



Wheelchair and Seating Services Modernisation: an action plan

NHS Quality Improvement Scotland
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Sense Scotland Response
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Introduction

Sense Scotland is a leader in the field of communication and innovative support services for people who are marginalised because of challenging behaviour, health care issues and the complexity of their support needs. The organisation offers a range of services for children, young people and adults whose complex support needs are caused by deafblindness or sensory impairment, physical, learning or communication difficulties. Our services are designed to provide continuity across age groups and we work closely with families and colleagues from health, education and social work. This breadth and depth of approach to service delivery helps us take a wider perspective on the direction and implementation of new policies.

General comments

Sense Scotland welcomes many of the proposals set out in the WSS Action Plan. The setting up of a Project Board and of a wheelchair user and carer group at NHS Board level, recognising the need to plan for changing demographics and a commitment to reflecting person centred approaches have the potential to contribute to an improved user experience. Inclusion of specific actions with due dates and identifiable processes will help in providing transparency of decision making and to monitor achievements.

Alongside these positive steps Sense Scotland has concerns about the direction of the WSS Action Plan. First, it has moved away from the recommendations contained in *Moving Forward Review of NHS Wheelchair and Seating Services in Scotland (2006)*. Secondly, the importance of user and carer involvement at all levels appears to have been downgraded. We think that these two important factors need to be maintained and strengthened throughout the WSS Action Plan so that positive improvements reflect stakeholder recommendations.

Moving Forward recommendations

The WSS Action Plan makes passing reference to the recommendations contained in *Moving Forward*, listing them here as numeric footnotes to the tables included as Appendix 2. It would have been helpful if the WSS Action Plan had been presented alongside with the recommendations contained in *Moving Forward*, or at least in conjunction with the recommendations agreed in the *Scottish Executive Response to Recommendations Made in the Report 'Moving Forward review of NHS wheelchair and seating services in Scotland' (2007)*.

This would have allowed readers to understand the thinking behind the proposed actions. Without such cross-reference it makes it difficult for most readers to understand the scope of and thinking behind the proposed framework. The only specific references contained to *Moving Forward* recommendations are the numeric references at the foot of each set of action points. It would have been helpful if, at the least, the details of those specific recommendations had been included to allow comparison.

User and carer involvement

Moving Forward represented a significant development in bringing together user groups, wheelchair and seating services (WSS), NHS Boards and Scottish Executive officials. The forty resulting recommendations presented a synthesised framework for providing integrated wheelchair and seating services. User and carer involvement was central to identifying the detail of that integrated service – at each level of local, NHS Board and WSS centre. The WSS Action Plan does emphasise the important principles of involving users and carers, and of delivering person centred care and that these are central to NHS Scotland thinking. It then proceeds to identify users' and carers' involvement in the following areas :

- NHS Boards establishing user and carer groups as part of their PFPI structures and processes.
- Contributing to product selection in accordance with PFPI.
- In each Community Health Partnership (CHP) where users and carers are to be "appropriately represented".
- When developing patient information.

It is useful to compare the level of involvement reflected in the above with Recommendation 13 in *Moving Forward*, in which the involvement of users and carers is central and features throughout its recommendations: in the nature and process of assessment; choice of equipment; obtaining feedback and using it to inform service development; and in relation to approaches to, and timescales for repairs and maintenance. The WSS Action Plan presents the modernisation agenda as a clinically managed programme, with its targets and performance indicators set by central services and monitored by NHS boards and WSS centres. The notion of user and carer involvement appears to have been severely downgraded.

Scottish services for wheelchair and seating required a root and branch re-structuring, recommendations in *Moving Forward* set out what was needed to deliver that re-design. The WSS Action Plan delivers a watered down version, with essentially the same service structure intact. Involvement of users and carers remains peripheral.

Project Board and Advisory Board

We are disappointed that an Advisory Board was not established and that responsibility for delivery solely given to the Project Board. The Advisory Board would have served an important function in ensuring that the Project Board delivered the kind of system that would meet user and carer needs.

We have some concerns regarding membership of the Project Board which we first drew to Scottish Government attention in our own response to the document *Scottish Executive Response to Moving Forward*. Out of twelve members only three represent non-health interests viz. CoSLA, Scottish Disability Equality Forum and a user representative. While priority for health membership is understandable it would be helpful if the Project Board included social services and education membership. This will allow more detailed planning to be made around the implications for

multidisciplinary team (MDT) involvement of social services and education with health. With the WSS Action Plan highlighting the important role played by assistive technology in maximising development and potential for children and young people, the presence on the Board of education and social services staff would help inform the structures of individualised and person-centred MDTs.

Recommendations omitted

Several recommendations contained in *Moving Forward* are omitted from the WSS Action Plan. Aside from Recommendation 1 which is covered by having set up the Project Board, those omitted are:

- [27] Provide appropriate staff training
- [34] Provide adequate space for clinical assessment
- [35] Ensure family friendly facilities
- [39] Provide extended equipment loan
- [40] Establish multi-agency links

We look forward to information on how these will be developed. For example, although multi-agency links are cited at WSS centre level it is not clear how these will link with CHPs or with specialist practitioners from other areas, including both education and the voluntary sector.

