

## Wheelchair Review Draft Action Plan

### SDEF Response

Taken from comments at the Consultation Event October 10, 2008 Gateway Centre, Perth.

### Funding

The document is not strong enough on whose responsibility it is to run the wheelchair service. **It is the health board's duty, not the centres', and the duty should lie with the health board.** Overall the consultation lacks a **shared vision** for the 14 health boards that would result in consistency across the country.

There are concerns that this plan is about absorbing the money rather than implementing Moving Forward. The business cases should have been aligned with the consultation and performance monitoring should be highlighted. The money health boards put into the service is different from what comes back to the patients. "The pounds don't follow the patients."

Some feel that the individual health boards should not receive the funding and that it should be given to the centres, which would result in greater accountability.

The service required approximately £32 million and has been neglected for many years. Wheelchair provision is no different from somebody needing a hip operation at £8k, so why are wheelchair users different?

There are questions over whether the service will be "**fit for purpose**", with some people feeling there is still a huge gap.

Improvements to the service need to be sustainable. There is a question mark over what will happen to the service in the next spending review. It is vital that improvements to the service are not lost and hence the need for proper data gathering to illustrate the case for continual improvement.

In addition to being free from funding issues there has to be accountability.

There have also been comments on the opportunities for **part funding** to buy more expensive wheelchairs if the wheelchair service is unwilling to provide equipment that meets people's needs. There is a voucher scheme in England that allows part purchase. This might be something that should be considered in the future. It would also allow people choice as to supplier. This might form part of the current debate about private top ups for NHS services and worries that a

two tier system based on personal financial resources.

The question of add-ons to NHS and privately funded chairs has also been raised with the service falling short of the support people need.

The consultation states that the service must be **person-centred**. The service should enable people to carry out day to day living. The service that users get from the NHS and the wheelchair service should be smooth and seamless and shift the balance from hospital to home.

The consultation also talks about **Mutualisation**: the theme is that it should be a partnership between the NHS, the user and carers.

There needs to be a **culture change** in the wheelchair service so it becomes more customer driven, with better communication and customers being listened to as opposed to service providers acting as experts. Community based services must be provided, with clarity of what is there in terms of equipment - there has to be a culture change for the service to improve.

The consultation should have **user involvement** with each individual health board. The consultation sets out how it is going to get there.

## **Rehabilitation**

It is unclear where rehabilitation sits within the health board, should the **leadership** be at **health board** level or within each of the **community health partnerships** or community hospitals? In Forth Valley patients have been wrestling with the Board about where the responsibility should sit: it should be in Stirling but as a Forth Valley wide service.

Rehabilitation is not just a service following a motorbike accident, for example. It can be lifelong. You have a condition that you have to manage which might change, or improve, but mostly it will deteriorate.

Clearly within the rehabilitation section it sets out clearly that the service is to enhance the daily living and **quality of life**.

On **Service redesign** the document talks about evidence based practice. However, it ignores the impact on information technology systems and is vague on best practice.

Some think most wheelchair centres have improved and users have been involved. However, in terms of the paper it is unclear where the outcomes stem from or if there has been user involvement.

The paper looks at **building capacity**. There is a diagram of a triangle with the wheelchair service at the top. However, it could work another way. If you enter the NHS scheme there should be a **filtering** so you only get to the wheelchair centre in the most complicated cases.

It touches on **patient transport**. This is problematic for service users - who orders it? It has to be your own **area** that deals with this. People are often given unrealistic appointment times like 9.30am. **Appointments** have to recognise the amount of time a user may need to leave home in the morning, distance to travel and the fact that the user may be dependent on **carers** to get them there.

Service also need to be provided locally as some users really cannot get to the major service centres.

## **The Assessment**

The paper talks about **flexible referrals** so that a user does not need to be recommended by his or her GP. Any health professional can refer someone to the wheelchair service. There is also a need for **self-referral**.

It talks about **optimum outcomes** but does not identify whose outcomes they are - the users' or the service providers. It mentions **planned reviews**. Often users get equipment that doesn't suit their needs or they cannot use. There should be an **automatic review** so service users are contacted after a period to see if adjustments need to be made.

Users and carers now have to be given a copy of the **assessment**. However, what is the appeals process if the user does **not agree** with it? The **carer's needs** must also be considered.

