feedback on what this standard should be is being sought currently. £3M per year is spent providing services for Berkshire including some across the County border.

There are two wheelchair services, one in RBH, and the other in Berkshire East. Berkshire West has just awarded the maintenance contract to a new provider. NHS Berkshire East will refurbish and recycle wheelchairs in-house. Telecare assisted-technology is linked to a Careline centre.

The current review will result in a universal contract for maintaining and repairing hoists.

A good out of hours service that meets customer needs will be established. The new, consolidated equipment service will aim to provide for children, something not currently included. Suggestions for improvements are being sought.

**Spinal injuries survivor.** The series of consultations on this review were not advertised in West Berks. (Noted and apologies given.)

#### **In a rapid session of final issues .....**

**Reading observer.** Important to have carers, patients service users involved and monitoring equipment service.

**Slough observer.** Disappointed that wider consultation had not taken place of the proposed new equipment service,

**Parkinson's carer.** Service delivery in Reading has been heading in the right direction.

**MND patient.** Please look at personal cases. 1. Difficult for some people to have assessment conversations in their workplace. 2. Computer equipment such as speech recognition software that could type for patient.

**Stroke carer.** We need another session to explore more issues.

**Spinal injuries survivor.** Repeated assessments should be unnecessary. The system should be more flexible, allowing service users to make more of the arrangements and leaving O/Ts more free to get on with other work.

**Wokingham observer.** People need to be allowed to be independent.

**Dementia interest.** Will funding be available?

**Alzheimer's Society.** Assistive technology is out there but there is a need to help people to start earlier after diagnosis.

**Un-attributed.** Suggested to set up a Facebook page to capture further ideas

**The host** thanked everyone following to conclude two hours of intense, broad ranging, perceptive and converging focus group work.

### **Common themes**

Equipment needs are related to individual circumstances

The use of an item of equipment may affect the use of or need for other equipment or help

The need for timely information about what equipment is available

The need to be alert to pressure sales and scams

The need for prompt and thorough assessments by qualified O/Ts or other specialists

The need to be offered and to get 'what is needed', not 'what is available?'

The need for equipment issues to be treated as a priority by everyone involved

The need for regular checks and maintenance

The need to recognize that unsuitable equipment is unlikely to be used and is wasteful

The need to recycle unused equipment as much as possible

The need to respond to progress in Telecare, electronic aids, and software development

The need for appropriate minor equipment may be as great as the need for big-ticket items

The need to accept greater levels of service user self management ref replacements, etc

The need for a more integrated equipment service generally

The need to transform the wheelchair service

The need for further focus group work on equipment and related issues

### **Recommendations**

This report should be circulated to local statutory sector equipment providers.

Service users should be made aware of the findings and implications of this report.



Service users should be reminded of the need for independent advice, professional assessments and how to access the equipment needed at least personal cost.

The shared equipment service should be consolidated between the NHS and local authorities insofar as may be practicable, including on a Berkshire-wide basis if this is possible. A single system of working should be established.

Equipment choice from such a service should be extended to meet the full and diverse spectrum of need.

Maintenance schedules should be established and followed diligently.

Regular efforts should be made to identify unused equipment, which should, where possible, be brought into use where it is needed.

Telecare should be centralised into one specialist service within the above.

The wheelchair service should be subjected to radical review and improvement.

A follow up review should be made by West Berkshire Neurological Alliance in 12 months from April 2011.

For further information about this focus group please contact:

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*West Berkshire Neurological Alliance*

Representing all people in Berkshire West affected by a neurological condition  
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