Funding

We welcome the Scottish Government announcement in February 2008 of £16m to fund wheelchair and seating services over the period 2008-11. We are disappointed that the figure represents only half the amount of money that was recommended in the *Moving Forward* report.

Document accessibility

As with the Scottish Government Wheelchair Review Report, the proposed WSS Action Plan is available as a web only publication. The consultation response form is also not easily accessible to people with physical or visual impairments, many of whom will be wheelchair users who are also unable to attend consultation events.

We would encourage Scottish Government to consider providing alternative formats for future reports. Many wheelchair users are elderly, have difficulty moving their hands and arms and either do not have a computer with access to the internet or cannot easily access an available computer. For them a web only version of the document is not always helpful.

There is a particular difficulty with the Respondent Information Form. The form can only be completed by printing out and handwriting, using a typewriter or re-producing the form in MS Word or other. The respondent information form does not appear to be available from Scottish Government website in Word compatible format or in accessible PDF format, either of which allow respondents to complete it using a computer and keyboard.

A number of additional options could be considered which would add little cost:

- Online form completion.
- A writable accessible PDF version available for download.

Further information about producing accessible PDF documents can be obtained from CALL Scotland (Paul.Nisbet@ed.ac.uk or Stuart.Aitken@ed.ac.uk).

Specific comments

Patient and user involvement (page 1 & 2)

We welcome the commitment to user involvement and the actions that follow. We also welcome the commitment to ensuring that each Community Health Partnership (CHP) will ensure representation on its local partnership forum.

We have a major concern at the lack of apparent connection between patient involvement at the CHP or local partnership forum level and their involvement at a service re-design level. This represents a major shortcoming in the proposed plan.

We welcome the commitment to a more 'whole person' approach to assessment, provision and maintenance. One area to consider is the effect choice of wheelchair can have on the ability to fulfil care plans. An example is the need to consider staff health and safety where the individual does not have, or cannot use a powered wheelchair.

We would encourage professionals to recognise the work of the 58 existing access panels. Substantial savings could be made and experience drawn on by involving those already working in council areas rather than setting up new groups.

Page 5 National Procurement agree NHS supply contracts in collaboration with WSS providers

We agree that there is potential for local wheelchair user groups to provide a network of advice for National Services Scotland (NSS) National Procurement. However, it is also clear that advice from National Procurement has not resulted in person centred approaches to agreeing contracts for care services. The recommendations made regarding user input to decision making will need to enable service users with complex disabilities, including communication support needs, to have their voice heard. This will include some people with the greatest need for a suitable wheelchair.

The comment "This does not preclude patients and service users from exercising personal choice and in seeking equipment to purchase independent of the NHS or statutory services if they wish to do so" implies a clear and straightforward appeals process. Where individuals feel that NHS decisions (and by implication National Procurement decisions) do not meet their needs, an appeal process should be available and straightforward to navigate. They should not have to go down a more expensive route when prescribed equipment may not be suitable.

Procurement decisions should also factor in costs to the user in such as charging up wheelchairs and hoists every day. In some cases we are aware of a powered chair

requiring many hours on charge which essentially means that the wheelchair is out of service for much of any 24 hour period.

Page 7 Progressive conditions

We welcome the identification of a need for anticipatory approaches to provision so that equipment is made available to accommodate changing needs. We are aware that children's needs are not always met promptly, with for example, a young person leaving school with a chair that was several years old, even though she had grown and it was completely unsuitable. National Procurement decisions should not compromise the ability of Wheelchair and Seating Services to respond to people's changing needs. Local arrangements should build in frequent review of processes and decisions, to ensure they are sufficiently responsive to different needs. We are aware too of often over-rigid approaches taken in some areas to the provision of occupational therapy equipment. We would hope that this is not reflected in the provision of wheelchairs.

Actions on service re-design (pages 10 & 25)

In our General comments we referred to a lack of real outcomes linked to actions. We also pointed to the need to involve wheelchair users to establish what these outcomes might be, a point that we addressed specifically in our response to actions proposed on patient and user involvement (pages 1 & 2 of plan).

There is a need to take patient and user involvement a stage further, to establish what improvements that the use of in-house "improvement measuring tools" will be used to measure. The WSS Action Plan does not make clear what the desired future state of the services will be. Usually this would come from an analysis of the current system and an understanding as to why it isn't achieving the required outcome. As we've noted, the *Moving Forward* report did provide such a detailed analysis and mapped out, and costed, the route forward through a series of forty linked recommendations. The Scottish Government response rejected some of these and presented a scaled down model (with half of the requested funding) and it is that which is now being proposed. Because many changes have been introduced to the original report it is not clear what the new system will be i.e. what desired future state of WSS the WSS Action Plan addresses. This is an important point because the use of lean management tools, in particular Rapid Improvement Events (RIEs) are proposed.