There is evidence in the assessment section that it is continuing on a **medical** rather than a social model. It states on page 18: "*The assessment is based on the level of function and the focus is on ...*" It does not mention your **lifestyle** or quality **of life**: Another indication that we are still on using a medical model approach.

The document also talks about **Clear Assessment Criteria**. The recommendation from the steering group that looked at the report **made a recommendation that assessment criteria be dispensed with**, but it is still in the consultation document.

There is no mention of **lifestyle** or **unmet need**. An assessment should be objective. It may be the service cannot meet the user's and carer's entire needs, but nevertheless the **unmet need** should be identified and recorded - that is the whole reason for many of the overtures made to politicians over the years. There needs to be concrete **evidence** so that government can be approached for

additional resources. Additionally, some think that the assessment tends to be for the minimum that the services can provide. As one user put it:

“When I got my new wheelchair and was shown four different ones, the one I wanted was too expensive and I got the cheapest one, but it does not meet my needs. The other wheelchair would have met my needs better.”

Another speaker commented on statistics for users and unmet need: “I think the statistics of people in wheelchairs - the latest figures are government figures. 2% - there are a lot more because people buy their own. You have to find out to show there is a bigger need than 2%.”

### **Powered wheelchairs**

There are concerns that people are not being provided with electric chairs when that best meets their needs and that services do not always distinguish between the need for different equipment for inside and outside the home.

One respondent qualified for a powered wheelchair for work, but would not have qualified medically for an electric chair in terms of the wheelchair service as he could get about his flat with a manual wheelchair. However, he would be a prisoner in his flat with a manual chair, particularly as his housing association flat had been built in a place that was not very accessible. “If I did not have a motorised wheelchair I would not get out and would have to just sit indoors looking out. They have to look at the whole criteria -otherwise it’s a one size fits all. I got that off the Scottish Executive website. I am fed up with people ticking boxes and action is not getting translated to ground level,” he said.

Another respondent experienced a difference in recommendation for equipment provision at GP level. One GP maintained he would not qualify for an electric chair despite being told that the user would not be able to lead an independent lifestyle. However, he later moved to another GP practice. The new doctor put him in for a referral as he was stuck in the house, and two weeks later the OT arrived to tell him he did not qualify. He later visited his doctor and reports that the doctor’s attitude was very negative.

“He said I did not need a powered wheelchair because I could push myself. He said, *do you get DLA?* I said *Yes*. And he said it would have a mobility component and I could buy my own wheelchair. I was so angry I won’t say what I said. But I could not get away quick enough, because I felt so humiliated. Later I got a letter to say *No Way* - I ended up having to buy my own. I think the criteria are too strict, made like that so they don’t have to give people wheelchairs.”

Another user summed up her experience:

“Ten years ago I asked for an electric wheelchair and was told if I could push four feet I did not need one. So I said that was OK if my TV and toilet were in the right place. It's about why people need things. The chap shook my hand, I could have crushed his hand ten years ago, but today I can't put butter on a piece of toast. I regret not getting an electric wheelchair quicker as I have missed out on a lot.

“I did have to go out and get my own 9 years ago, at a cost of £6k approximately then.

“There are people having to fit into wheelchairs which are already made, rather than the wheelchair accommodating the person and their needs. I have an electric wheelchair at home, without much support. I always have to be cautious that the arm is down so I don't fall out. I have had to change it and it's very uncomfortable but to try to get through to them to change that. This is my outdoor one. I have three. They all do different things. I tried to get a different push along one, as my son was ill and I had to quickly get to the toilet to help him, but with my old Remploy wheelchair I could not help him and he lost a lot of blood. But to try to explain this to them, asking for something a bit nipper - they would just not accept that.

“I'm on a disability group and I brought this up and they suggested I go back to them as they have more money. But I already have a wheelchair so they said no. That's it. They did point me to a website where I could have bought one though.”

This would indicate a need for a **reassessment** process: individuals should have the opportunity to be reassessed if they need it as many people who are wheelchair users have progressive conditions and their need for wheelchair and other equipment alters so regular assessments should be undertaken.

It should be highlighted that for people with profound learning difficulties, the spine changes over time and there is no true assessment of the transition areas of their lives. They should be reassessed at regular times. They are done at the TORT service and it can be very stressful for them. Outreach centres could be used. They are crucial for them.

