

30 October 2008

Janet Garcia
The Scottish Government
St Andrews House
Regent Road
Edinburgh

Dear Janet Garcia,

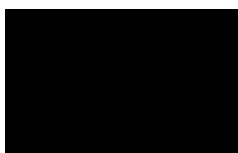
**WHEELCHAIR AND SEATING SERVICES MODERNISATION – AN ACTION
PLAN PERSONAL RESPONSE**

The following are my own personal opinions on the parts of the draft action plan I feel most competent to comment on as the full time carer of a daughter who is a wheelchair user.

Brief Background

My daughter uses a manual chair supplied by Highland wheelchair services. It is a basic model (as all NHS chairs are) suitable for use in supermarkets, shopping centres and on modern brand new asphalt pavements. As none of these exist in our village it limits her mobility considerably and leads to increasing social exclusion. Having spoken to hundreds of long term carers and users of the wheelchair service I have yet to find one that is happy about the quality of equipment provided (this being distinct from the quality of service provided by the staff within the service). It is an embarrassment and shameful that a rich developed nation such as our own has consistently under funded a service which is so vital to one of the most vulnerable groups in our society.

My comments come mainly from the perspective of the long term wheelchair user for whom the chair is not merely a temporary aid but an integral part of their lives. I feel they must be treated distinctly from the majority of users who may require a chair to recover from an operation or while a broken limb is mending. If you have to spend all your waking life using a chair you deserve a far higher standard of equipment than that on offer at present.



General Comment on Plan

Although it contains many proposals which if properly funded and not watered down could lead to improvements in the service it seems to approach things from the wrong perspective.

I believe that each wheelchair user should be at the top of any 'pyramid' supported by carers and staff to provide them with the package most suited to them. Thus the action plan has to start with the needs of the users and not the needs of the service / NHS.

It should begin with the universal premise that each individual user requires an individual assessment which takes into account their clinical needs, wants, individual personal circumstances and lifestyle aspirations. The qualified professionals would then in consultation with the user/carer make their recommendations as to the package of care and equipment most suitable to meet that individual's needs, up to this point any 'financial' restrictions should not play a part in a purely clinical decision.

After the 'perfect' option has been assessed and the cost worked out only then it is appropriate for financial considerations to come into play. This would mean that the user and the public at large would easily be able to identify under funding where it existed and make their own minds up about the fairness of decisions or otherwise.

Specific Comments on Points in Plan

1. The mechanism for user / parent involvement in influencing product selection must include specifics so that their views cannot be ignored. What say will they have, how will representatives be chosen, what actual powers will they have when it comes to budgetary decisions?

2. 'appropriately represented in their local partnership forum...'
This has to be specifically defined and information better disseminated than it was with this consultation process.'
3. "Meaningful partnerships need to be established between wheelchair and seating centres and their local authority partners responsible for equipment provision and adaptations to support case management" Unfortunately these schemes are also massively under funded and involve long waiting lists, the danger here is that by linking them you may slow down the wheelchair provision.
4. Provision of local clinics, facilities, child centred etc. Here the fear is that the entire budget will be swallowed up by shiny new architect designed waiting areas when the number one priority for users is new, modern equipment. Training for staff in paediatric aspects of chair provision is essential and there should be accessible facilities but a box of lego and some books are more than enough to make somewhere child centered.
5. Need for carer assessment is a good idea and is essential to avoid equipment being issued but lying unused as carers needs not taken into account.
6. "*The provision of equipment will take into account the lifetime costs of the chair and the costs associated with not providing a suitable wheelchair to meet user/carer needs.*" This is essential many carers/users require additional physiotherapy and hospitalisation as a result of not having adequate equipment. The extra costs to the NHS of this far outweigh any possible equipment costs. I hope also that costs of social and work exclusion are to be taken into account.
7. Assessments should also take into account local area, whether it is rural etc. and also lifestyle choices of user and their family.
8. "*Wheelchairs are selected from the agreed range of products on the NHS national contract and this range of equipment needs to reflect the needs of users and their carers.*" There are many

examples currently where stock chairs can be said to be good for the average chair user if only there was such a thing as an average chair user. Two improvements are possible; firstly the number of different chairs must be greatly expanded over the choice currently offered by individual wheelchair services; secondly there should be the option for one off purchases where a particular need has been identified for an individual user. This may or may not include an additional financial input from the user or a charitable organisation on top of the budget of the wheelchair service.

9. A model of fleet renewal and the introduction of new technology as standard linked to costs needs to be developed... The present fleet of manual chairs needs to be completely scrapped, years of only funding cheap poor quality chairs means that you would find it very difficult to source large numbers of quality chairs from this country. Manufacturers have had no demand for them as the NHS has not been willing to pay for quality or innovation. I suspect that a proper investment in the tens of millions per year would be required.

To End my submission

There are many aspects of this plan that are praiseworthy, some aspects I have not commented on as I have no knowledge, some as I see them as fair.

My main worries however are twofold. Firstly this whole exercise since 2005 has taken far too long and as yet there is little sign of the most important aspects being implemented. Already it is too late for large numbers of wheelchair users and their carers who have suffered decades of neglect and poor service. Their complaints and grievances have been and still seem to be largely ignored by the political and bureaucratic classes. My second worry is funding. The amounts talked of so far (16 million over three

years) are simply not enough to improve the service to any extent that will make a real difference to those who need it most. I am frightened it will only be enough for a cosmetic make over when what it really needs is radical surgery.

Sincerely,

Donald I Greasley