We have a particular concern about the use of Rapid Improvement Events (RIEs) to improve service re-design. RIEs are referred to in the WSS Action Plan as an example of lean principles for managing the flow of work. While RIEs can work in this way they achieve this only in closed systems, where the analysis has been performed, and the end result agreed. This now doesn't apply to WSS. WSS are only a partial closed system – when limited only to the five WSS centres – but not once NHS Board and CHP levels with multi-disciplinary input are involved. We would urge caution in applying this technique.

Staff working in current wheelchair and seating services are widely known to be demoralised with a feeling of change being introduced from outside. We have a real concern that the RIE approaches cited in the WSS Action Plan are likely only to exacerbate that feeling.

Before any RIE or lean management principle is introduced we would like to see a much clearer focus on the user, to identify what the provision of wheelchair and seating should look like from their perspective. *Moving Forward* began that process. The WSS Action Plan appears to represent a return to tinkering at the edges with the current system.

User and carer involvement is central to success in delivering a better system. The WSS Action Plan notes that RIE sessions will involve WSS Project Manager, NHS Redesign Teams and WSS Centres – but not users or carers.

Page 18 Lifetime costs and opportunity costs of not providing

We suggest re-wording the phrase:

“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.”

to read:

“The provision of equipment will take into account the lifetime costs of the chair and the costs to the person in all areas of their life, with not providing a suitable wheelchair to meet user/carer needs.”

We welcome the focus on user involvement. Elsewhere we emphasise the need, with children, to address liaison with multi-disciplinary teams, in particular input from education services. Examples include the benefits of providing riser seats to allow young people to access to all areas of the curriculum. Often this is not done because budgets are allocated in piecemeal fashion with specialist seats and furniture coming out of separate budgets from wheelchairs. Overall, however, the real cost to the public purse is greater.

There should be a clear process for informing users, carers, social work and other staff, of the Action Plan, and of their contribution to improving services. There should also be feedback on what points were taken forward and why others were not actioned.

Page 21 IT and information management

We understand why service re-design will want to ensure that information management systems conform to national data standards and definitions. To do this effectively it is important that there is sufficient representation of user and carers to inform the design of both datasets and data standards. Without this representation, we are concerned that the information being managed may not inform effective outcomes for users. It is worth noting that the Minutes of the Project Board meeting of 23 June 2008 give over much of the discussion to addressing IT System

Requirements, without saying what the system will measure and without input from service users.

Page 22 Repairs and maintenance

It would be helpful to include agreed response times for repairs and maintenance. This requirement needs to apply to NHS Board, WSS Centre and other specialist service providers. The proposal on planned maintenance scheduling will reduce the need for providers to react to frequent repair requests. However, it will still be important that users, carers and service providers are aware of what to expect. When people don't have access to their wheelchair it can cause significant difficulties not only for the user but for those offering support services and everyone else involved in their day-to-day life. It would be helpful to have a courtesy wheelchair available when repairs are being undertaken.

There should also be more flexibility with repair arrangements. In some rural areas and islands it is the local garage which has the contract to do repairs and this can work well provided standards are clear and maintained.

Page 26 Outcome measurement

Reference to outcome measurement and the use of improvement measuring tools is described in the context of National Service WSS Centres and WSS Project Manager. Again we would like to see greater prominence given to involvement of service users in deciding what is to be measured and how. Minimum performance standards of this type need to be informed by the people who use the service. The Project Board is light on representation of service users and carers. We would urge Scottish Government to reconsider establishing an Advisory Board, to help ensure that outcomes measured are important to those who will benefit from the service.

4.7 Teams to Deal with Children

The Executive response appears to consider the role of child, family, teachers and others as essentially passive in that they will be "aware of decisions made by service staff" and "participate as necessary". The Executive, Joint Board and Advisory Group each need to raise the profile of inter-agency working arrangements and how this will be effected. In the example given it is likely that teachers will be most aware of the issues that need to be addressed to improve a child's access to mobility within an education setting.

Terminology

The use of disabling language should be avoided. The term "suffer" should be replaced with "have". (page 4, para. 5).

Typos

Page 17 para. 3 line 4: We suggest re-wording the statement "...user and/or their carers who will receive...a copy of the equipment"

Scottish Executive Response to the Recommendations made in the report 'Moving Forward: Review of Wheelchair and Seating Services in Scotland'

04 August 2008

Response from Sense Scotland

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Senior Consultant
Sense Scotland
31 October 2008

Respondent information form: Wheelchair and Seating Services Action Plan

Please complete the details below and return it with your response. This will help ensure we handle your response appropriately. Thank you for your help

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1. Responding as: an individual on behalf of a group or organisation?

On behalf of groups of organisations

3. The name and address of your organisation **will be** made available to the public on the Scottish Executive library and/or to the Scottish Executive website). Are you also content for your **response** to be made available?

Yes

Sharing responses / future engagement

4. We will share your response internally with other Scottish Executive policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, we require your permission to do so. Are you content for the Scottish Executive to contact you again in the future in relation to this consultation response?

Yes