After an initial assessment both parties should come to an agreement for a time for a review, say 18 months, so both parties agree on a structure, a timetable to review the wheelchair and someone's needs.

Provision of an electric wheelchair should be around quality of life rather than how far someone can self-propel. Sometimes people get equipment that does not suit them so they put it away and forget about it and continue to be immobile. Consideration should also be given to the needs of carers so that there is greater provision on lightweight chairs.

There is little mention about **bio engineering** for people with really complex

seating requirements, which carries long waiting times. This is particularly pertinent to parents of children wheelchair users requiring special seating. When asked about this problem many parents say that if they had the money they could meet their needs from equipment available in the market place. So the issue is funding.

One person commented on what happens when people are initially assessed as needing a wheelchair and are not provided with a ramp so that they end up unable to get out and about: "The emphasis of the hospital seems to be about whether you can function inside your home. Whether you can get out of the house is not their priority. This leads to feelings of isolation, and not everybody has family or support to help you leave the house for hospital visits, so you are stranded. So there is a need for the provision of ramps alongside the provision of a wheelchair. "

The consultation document talks about a **standard assessment**. All factors should be taken into account, and people should be assessed in their home as well as a clinical environment. The layout of the house should be part of the assessment and questions should be asked. The provision of ramps is the responsibility of the **local authority** and it is the liaison of the wheelchair service and the local authority with two different organisations going at different speeds, that can lead to problems. The wheelchair service will not supply a powered wheelchair for use if there is no ramp in place. So there are problems in terms of liaison and getting things done in the timescale.

Another respondent was astounded that the occupational health women's criteria did not take into account whether the person could take the wheelchair outside, it was just concerned with what was on the inside of the house and noted that: "If the person can't have a shower or bath, that is not considered essential, just that there is a rail and they can get themselves to a different room. This is about isolation."

Assessments at present are different across Scotland and there are varying priorities in different areas. A standard assessment would be an improvement in terms of consistency.

There should be a standard assessment that could be shared by professionals. It should record whether someone is a casual or essential user to ensure that essential users are not left in a position where they are rendered immobile and cannot use, for example, the bathroom in their home.

If somebody is going down the private route a quality assessment from the NHS would give them an idea of what to look for and would make them more confident about buying a chair from a private supplier. However, people are keen to that the NHS resources the service properly as one person put it: "We are on dangerous ground here. We are talking about a wheelchair review and hoping

the Scottish Government will provide us with more, and when we start talking about buying for ourselves that takes the responsibility away from them. A dangerous road.“

**Hospital discharge** was identified as another problem. People are discharged when staff know they need a wheelchair, rails and bathing equipment, but the empty bed is the priority. The equipment should be in place first. One respondent had to hire a wheelchair after a five-week wait having been told there were none available to borrow. The assessment did not take account of who was going to supply the inside equipment. That person had to pay for equipment from personal savings. However, not everyone can afford to do this.

There is a question of **signposting**. There are many **voluntary organisations** such as the Red Cross that can provide standard units only, which is sufficient for immediate emergency situations. However, NHS staff are not always aware that these services exist.

People trying to access wheelchair provision arrive by different pathways. There needs to be better information provision for people and paid staff.

The question of **equipment** for people with profound and multiple learning disabilities was also raised as sometimes the equipment is there but for people in **supported accommodation**, there is no **training** for staff.

The consultation identifies that there must be a **demonstration** and **information** on the equipment. It is evident from comments made that there is a big gap that needs to be filled.

Nothing is mentioned about sufficient space for assessment or it being a family friendly place or extended programmes.

It goes on to talk about **delivery** to the user and that there should be more **information** provided and equipment should be **demonstrated**, but there's no mention of **follow up**.

It should also be possible for users to take a wheelchair home for a trial period to see if it is suitable or if adjustments are needed. Wheelchair users should also be provided with training for whatever piece of equipment they receive.

## **Equipment and repairs**

Again the question is around "fit for purpose"? Most of the services are embarking on **planned preventative maintenance** but what does that mean in

reality?

It is hoped that **planned preventative maintenance** should cut down on recycling because there will be the opportunity to replace out of date equipment.

The question of spares is not addressed as a big difficulty is that nobody keeps huge stocks of chairs any more.

It is heartening to see that the consultation document talks about **Out Of Hours service**. It is a definite improvement.

Users have experience of being left with nothing if their chair goes away for repair, finding it difficult to even go to the bathroom. NHS Tayside, for example, tries hard to get repairs done as soon as possible, and if there are issues around independence, tries to get repairs done within one working day, but there are problems at weekends that it is hoping to address that with a National project.

Some 98% of repairs are done at a person's house, so NHS Tayside don't have to take the chair away. The service is sensitive to these issues for people and tries not to take the chair away. Repairs should also be carried out at times that suit users rather than to suit the service.

"I had a problem yesterday. My chair broke last week and I'm still waiting for them to come. On Monday they put a card through the door, and yesterday they phoned and I waited and waited, and again they put another card through the door. I have not had a chair for two weeks. This chair is borrowed from a friend. If I did not have this I would be stuck."

In terms of out of hours provision many people would like to see a weekend service. There has been a pilot in Glasgow which had low take-up but that might be a question of marketing and information.

### **Information management and technology**

**IT and information management** do not at present support service provision. Some of the wheelchair centres are not gathering and maintaining the data, so there is incomplete information available. They don't make use of CHI number and the report produced by one of the sections of the **Scottish Executive** suggested the IT system needs to be rewritten. However, there is no mention of this in the report and there are views both for and against the £16million allocated by the government being used to improve the IT infrastructure. The service cannot be run properly without investment in IT and this lack of back office support is a real hindrance to service improvement.

In terms of **Quality and governance** appeals will be through users' health

boards and not the wheelchair centres. The document notes that standards should be evidence-based.

The centres should share **best practice** and there should be detailed **service agreements**. There should also be more clarity over how patients' values guide decisions.

The report talks about things being **safe, effective, efficient and equitable**, but to whom? Does this mean it acceptable to users and carers?

There are a number of recommendations not covered by the consultation document:

**Appeals** (recommendation 19) should be done on a **National basis** as the steering group recommended there should be one service for the whole of Scotland, not five.

The consultation report is silent on recommendation 20, saying **repairs** should be done at **any** wheelchair centre.

There are also comments about the disparity in waiting times for those who buy their own spare parts and length on waiting time for those with NHS chairs which need repairs or spare parts and whether there is a process here which could be improved.

There needs to be improvements in **breakdown repairs**. There is no mention of courtesy chairs, and there are occasions when it is not possible to repair the chair at your home.

Someone should be able to go to any of the services throughout Scotland and receive the same service wherever they go. Someone reported: "My electric wheelchair was provided by Tayside, so when it broke down in Edinburgh it they should not have tried to take it off me." In this case the different centres were using different eligibility criteria.

It does not say much about recommendation 27. The person who brings you your new wheelchair with the footplate that has not been adjusted will say it is nothing to do with him.

## **User Groups**

There is support for **PFPI** and wheelchair **user groups**. Although not everyone thought their wheelchair service would take notice of them.

User groups should be attached to health boards and they should be representative of the different user groups in their area. Appeals should be to the

health board and not the wheelchair centres. If complaints come before a user group, pressure can come to bear.

Some think that user groups can take place at special board level as part of PFPI.

There is a question over who takes leadership in the health board for this, directors of nursing or allied health professionals, for example? Not every health board has a director of AHPs. That is a National service desirable.

The issue of **Disability awareness** and **equality training** was also raised. Some think this should be provided by health boards as they have an obligation under the **Disability Equality Duty** and that the funding for the wheelchair service should concentrate on frontline activities whilst others think it could come from either budget. There is agreement that training is crucial but concern as to whether it is appropriate to fund it from the wheelchair money.

“Those who have had Disability awareness training are more able to help with my needs. Somebody who has had the right training will come round to the front of my chair and address me like that, so training is a good thing to invest in. They come from all different lives and need to know.”

The ethos of the service comes from the top down. Users would like to see professors and consultants undertaking training and aspiring to best practice.

Service providers should be able to provide the knowledge and advice for people about the best piece of equipment and there is a wealth of knowledge for people with complex needs.

There is a huge training need, especially relating to provision of equipment and services for those with multiple and complex needs.